

Bournemouth University

**Thinking self after bowel cancer:  
an embodied interpretation and *art*-iculation**



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the requirements of Bournemouth  
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“Eyes tightly open ... can’t bear not to look”: interpretive *art*-iculation  
of participant’s experience of cancer 20 years post-treatment  
(DProf practice part).

# Abstract

## Thinking self after bowel cancer: an embodied interpretation and *art-iculation* - Kathleen Vandenberghe

This study contributes to an understanding of the experience of cancer survivorship by focusing on survivors' "comprehending" of self vis-à-vis cancer, specifically by exploring embodied dimensions of their comprehending. This approach sits within an interpretive phenomenological paradigm. It draws, in particular, on theories that are aligned with embodied existential phenomenology and enactive cognitive science.

The participants in this research project were adult survivors of bowel cancer who had no active disease and were between a few months and 20 years after finishing their cancer treatment. Twelve participants were recruited via a hospital support group and a hospice social media platform. Data obtained during a previous on-the-job case study has also been included.

Participants' metaphorical comprehending of self in relation to cancer, their experiences with medical consultants, and general understandings of self were explored during explorative sessions. Those were semi-structured and also involved the use of creative materials. The sessions were audio-recorded and non-verbal data were photographed.

The data inquiry process consisted of highlighting and comparing the body schematic structure of participants' metaphors (numbering 20), followed by an ordering of the latter according to a body developmental logic. This resulted in the construction of nine clusters of 'self and cancer comprehending', i.e. presenting and positioning, handling and rising, moving in space, expressing a viewpoint on the future, moving forward, surpassing and assessing, ending, registering and holding. An exploration of the role of the wider self and of the transactions with consultants in the comprehending of self vis-à-vis cancer has contributed to a more holistic and dynamic understanding. This process of 'analytical' inquiry was preceded by an 'embodied' enquiry of the data.

In the literature, cancer survivorship seems to appear as a process of recovery, change, growth, liminality or framing. The findings of this study contribute to the further interpretation of previous research.

The practice part of this Doctorate in Professional Practice consists of what has been called an "*art-iculation*" of the findings. In collaboration with an artist-painter the findings were carried forward in the shape of painted expressions of the aforementioned 20 metaphors. The paintings will be used in workshops with health care practitioners and cancer survivors with an eye on engaging empathic and actionable understanding.

# Table of Contents

<b>Abstract</b> .....	<b>4</b>
<b>Table of Contents</b> .....	<b>5</b>
<b>List of Illustrations</b> .....	<b>11</b>
<b>List of Tables</b> .....	<b>12</b>
<b>List of Vignettes</b> .....	<b>12</b>
<b>Accompanying material</b> .....	<b>12</b>
<b>Acknowledgments</b> .....	<b>13</b>
<b>Dedication</b> .....	<b>15</b>
<b>INTRODUCTION</b> .....	<b>16</b>
<b>1. BACKGROUND</b> .....	<b>21</b>
<b>1.1 Post-treatment cancer survivorship</b> .....	<b>21</b>
1.1.1 Definition of cancer survivorship .....	22
1.1.2 Cancer survivorship is a psychological experience sui generis .....	23
1.1.3 Cancer survivorship acknowledged as a health care issue.....	25
<b>1.2 Self vis-à-vis cancer</b> .....	<b>26</b>
<b>1.3 On-the-job case study at the inception of research topic and approach</b> .....	<b>31</b>
1.3.1 Bowel cancer .....	31
1.3.2 The self at different times post-treatment, including long-term survivorship .....	32
1.3.3 Sensori-motor embodiment of metaphorical conceptualising of self .....	34
1.3.4 Self in response to medical interactions and other life events .....	37
1.3.5 Interpreting direction of change of self conceptualisations .....	38
<b>1.4 A quest for comprehensiveness</b> .....	<b>38</b>
1.4.1 Pursuit of data variations .....	39
1.4.2 Complementary exploration of research and case study data .....	39
1.4.3 Development of a multiple embodied research lens .....	40
<b>2. NEUROLOGICAL EMBODIMENT OF SELF AND THINKING</b> .....	<b>42</b>

<b>3.</b>	<b>RESEARCH AIM, QUESTIONS, APPROACH AND OBJECTIVES .....</b>	<b>51</b>
3.1	Research question and aim.....	51
3.2	Research approach.....	54
3.3	Research objectives and sub-questions.....	55
<b>4.</b>	<b>PHENOMENOLOGICAL EMBODIMENT OF SELF AND THINKING .....</b>	<b>59</b>
<b>4.1</b>	<b>Non-dualism and Enactivism .....</b>	<b>59</b>
4.1.1	Representational Realism.....	60
4.1.2	Transcendental Idealism.....	62
4.1.3	Existentialism.....	64
4.1.4	Embodied Existentialism.....	65
4.1.5	Enactive Cognition.....	70
4.1.6	Research approach, questions and title revisited.....	76
<b>4.2</b>	<b>Five dimensions of embodiment .....</b>	<b>79</b>
4.2.1	Sensori-motor embodiment and 'conceptual metaphor'.....	79
4.2.2	Experiential embodiment and 'felt sense'.....	90
4.2.3	Bio-chemical embodiment and 'viability'.....	95
4.2.4	Transactional embodiment and 'affordances'.....	99
4.2.5	Developmental embodiment and 'personal dynamics'.....	102
<b>4.3</b>	<b>A quest for holism.....</b>	<b>104</b>
<b>5.</b>	<b>EMBODIED OUTLOOK ON CANCER SURVIVORSHIP RESEARCH: LITERATURE REVIEW .....</b>	<b>106</b>
<b>5.1</b>	<b>Aim and approach.....</b>	<b>106</b>
<b>5.2</b>	<b>Metaphorical perspectives on cancer survivorship.....</b>	<b>108</b>
5.2.1	Getting back on track.....	110
5.2.2	Walking a different track.....	115
5.2.3	Taking the hurdle leads to a new track with unexpected heights.....	119
5.2.4	Moving betwixt and between Angst and Normalcy.....	122
5.2.5	Framing cancer experiences.....	127
<b>5.3</b>	<b>Discussion and conclusion.....</b>	<b>132</b>

<b>6.</b>	<b>ENACTIVE HERMENEUTIC PHENOMENOLOGY: METHODOLOGY.....</b>	<b>135</b>
<b>6.1</b>	<b>From theory to methodological aspects.....</b>	<b>135</b>
6.1.1	'Pointing to' what is really expressed .....	137
6.1.2	Hermeneutic 'dance' .....	138
6.1.3	Richness of description and expression .....	140
6.1.4	Awareness that understanding is an ongoing process.....	141
6.1.5	Relationality and empathic openness .....	142
6.1.6	Comprehensive reflexivity.....	146
6.1.7	Active engagement of metaphorical understanding .....	148
<b>6.2</b>	<b>From methodological aspects to rigour .....</b>	<b>151</b>
<b>7.</b>	<b>RESEARCH METHODS .....</b>	<b>155</b>
<b>7.1</b>	<b>Sampling and Recruitment .....</b>	<b>155</b>
7.1.1	Sampling size .....	155
7.1.2	Initial sampling criteria .....	156
7.1.3	Recruitment sites.....	159
7.1.4	First recruitment stage.....	160
7.1.5	Ongoing sampling.....	161
7.1.6	Second recruitment stage.....	164
7.1.7	Ending recruitment.....	165
7.1.8	Reflexive notes .....	166
<b>7.2</b>	<b>Procedures.....</b>	<b>167</b>
7.2.1	Ethical considerations.....	167
7.2.2	Risk assessment.....	168
7.2.3	Patient and public involvement .....	169
<b>7.3</b>	<b>Methods of data generation .....</b>	<b>170</b>
7.3.1	Research Exploration Plan .....	170
7.3.2	Methods and techniques.....	173
<b>7.4</b>	<b>Methods of data inquiry .....</b>	<b>183</b>
7.4.1	Embodied Enquiry into individual data.....	185
7.4.2	Analytical inquiry into data parts .....	187
7.4.3	Analytical inquiry into embodied dimensions of data .....	188
7.4.4	Updating the case study inquiry.....	192
7.4.5	An ongoing process of inquiry.....	192

<b>8. FINDINGS AND DISCUSSION</b> .....	<b>193</b>
8.1 Participants.....	193
8.2 Method of presentation.....	198
8.3 <b>Nine clusters of individual comprehendings</b> .....	<b>200</b>
8.3.1 Enaction 1: Presenting and Positioning.....	203
8.3.2 Enaction 2: Handling and Rising .....	211
8.3.3 Enaction 3: Moving in Space.....	218
8.3.4 Enaction 4: Expressing a Viewpoint on the Future.....	225
8.3.5 Enaction 5: Moving Forward.....	231
8.3.6 Enaction 6: Surpassing and Assessing .....	236
8.3.7 Enaction 7: Ending .....	242
8.3.8 Enaction 8: Registering .....	247
8.3.9 Enaction 9: Holding .....	253
8.3.10 Boundaries of viable comprehendings of self in cancer survivorship .....	258
8.4 <b>Discerning the overall process</b> .....	<b>262</b>
8.4.1 Metaphorical outlook.....	262
8.4.2 Developmental outlook.....	264
8.4.3 Enaction of liminality .....	273
8.4.4 Dynamic outlook.....	286
<b>9. CONCLUSION</b> .....	<b>295</b>
<b>10. RESEARCH ART-ICULATION TO AID MULTIPLE PRACTICES</b> .....	<b>301</b>
10.1 An ongoing enactive interpretation .....	302
10.2 A relational artistic interpretation of research findings .....	304
10.3 Using research based paintings in health care education and practice .....	307
<b>11. THINKING SELF DURING AND AFTER RESEARCH</b> .....	<b>311</b>
<b>REFERENCES</b> .....	<b>314</b>
<b>APPENDICES</b> .....	<b>339</b>

<b>APPENDICES A</b> .....	<b>340</b>
APPENDIX A0: Case study .....	340
APPENDIX A1: Case study Participant Information Sheet + Consent form.....	348
APPENDIX A2: Ethical approval from BU to use case study material .....	353
<b>APPENDICES B</b> .....	<b>354</b>
APPENDIX B0: Primary Metaphors examples.....	354
APPENDIX B1: Primary metaphor resource document (extract).....	355
APPENDIX B2: Research literature search criteria .....	356
<b>APPENDICES C</b> .....	<b>358</b>
APPENDIX C0: Body schematic structure of phenomenological ‘openness’ .....	358
APPENDIX C1: Reflexivity .....	364
APPENDIX C2: Body schematic structure of hermeneutic metaphors .....	367
APPENDIX C3: Overview research design (master table) .....	370
<b>APPENDICES D</b> .....	<b>371</b>
APPENDIX D0: Letters of agreement to recruit.....	371
APPENDIX D1: Information to hospital support group.....	373
APPENDIX D2: Participant Recruitment Poster – First recruitment.....	374
APPENDIX D3: Participant Recruitment Poster – Second recruitment .....	375
APPENDIX D4: Extract hospice website as part of second recruitment .....	376
APPENDIX D5: Extract Facebook as part of second recruitment.....	377
APPENDIX D6: Email as part of second recruitment.....	378
APPENDIX D7: Flow chart Participant Recruitment and Research Contacts .....	379
APPENDIX D8: Participant Information Sheet and Covering Letter .....	380
APPENDIX D9: Initial Conversation Schedule .....	387
APPENDIX D10: Invitation to introductory meeting + Health and Care Questionnaire .....	388
APPENDIX D11: Consent Form .....	391
APPENDIX D12: Introductory screening meeting schedule.....	392
APPENDIX D13: Letter to GP .....	393
APPENDIX D14: Ethical considerations (extract NHS Ethics Application) .....	393
APPENDIX D14: Ethical considerations (extract NHS Ethics Application) .....	394
APPENDIX D15: Ethical approval NHS, R&D MCHFT and BU .....	397
APPENDIX D16: Public Engagement – Conference poster .....	401
APPENDIX D17: Shells and stones used during data generation .....	402
APPENDIX D18: Flexible use of Research Exploration Plan (REP).....	403
APPENDIX D19: Details introductory stage of explorative sessions .....	406
APPENDIX D20: Reflexive notes with regards to data generation .....	409

<b>APPENDICES E .....</b>	<b>412</b>
APPENDIX E0: Summary of Ann’s research data .....	412
APPENDIX E1: ‘Individual file’ (example: Ann) .....	415
APPENDIX E2: Interpretation of chosen shells and stones .....	416
APPENDIX E3: Individual primary metaphor work document (example) .....	418
APPENDIX E4: Group primary metaphor work document (extract) .....	419
APPENDIX E5: Plutchik’s ‘wheel of emotions’ .....	421
 <b>APPENDICES F.....</b>	 <b>422</b>
APPENDIX F0: Case study data E-fog .....	422
APPENDIX F1: Case study data E-Terrorist.....	423
APPENDIX F2: Summary of Linda’s research data .....	424
APPENDIX F3: Summary of Rosy’s research data .....	428
APPENDIX F4: Summary of Karl’s research data.....	431
APPENDIX F5: Case study data E-Theatre play .....	434
APPENDIX F6: Summary of Mark’s research data .....	435
APPENDIX F7: Case study data E-Unknowable.....	438
APPENDIX F8: Summary of Simon’s research data.....	440
APPENDIX F9: Case study data E-Adopting .....	442
APPENDIX F10: Summary of Noel’s research data.....	443
APPENDIX F11: Case study data E-Veteran.....	445
APPENDIX F12: Summary of Boris’s research data.....	446
APPENDIX F13: Summary of Tony’s research data .....	448
APPENDIX F14: Summary of Jack’s research data.....	450
APPENDIX F15: Summary of Dan’s research data.....	452
APPENDIX F16: Case study data E-Horror .....	455
APPENDIX F17: Summary of Wendy’s research data .....	456
APPENDIX F18: Case study data E-Healed.....	459
 <b>APPENDICES G .....</b>	 <b>460</b>
APPENDIX G0: Occurring and affording different degrees of cancer awareness .....	460
APPENDIX G1: Specific contribution of case study versus research participants.....	461
APPENDIX G2: Body schematic process of survivorship as ‘movement exercise’ .....	463
APPENDIX G3: Delineations within cancer survivorship.....	464
APPENDIX G4: Occurring and affording of PTG and self-actualizing .....	465
APPENDIX G5: Occurring and affording of resilient self continuation.....	466
APPENDIX G6: Occurring and affording of negated liminality .....	467
 <b>APPENDIX H .....</b>	 <b>468</b>
APPENDIX H0: Request and information to artist-painter.....	468
APPENDIX H1: In the shadow of survivorship .....	472

## List of Illustrations

Figure 1: Five levels of embodiment and their impact on self .....	49
Figure 2: The expressing and conceptualising of the experiencing of self .....	51
Figure 3: Five embodied lenses used to shed light on comprehending of self.....	53
Figure 4: Five embodied processes impacting on the comprehending of self .....	58
Figure 5: Traditional perspective on world, body, brain, mind and self .....	62
Figure 6: Body as subject and object.....	66
Figure 7: Concepts and language as second version of experience.....	69
Figure 8: A line made by walking by Richard Long .....	74
Figure 9: Metaphorical expression of interviewing .....	144
Figure 10: Flamenco – courtesy @ Camille Kleinman .....	149
Figure 11: Summary of sampling and recruitment process.....	163
Figure 12: Evolving list of enactions .....	190
Figure 13: Variations in Presenting and Positioning .....	209
Figure 14: Variations in Handling and Rising.....	217
Figure 15: Variations in Moving in Space .....	224
Figure 16: Variations in Expressing Viewpoint on Future .....	231
Figure 17: Variations in Moving Forward .....	235
Figure 18: Variations in Surpassing & Assessing .....	241
Figure 19: Variations in Ending.....	246
Figure 20: Variations in Registering.....	252
Figure 21: Variations in Holding.....	257
Figure 22: Body schematic structure of metaphors at different times post-treatment .....	265
Figure 23: Overview nine enactions and four types of self .....	268
Figure 24: Four types of self-cancer comprehendings.....	283
Figure 25: Research-based paintings of comprehendings of self and cancer .....	310
Figure 26: Virginia Parker, Triple self portrait .....	364
Figure 27: Shells and stones used during data generation.....	402
Figure 28: Ann's expression with shells & stones .....	414
Figure 29: Plutchik's 'wheel of emotions' .....	421
Figure 30: Linda's expression with shells & stones.....	427
Figure 31: Rosy's expression with shells & stones .....	430
Figure 32: Karl's expression with shells & stones .....	433
Figure 33: Mark's expression with shells & stones .....	437
Figure 34: Simon's expression with shells & stones .....	441
Figure 35: Noel's expression with shells & stones .....	444
Figure 36: Boris's expression with shells & stones .....	447
Figure 37: Tony's expression with shells & stones .....	449
Figure 38: Jack's expression with shells & stones.....	451
Figure 39: Dan's expression with shells & stones.....	454
Figure 40: Wendy's expression with shells & stones .....	458
Figure 41: Delineations within cancer survivorship .....	464

## List of Tables

Table 1: Aspects of Enactive Hermeneutic Phenomenology (EHP) .....	136
Table 2: Research Exploration Plan (REP) .....	171
Table 3: Data generation methods .....	174
Table 4: Data inquiry methods .....	184
Table 5: Overview participants' treatment packages .....	194
Table 6: Characteristics of participant group .....	195
Table 7: Characteristics of individual research and case study participants.....	198
Table 8: Presentation of findings method .....	199
Table 9: Cancer positioned in space and time .....	276
Table 10: Spatial and relational liminality .....	285
Table 11: Case study findings - part 1.....	346
Table 12: Case study findings - part 2.....	347
Table 13: Primary metaphor resource document (extract) .....	355
Table 14: Research literature search criteria.....	356
Table 15: Master research table.....	370
Table 16: 'Individual file' (example) .....	415
Table 17: Individual primary metaphor work document (example) .....	418
Table 18: Group primary metaphor work document (extract) .....	419

## List of Vignettes

Vignette A: Occurring and affording of the end of patienthood.....	291
Vignette B: Occurring and affording different degrees of cancer awareness.....	460
Vignette C: Occurring and affording of PTG and self-actualizing .....	465
Vignette D: Occurring and affording of resilient self continuation .....	466
Vignette E: Occurring and affording of negated liminality.....	467

## Accompanying material

Power Point presentation with painted images on attached portable data-storage device

## Acknowledgments

*“A thesis, like any other book, is not a product of one person. It is an inextricable network of unlimited tracks, impulses, metaphors, motivations, obstacles and struggles with multiple and untraceable origins. It is a network of which the effects cannot be predicted”*

*(Ronnie Lippens 1997, p.III, translated from Flemish).*

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***It is with love and longing  
that I dedicate this work  
to my mother***



## Introduction

In this thesis I explore how survivors of bowel cancer who were between a few months and about twenty years post-treatment presently comprehend their self in relation to the way they experience or think of cancer. In other words the focus is on their self vis-à-vis cancer rather than their self in general.

The aim of the study is to explicate and understand a variety of experiences of self during cancer survivorship. When healthcare practitioners, but also survivors themselves, gain a more refined understanding of the variety of experiences that make up the survivorship process, a more empathic and realistic approach becomes available. It is from my own counselling experience with survivors in the health care sector in the U.K. that I believe this process-oriented research is relevant and able to complement a growing trend of goal-oriented support.

In this study the view on 'self', 'experiencing' and 'thinking' has been grounded in cognitive scientific as well as in philosophical perspectives that consider the self to be both a body-self and a process. Within these perspectives, experiencing, thinking and language are considered as intertwined and in this study the term 'comprehending' has been used to capture all three.

Theories of embodied cognition have taught me that the metaphorical character of language is the clearest manifestation of the body at work in talking, thinking and experiencing. Therefore I decided to shed light on research participants' comprehending of self vis-à-vis cancer by focusing on their metaphorical expressions.

Five bodily dimensions and their role in the emerging and comprehending of self were delineated and subsequently used to shed light on the metaphorical

comprehendings expressed by the research participants. These objectives (see 3.3.) took the following form: While highlighting the body-schematic structures that shaped the metaphors (objective 1) and pointing out those structures that were not present (objective 3), the comprehendings of self were ordered according to a developmental bodily logic (objective 5). The impact of the wider self (objective 2) and of the transaction with consultants (objective 4) on the structure of the metaphorical comprehendings has also been explored.

The central role given to the body in talking, thinking and experiencing in theories of embodied cognition resonates with a philosophical paradigm that puts human embodiment forward as the ground for a non-dualistic conceptualisation of mind and body, and body-mind and world. This means that a person's body and embodied mind are seen as both enabling and restricting the world they can take part in, and that features of this world are seen as enabling and restricting what the body and embodied mind can engage with. Consequently, how human beings 'comprehend' is seen as a constantly changing fusion of embodied mind and world. This fusion is always happening from a certain position (it happens from a place and is embodied). This makes all understanding an embodied interpretation.

In this thesis I use the word 'enaction' as a synonym for 'embodied'. The term originates from neuro-phenomenology but captures how thinking, talking and experiencing are directly shaped by embodied being and acting in the world. It also indicates that the neurological imprint of this embodied being and acting further enacts our thinking, talking and experiencing. This paradigm has informed the methodology, which I call 'enactive hermeneutic phenomenology'. This in turn has guided the research methods, practice development and personal narrative.

As part of this thesis, based on the research findings, a series of painted images have been created. These can be viewed on the attached portable data-storage device. The experience of the particular process of creation of

these paintings could be useful for other researchers who are interested in methods for art-based research dissemination. Therefore the penultimate chapter includes an account of this process, in addition to a discussion of how the paintings could be used in future health education and care.

Doing a DProf comes with a formal encouragement to attend to the personal experience of the research process. In my case the topic and opportunity for this DProf research occurred after 25 years of health care and counselling practice. Initially the research project felt like a task at the fringes of my ongoing professional practice and as an activity at the close of my professional life. Yet, research has taken centre stage in my life. As it has enabled me to take up a lecturing post at a university, and with the dissemination of research results still ahead, finishing this study does not feel like closure. I will explore in the final chapter of this thesis what it means to be in a place with such a strong sense of beginning while not wanting to dismiss the original aspiration to create closure.

### **Presentation of thesis**

In the **first chapter** the origin of the topic and the origin of the approach of this study are presented. First, I address how the aim to unravel the psychological process of cancer survivorship is embedded in my professional experience with cancer survivorship approaches in the health care sector. Secondly, it is explained how it came to my attention that conceptual metaphor theory and an understanding of comprehending as embodied, non-conscious and metaphorical can form an effective framework for the study of survivors' comprehending of self.

In other words this background chapter should reveal that with this thesis a dual aim is pursued: 1/ to deepen the understanding of survivors' comprehending of self and cancer and 2/ to do this from an embodied perspective on comprehending. The latter serves two purposes: I will argue

that it is an appropriate method for the exploration of the process of survivorship. Furthermore, as it is a relatively new theoretical perspective on cognition there is still a lot of scope for its application, especially in the field of health care research.

Where traditionally the first chapter may be followed by a review of the existing research literature on the study topic, in this study priority was given to the development of the theoretical framework. For a literature review to be purposeful and congruent with the approach of the study, it seemed necessary to explicate the theoretical framework first. In addition, the research objectives themselves were a concretisation of the approach.

What it means for comprehending and self to be embodied will be explored from a neurological and from a phenomenological perspective. In **chapter 2** the embodiment of self and thinking is explored from a neurological perspective. This allowed for the delineation of five dimensions of embodiment.

In **chapter 3** the five dimensions of embodiment are taken forward in five research objectives. It is also explained how the theory of embodied cognition in this study is brought together with an interpretive phenomenological approach.

In **chapter 4** I explore the general phenomenological underpinnings of an embodied viewpoint on understanding. They run parallel with the neurological ones addressed in chapter 2. In addition I explicate a number of secondary theories that are based in embodied phenomenological philosophy and that have informed the five research objectives which were explicated in chapter 3.

Having thus presented both the topic and the theoretical approach, in **chapter 5** I turn to the cancer survivorship research literature. With this review I hope to be able to demonstrate the earlier made claim of originality of my

exploration of survivorship and of the approach mobilised therein. However the review also serves to enhance an awareness of the context of survivorship. It clarifies where the present study positions itself in this field of research.

**Chapter 6** builds on the conclusions of chapter 4 and reflects on a number of methodological aspects. Those in turn will guide the methods of data generation and data inquiry described in **chapter 7**.

In **chapter 8** I present and discuss the findings of the inquiry. This chapter also includes references to the painted formats of research participants' comprehendings.

In bringing this thesis to a close a format has been chosen that reflects the hermeneutic principle that interpretation is an ongoing process.

First, in **chapter 9**, the research objectives are discussed in view of the research findings. Strengths and weaknesses and suggestions for further research are pointed out.

Secondly, in **chapter 10**, which forms the practice part of this thesis, it is discussed how a collaborative artistic interpretation of the research findings generated a series of painted images. How the paintings did have an impact on the understanding of some of the research findings is discussed in chapter 8. In chapter 10 it is explained how the paintings will be used as a tool in health care education and care, which is believed to generate further interpretation of the research findings. The very process of artistic co-creation will be discussed here as a form of art-based research practice. Insights from this co-operative work will be examined.

Thirdly, in **chapter 11** I contemplate the impact of both the content and process of this research project on myself. I reflect on what it means to bring this thesis to a close.

# **1. Background**

As indicated in the introduction the topic of this thesis is the self vis-à-vis cancer as experienced by bowel cancer survivors at different times post treatment. 'Enactive cognition' forms the theoretical framework that encapsulates the way this research topic has been explored. In this first chapter the causes and reasons that have led to this topic will be explained. First the focus on post-treatment cancer survivorship will be situated in my professional context as a hospice counsellor. Next the meaning of the focus on the self is clarified in relation to my counselling context and to other survivorship support approaches. Reflections on an on-the-job case study informed the decision to home in on bowel cancer survivors and to elicit expressions of self at different times post-treatment, including expressions of self from long-term survivors. In the final sections of this chapter three more aspects of the case study that formed the initial building blocks of the research approach are pointed out. These aspects are the experience of exploring self-expressions through a lens of metaphor and sensori-motor embodiment, the occurrence of self-expressions in interaction with cancer clinicians, and the overall direction of change of the self-expressions.

## **1.1 Post-treatment cancer survivorship**

It was in 2005 that post-treatment cancer survivorship began to emerge as a theme within my professional life in a number of ways. This eventually led to a decision in 2013 to research the topic as part of a doctorate. Before exploring the different ways 'cancer survivorship' initially presented, I will first define how the term is used in this thesis.

### **1.1.1 Definition of cancer survivorship**

The meaning of the words 'cancer survivor' and 'cancer survivorship' has evolved over time and varies between professional disciplines and countries. Overall the term 'cancer survivor' may be used from diagnosis onwards but the term 'survivorship' usually refers to the period after finishing initial treatment (Bell and Ristovski-Slijepcevic 2013; Jefford et al. 2013). I will follow this practice. Consequently, in this study the words 'cancer survivorship', 'post-treatment cancer survivorship' and 'post-treatment cancer survivors' all refer to the same. In this thesis I use the term 'cancer survivors' as this term is commonly used in research, but I would urge health care practitioners to keep in mind that a considerable number of 'survivors' do not identify with or reject the term for a variety of reasons, e.g. the term overstates the risk of death, or it understates the risk, it suggests that survival depends on personality, or it suggests (unwanted) advocacy (Khan et al. 2012).

Cancer patients who have finished their treatment may be 'beyond cancer' while others may be 'living with cancer' (National Cancer Survivorship Initiative 2013). The expression 'beyond cancer' means that the patient is considered to be cured or at least there is no active disease known or visible, while for others the cancer needs to be controlled with ongoing or intermittent treatment and therefore the term 'living with cancer' seems more accurate. In this research I will focus on the experience of post-treatment cancer survivors who have not needed further treatment after finishing the treatment offered in response to the initial diagnosis (this could have been surgery, radiotherapy and/or chemotherapy). In other words I focus on survivors who have medical grounds to hope that they are or will be living 'beyond cancer' and for whom long-term survivorship becomes a realistic possibility. It is part of cancer survivorship that there never is complete certainty about the cancer not returning. This can be noticed in the way cancer survivors refer to the physicality of their cancer post-treatment. In my practice some patients say 'the cancer is not there anymore', others use descriptions that incorporate the

uncertainty about it being removed beyond return. They may say ‘cancer is not there at the moment’ or ‘the treatment has made the cancer inactive’ or just ‘there is no visible cancer at the moment’. In this study, when participants refer to cancer in relation to themselves as something that psychologically exists for them while they consider it unlikely to be physically present or growing, I will use the terms ‘inactive cancer’ and ‘no known active disease’.

In my professional life, post-treatment cancer survivorship presented first and foremost as an experience that was in need of support and better understanding in my own individual counselling practice. This opened up reflections on the role of hospices in survivorship support and turned my attention to research findings of national and international health care organisations. In the next sections these aspects will be further discussed. What follows is also an illustration of my early experience of research as a journey which direction is at least partially determined by reflections that unexpectedly spring from both spontaneous and deliberate accumulations of experiences and thought processes.

### **1.1.2 Cancer survivorship is a psychological experience sui generis**

During the last 25 years I have worked in hospices that care for adult patients and their families. In my experience, about 15 years ago the number of patients who were asking for counselling support while they were considered to be moving into the realm of ‘surviving cancer’ steadily increased. One of these patients was Edward (pseudonym). Listening to him brought it home to me that a new psychological experience was described to me in my professional practice.

In October 2006, Edward looked back to the time when he really felt and thought he was dying from cancer and how this changed.

“My conviction stemmed from the way my doctors were talking about the state of my cancer but probably even more from feeling physically that ill that dying seemed very plausible. People around me shared

the same view. And God was there. But once I experienced dying as a certainty and real I regained my ability to take complete control over my way of being. I remember doing the things that I wanted to do. But then the physical experience changed and after a while my body knew I was not dying. Dying lost its realness. You cannot keep dying and not do it. It leads to shame. I could not live like that. I needed to let go of dying and I felt I had to renegotiate my life – I needed to trust.”<sup>1</sup>

Edward knew he had to turn his gaze away from dying and I knew that in order to understand him, I had to turn my gaze away from the models of loss that were up to that time predominant in my hospice work as they captured the experience of people who were terminally ill or bereaved and for whom ‘death’ was present as a certainty. No doubt many parallels can be drawn between all experiences of loss but at that point in time it stood out for me that cancer survivors’ experience of death as a threat rather than as a certainty was a difference that had to be considered as potentially creating a unique psychological experience. I agree with Little et al. (2002) who argue the importance of understanding cancer survivorship as an experience *sui generis*. In those early days, for me, thinking of cancer survivorship was mainly an experience of ‘unknowing’ and ‘not knowing’ and certainly ‘not understanding’. It felt as if I was looking into a valley through unfocused binoculars. As being able to understand and empathise with clients’ experience is believed to be a key therapeutic factor in person-centred counselling (Rogers 1957), I was motivated not only to enhance my understanding by listening to clients, but also to research what cancer meant for people after they finished treatment and when there were medical indicators to believe that their life was no longer, or at least not imminently, under threat.

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<sup>1</sup> This quote is part of an extensive case study which is presented in its entirety in appendix A0. I will refer to this case study throughout the thesis as it has informed my research question, methodology and method. The case study will be included in the discussion of the research data. Permission to include this material was obtained from the case study participant (appendix A1) and Bournemouth University (appendix A2).

### **1.1.3 Cancer survivorship acknowledged as a health care issue**

Cancer survivors did not only access counselling but also other support services in the hospice I worked in and the same was happening in some other hospices. This reflected cancer survivors increasingly reporting a need for a wide range of support (Stanton 2006; Corner and Wagland 2012). Based on a general ethos of openness there was an encouragement for hospices to respond to survivors' needs and expand the traditional focus on terminal illness (Corner 2013; Payne et al. 2013). Present definitions of Hospice care specify their focus on terminal and life-shortening conditions (Hospice U.K. 2019). This means that supportive care for longer term survivors is limited or at least not openly available.

At the time when cancer survivors came forward in hospices, ever more national and international voices mentioned the need for more support for cancer survivors and for research into the specificity of their experience. Although the American National Coalition for Cancer Survivorship replaced the word 'cancer victim' with 'cancer survivor' in 1986 (NCCS 2016), it was not until 20 years later when Feuerstein (2007) specifically addressed health care professionals in general with his 'handbook of cancer survivorship'. Also in 2007, the National Cancer Survivorship Initiative (NCSI), a partnership between the Department of Health (DoH), MacMillan Cancer Support and NHS Improvement, was launched in the U.K. (DoH 2010). Supported by patient surveys a wide range of survivorship research and health care developments was initiated (NCSI 2013). A better understanding of the survivorship experience is deemed important as already 2.5 m people in the U.K. live with cancer (Macmillan Cancer Support Media Centre 2019). Cancer Research U.K. statistics show that, in England and Wales, since 2010, 50 % of people who were diagnosed with cancer (2019b), and 57 % of people diagnosed with bowel cancer (2019a), survive for 10 years or more and this figure is expected to increase. Lickiss (2009) echoes the World Health Organization in asking researchers to explore vulnerability at all stages of survivorship.

It was the realisation that more and more people will live beyond cancer, my personal confrontation with and wider information about cancer survivors' request for support, and the realisation that there was plenty of scope for improving the understanding of their experience, and therefore, of the therapeutic effectiveness of support, that formed the basis for my motivation to research the experience of cancer survivorship.

Cancer survivorship is a multi-faceted experience and is researched from a wide range of angles (see the literature review in Chapter 5). In the next section I describe the background of my choice to explore specifically how survivors experience their self vis-à-vis cancer.

## **1.2 Self vis-à-vis cancer**

As a counsellor I listen to how survivors express and explore what cancer means to them. Initially this is also how the topic of this research was presented to potential participants, i.e. by using the phrasing "how does the meaning of cancer progress during cancer survivorship?" in participant recruitment material. However, as my own awareness of my implicit focus refined, I realised that I was specifically interested in what cancer means for their experience of self. Moreover I noticed that at times the meaning people attribute to cancer shapes their view of self, while at other times their view of self shapes the meaning they attribute to cancer. Consequently, it felt more accurate to present the experience of self in interrelation with cancer as the topic of this study.

The phrase 'self vis-à-vis cancer' has been chosen as this arguably best captures the self facing cancer whilst it also considers the relationship between self and cancer but without personalising cancer, which I feel happens, with phrases such 'in relation to' or 'in interrelation with'. On the other hand synonyms like 'with regard to' or 'concerning' miss the potential mutual influence between the sense of self and the sense of cancer.

During the research sessions, the focus on participants' self did not mean that their narratives about the meaning cancer has or had for e.g. their family relationships, their ability to obtain insurance, or their reintegration in work, were discarded. Such narratives are all relevant as they co-constitute the experience of self. It has meant though that rather than asking participants "what does cancer mean for you?", opening questions were formulated in a manner that was less cerebral and that brought their *experience* of self in relation to cancer more to the fore, e.g. "how do you feel in relation to cancer at the moment?" In face-to-face conversation I believe the expression 'in relation to cancer' was appropriately neutral, whereas the expression 'vis-à-vis cancer' seemed too formal.

Although there seems to be no uniform use of lower or upper case to indicate the self in the literature, the self and the Self can refer to slightly different experiences. I have been guided by a description by Francisco Varela, Evan Thompson and Eleanor Rosch (1991, p.124) who refer to a distinction made by Minsky

"... the word *self* is a convenient way of referring to a series of mental and bodily events and formations, that have a degree of causal coherence and integrity through time. And the capitalized *Self* does exemplify our sense that hidden in these transitory formations is a real, unchanging essence that is the source of our identity and that we must protect."

The self as topic of this study will be written in lower case for two reasons. First, participants' expression of the experience of self vis-à-vis cancer may or may not coincide with the Self they identify with and which may also be called their 'true Self' or 'authentic Self'. Comparing participants' experiences of self may reveal such differentiations. But my research interest is wider than exploring whether the way people experience their self in relation to cancer coincides with what they consider their true Self. My interest is in the exploration of their experience of self vis-à-vis cancer in general. Whether this experience falls together with their true Self, or whether they accept or rebel against this experience of self vis-à-vis cancer in that moment is all part of this. In other words the focus of this study is on the experienced self; also

when this does not coincide with the Self people consider their authentic Self. Secondly, as will be addressed below, in this study the self is not explored as an essence but as a process, more specifically an embodied process. This correlates more with a lower case self.

In the remainder of this section the choice to research survivors' experience of self vis-à-vis cancer will be situated in relation to the dominant survivorship approaches in the health care sector.

Researchers report that cancer survivors have a fear of cancer recurrence and are on alert for a long time after finishing treatment (see the literature review in Chapter 5). This is an experience that most people empathise with as it is not uncommon to think of cancer as a potential life-threatening illness and that, notwithstanding innovations in cancer treatment, not enough progress is being made (Ramers-Verhoeven et al. 2013). It is also an experience that is backed up by neuro-biological explanations of the role of fear for survival (see below). Macmillan Cancer Support (2019, p.1) reports that "even 10 years after treatment 54 % of cancer survivors still suffer from at least one psychological issue."

Support services employ different approaches which could be explained by referring to differing views on e.g. therapeutic effectiveness, cost-effectiveness, best practice, and so on. It falls outside the scope of this thesis to explore the rationale behind the different approaches but I wish to explore briefly the meaning of the focus on the self vis-à-vis cancer in this study, in relation to support approaches.

With numbers of cancer survivors rising, the provision of support programmes has increased. In the UK, the NHS and Macmillan are the main providers of cancer survivorship support. These programmes focus on coaching cancer survivors towards healthy life-style changes and towards the self-management of medical and other needs. Clinicians consider the diagnosis as fertile ground for learning and are trained in taking the role of specialist

advisors and in structuring their support as personalised 'market place' contacts between patients and themselves (Fenlon and Foster 2009; Department of Health et al. 2010; National Cancer Survivorship Initiative 2013). Based on an exploration of the psycho-social clinical literature, Bell (2012) confirms this approach underpins most cancer survivorship support. This goal oriented approach, aimed for by focusing on behavioural changes, implies that patients are encouraged to put aside thoughts about cancer and to disconnect from the trauma of the cancer diagnosis, or, as Bell puts it, in most cancer survivorship support interventions it is deemed desirable and possible to 'cut off' from what has happened, and to accept a tabula rasa thinking from where the 'remaking of the self' can start.

In my own counselling practice many cancer survivors express this wish to 'cut off' from cancer. What brings them to counselling though is often a struggle to manage this. In counselling this struggle is likely to be seen to be brought about by incongruence between the behaviour aimed for and the thoughts and feelings in relation to cancer. The therapeutic approach will be one of engaging with cancer, which entails a focus on what may be seen as negative thinking and dwelling in vulnerability. Certainly from a person-centred approach this is believed to be the route to integration and well-being. What caught my interest though are the varying expressions of self in relation to cancer. The person who has just completed treatment may relate in a different way to cancer than the client who finished treatment a year ago, or five years ago or the occasional client who finished 10 years ago. The way people relate to cancer when they access counselling, is not only different depending on where they are in this process. It may also differ depending on how they felt before they experienced a need for support, or how they hope they will feel in the future.

In this study the aim is to be open to the experience of cancer. I am aware that exploring the meaning of the relationship between self and cancer can be particularly relevant for therapists who find it useful to explore rather than put aside survivors' relationship with cancer. I am also aware that a lack of

understanding of the variations in the relationship between self and cancer could contribute to the widespread focus on the experience of 'cutting off'. There is also an advocatory drive behind my choice of topic as I hope this research will help to break down the view that the complex reality of self needs to be managed rather than embraced. This outlook resonates with voices that plead to leave behind an over-emphasis on positive thinking in cancer care (Holland and Lewis 2000; McCreddie et al. 2010), with those that encourage doing the 'invisible work' of hearing all of patients' human experience (Ellis-Hill 2011) and with those that urge to explore experiences with openness to both vulnerability and agency (Dahlberg et al. 2009).

For reasons of clarity I would like to make two more points:

By attending to cancer survivors' self vis-à-vis cancer I do not wish to deny that cancer survivors simultaneously experience their self in ways that are unrelated to cancer. In other words the self vis-à-vis cancer is, what has been called, a 'self-aspect' (McConnell 2011).

The topic of this study originated in my experience with survivors in counselling. Their relationship with cancer was often experienced as distressing. This research however is deliberately not restricted to the experience of survivors whose self vis-à-vis cancer was experienced as distressing and this will be reflected in the participant recruitment and sampling process. The topic is the experience of self vis-à-vis cancer, in general. I am as much interested in people's experience when they consider cancer as a non-issue as when they consider it as deeply disturbing for their self. The choice to widen my research to include the experience of cancer survivors whose experience did not create a need for counselling only gradually emerged as an option. It was with hindsight that I realised how I had been emotionally attached to the topic as I knew it from my professional experience. As described by Etherington (2004) I have experienced this move beyond my own experience as an important step in becoming a doctoral researcher. I believe that exploring a wider range of cancer

survivorship experiences has led to a deeper understanding of the experience.

So far only the general background of my research topic has been described. To explain further details I need to refer to an on-the-job case study. Reflections on the case study experience have determined how the research topic has been further honed, while the theoretical framework generated in the case study has significantly influenced the development of the research approach.

### **1.3 On-the-job case study at the inception of research topic and approach**

In 2005 my professional interest in cancer survivorship led to the start of a five year case study with the aforementioned Edward as the case study participant. This case study focused on the gathering and exploration of eight metaphorical reflections that were formulated by the participant to express how he experienced and conceptualised his self at different times after finishing the cancer treatment.

In appendix A0 I explain how this focus on metaphors came about and how data were gathered. The findings of this case study motivated the present research in general but more specifically, as is described in the next two sections, they influenced the decision to focus on bowel cancer and to include the experiences of long-term survivors. In the following three sections it will be clarified how this case study has also shaped the research approach.

#### **1.3.1 Bowel cancer**

In the research at hand a deliberate choice was made to work with one tumour group. I wished to exclude variations in people's survivorship

experience that were directly informed by differences in life-expectancy based on the type of tumour. Bowel cancer was selected because it is a diagnosis that affects both men and women and has a high percentage of survivorship (Cancer Research UK 2019a). It was also the diagnosis of the case study participant. This supported the choice for bowel cancer as I wanted to explore and present the research findings in conjunction with the case study findings (see 1.4.2 and Chapter 8).

### **1.3.2 The self at different times post-treatment, including long-term survivorship**

During the first year post-treatment the case study participant had expressed two distinct experiences of self in interrelation with cancer. However, during the transition from the first to the second year four more emerged and two more metaphors were taken down around the third and fourth year post-treatment. In 2009 the case study had to be put on hold but not only was the ongoing change in the experience of self in relation to cancer confirmed by my experience with other counselling clients (see above), there was also a feeling that more variations would occur.

Neuro-biological insights expressed by Cozolino (2006) strengthened my belief that it was not irrational to expect survivors to be on the alert in relation to cancer for much longer than people who have not been diagnosed with cancer might expect. Cozolino argues that when something happens that might undermine survival, a fear response is automatically triggered. Fear resides in the amygdala whose role it is "to remember a threat, generalise it to other possible threats and carry it into the future" (Ibid., p.319). We are biased towards fear; it is the body's way of being alert for ongoing survival threats.

"Based on our neurobiology fear outranks and outwits love in a number of ways. Fear is faster, automatic, unconscious, spontaneously generalised to other stimuli, multisensory, resistant to extinction" (Cozolino 2006, p.318-319).

Cancer survivors may have felt threatened in their survival to different degrees but it is reasonable to expect that for the majority of survivors their journey of recovery will have started with a strong fear response. Expecting it to fade swiftly is somehow contrary to neurobiological understandings of the function of fear. The overall impact of fear on the brain is that its capacity for integrating information decreases. This means that bodily, emotional and thought processes do not unite appropriately (Ibid., p.32). This helps to understand why survivors struggle to go back to 'normal' as is often expected.

Yet this does not completely paralyse people. On the contrary, in situations of stress, stress hormones are released which instigate biological changes that augment neural plasticity and enable adaptive coping and learning (Huether 1998 cited by Cozolino 2006, p.214). Cozolino also explains that the human brain is a social brain; it has an innate capacity to connect with people. It is this tendency to engage and connect, to love, that has the power to counteract fear (Ibid., p.316). That survivors seek to maintain connection with people who understand the source of their fear and engage in programmes that are geared to find new ways to cope, seems supported by these neuro-biological findings.

A not unimportant note for health care practitioners is that when people have been confronted with extreme stress, at a young age or for a long time, their behaviour and brain functioning becomes rigidly organized around fear. Avoiding exploration and stimulation becomes the norm and this further jeopardizes their skill to counteract fear (Ibid., p.214).

This idea that the re-conceptualisation of self in relation to cancer might continue for a long time and perhaps even as long as people live post cancer treatment, spurred me on to recruit participants who were up to 20 years post-treatment. This expands the five year remit of the case study and it takes into account that nowadays more than 50 % of bowel cancer patients survive for 10 years and longer (see above). The literature search also revealed that

only a limited number of qualitative studies have researched the experience of longer term bowel cancer survivors (Appleton et al. 2013).

### **1.3.3 Sensori-motor embodiment of metaphorical conceptualising of self**

At the start of the case study, the metaphorical nature of the participant's expressions caught my attention. I wanted to explore the metaphors but initially I was - if I can use creative language - in need of a 'muse' to find an original approach. This came coincidentally when I was introduced to embodied cognitive science via George Lakoff and Mark Johnson's Conceptual Metaphor Theory. Later in this thesis the term 'enactive' will be used as a more specific, but nevertheless synonymous term for 'embodied' as far as Lakoff and Johnson's theory is concerned. This theory and the term 'enactive' will be explained in more detail in Chapter 4. At this stage I will summarize three points: First, Lakoff and Johnson (1991) argue that the 'what' and 'how' of conceptualising, including the conceptualising of the experience of self, is a neurological achievement that is not only happening within a body and within a brain, but is influenced – they use the term 'shaped' (ibid, p.16) - by the features of the human brain and body, and the implications of these bodily features for the way people engage in the world. Secondly, they focus specifically on the impact of sensori-motor-spatial embodiment on conceptualising (an example follows). Thirdly, they consider *metaphor* as the *non-conscious neurological mechanism* that links sensori-motor-spatial embodiment with conceptualising. In other words conscious conceptualising is considered as sitting on a vast amount of non-conscious, pre-conceptual thinking. This non-conscious part, the "hidden hand" beneath conscious thought, is seen as taking up 95% of thinking (Lakoff and Johnson 1999, pp.11-12) and thinking is considered as embodied and as metaphorical. In relation to the case study, Lakoff and Johnson's Conceptual Metaphor Theory spurred me on to pursue an exploration of the case study participant's experience of self by zooming in specifically on the metaphorical expressions

and on highlighting the sensori-motor and spatial features of the subjects conjured up in the metaphors (see the example below). This method of exploration will be revisited and adapted for the research data inquiry (see at 7.4.3.1). Experiencing the results of this exercise led to the decision to use this perspective for the research for three reasons.

First, highlighting the embodied features in the metaphors proved to be a criterion that enabled a systematic and detailed differentiation of a variety of expressions of self. This meant that comparisons were possible and this enabled me to shed further light on the specificity of each of the experiences. The following examples may clarify what I mean by claiming how the spatial and kinaesthetic features embedded in metaphors can be used as criteria to differentiate metaphorically expressed experiences. Earlier I referred to the expressions 'cutting off' and 'not cutting off' from cancer. For example a survivor may express their sense of 'cutting off' as "cancer is like a terrorist who has left the country", while somebody else may specify it as "having kicked cancer in the long grass". In both metaphors cancer is put in a different space than the self (cut off), but the kinaesthetically passive versus active self makes that the first metaphor speaks of an anxious tension while such tension is absent in the second metaphor. The expression 'not being cut off from cancer' could be specified as "cancer trips me up", but it could also mean "having a grip on cancer". Metaphorically in both cases cancer is in the same space as the self, but in the former cancer controls the self kinaesthetically, while in the latter the self is controlling the cancer.

Secondly, the choice to take this cognitive embodied approach forward into this research was further consolidated when I experienced that an engagement with the highlighted embodied features of the metaphors triggered a quasi-automatic embodied empathic response in me. I anticipated that research findings that took such an embodied form would impact in a similar way on survivors and health care practitioners with whom I intend to share the findings. This will be explored in the practice part of this thesis (Chapter 10).

Thirdly, exploring self-expressions through a lens of embodiment is both an acknowledgment of the body as 'enabling' thinking but at the same time as 'shaping and therefore limiting' what can be thought.

The use of spatial and kinaesthetic bodily experiences to express experiences occurs un- or non-consciously, and automatically. Although some authors (e.g. Lakoff and Johnson) use the term 'un-conscious' I will use the term 'non-conscious' in relation to cognition and other sub-personal processes addressed in this thesis (except when used differently in quotes). This is to avoid confusion with the meaning of un-conscious in psycho-dynamic theories, where it suggests 'suppression' and the need for psychological treatment, rather than the merely and neutrally non-conscious.

Based on the three reasons mentioned above, the decision was made to adopt this strategy (i.e. eliciting metaphorical expressions and shedding light on their spatial kinaesthetic features) for my research. Two more considerations need to be made here. First, I did not wish to dismiss that Lakoff and Johnson's outlook stands on a premise that is contrary to the disembodied view on conceptualising and language that had influenced my and many people's education. If embodied cognition was to be the theoretical basis of this research it seemed apt to explore the roots and implications of this view in more depth. In Chapter 2 I will attend to neurological insights that underpin this view, while in Chapter 4 I will cover phenomenological philosophy that supports this outlook. Secondly, Lakoff and Johnson's Conceptual Metaphor Theory focuses on the impact of the neurological embodiment of sensori-motor experiences on conceptualising. This meant that during the case study the exploration of the meaning of the experience of cancer in interrelation with the self was focused on the meaning as expressed with reference to the sensori-motor 'logic' embedded in the conceptual metaphors. These opened up questions about other forms of embodiment and how their neurological imprint might impact on conceptualising, and about whether I needed to widen the embodied lens of the research (see below).

#### **1.3.4 Self in response to medical interactions and other life events**

It was a given from the start that the conversation between the case study participant and myself would evolve around his experience of self in relation to cancer post-treatment. What became apparent later on was that the trigger for new conceptualisations of self was, more often than not, the case study participant's experience of contact with his medical consultant, or his view of their role in his present health status. Communication with other clinicians also impacted on his illness experience but did not seem to change the way he thought about his cancer. This is not really surprising as it is mainly through the clinical and technical assessments of consultants that survivors gather information about the presence, absence or state of cancer in their body.

As the experience of cancer, in the case study, seemed to be related to the participant's interactions with consultants, it seemed relevant to include this angle in the research project at hand as well. I did not presume that the research participants would equally focus on their consultant. I therefore decided to explore how participants perceived their relationship with whomever they considered to be the main clinician. However, most participants referred to their consultant and consequently it is this interaction which has been explored in the data inquiry.

During the case study the actions of cancer clinicians and consultants were implicitly accepted as the instigator for the participant's experiences and conceptualisations. The relationship between conceptualising of self and interacting in the world is a core element in theories of 'embodied cognition' and led to a revisiting of my initial unilateral perspective (see below).

### 1.3.5 Interpreting direction of change of self conceptualisations

A comparison of the different metaphorical conceptualisations of self in the case study led to a tentative conclusion that the conceptualisations were increasingly intricate. This showed itself in an increase of the sensori-motor complexity that shaped the metaphors. Content-wise it referred to a self that seemed to feel increasingly in control over cancer and overall more engaged in the world. From a person-centred counselling perspective this picture resonates with the concept of a basic self-actualising tendency (Rogers 1951). In the research literature on cancer survivorship this idea seems expressed in Joseph's (2011) theory which defines survivorship as a process of posttraumatic growth. At the start of the design of this research the question to answer was how this phenomenon is understood within the theoretical framework of this thesis (see below).

## 1.4 A quest for comprehensiveness

In summary, in this study I will explore the experience of self vis-à-vis cancer as it is metaphorically experienced and conceptualised by bowel cancer survivors who have not had active disease since finishing their treatment, and who are spread out over time between 6 months and 20 years post-treatment.

I have a longstanding interest in a holistic understanding of people's experiencing and this has motivated a comprehensive study approach. It has been a strenuous exercise and the urge to do so I see best expressed in the following words:

“Comprehensiveness requires a disposition to be *alert to new orders of significance and also a sense for the whole*, held without any assurance that a definition of it is adequate” (Weinstein 1985, pp.14-15).

Below I describe three ways in which I have actively searched for 'new orders' and a more complex 'whole'. First, at the inception of this research the focus

is on the delineation of an unrestricted number of different expressions of self vis-à-vis cancer. Secondly, the findings of the on-the-job case study that instigated the research will be considered and presented together with the research findings. Thirdly, a theoretical and methodological framework that takes account of the multiplicity of human embodiment will be developed and used to interpret the totality of findings.

#### **1.4.1 Pursuit of data variations**

I claim that a focus on the self with the aim to shed light on as many variations as possible during survivorship is complementary to the perspective that underpins the majority of cancer survivorship support programmes. It is an approach that values an exploration of experiences that are often hidden and speak of vulnerability. Such experiences are more likely to remain under the surface when the usual focus, seems to be, both in policy and in practice, on the strong autonomous and goal-oriented conscious self.

Exploring the experience of self by concentrating on the embodied non-conscious dimension of the metaphorical expressions and conceptualisations of the experience is, I believe, an original and effective way of exploring subtle but meaningful differences in the experiences of self during cancer survivorship, and of deepening the understanding of these experiences. In the literature review I will revisit this claim of originality.

#### **1.4.2 Complementary exploration of research and case study data**

So far it has been explained how the on-the-job case study instigated this research, how the preliminary findings guided initial choices regarding the research topic and approach, and how the study had triggered an aspiration for a wider theoretical consideration of the meaning of embodiment for the experience and conceptualisation of self.

From the start it was also the intention to include the case study findings in this thesis. First, as indicated in the introduction, I consider a Doctorate in Professional practice to be a platform where understandings that have emerged in a professional context can be acknowledged. Secondly, cancer survivorship incorporates the experience of widely varying degrees of illness severity but the number of participants one can recruit for a qualitative study is limited. The case study participant had been diagnosed with a rather severe degree of cancer. In order to widen the scope of experiences explored, a number of research participants have deliberately been recruited for their lesser illness severity (see 7.1.2).

It is with confidence and integrity that the case study findings have been included in this thesis as the data have been gathered with rigour and ethical awareness (see appx.A0). Although the aim of this study is to build an integrated picture of the experience of self during cancer survivorship, the data will be explored and the findings presented in a manner that at all times makes it easy to distinguish the data from the research participants from the case study data.

### **1.4.3 Development of a multiple embodied research lens**

The questions in 1.3.3, 1.3.4 and 1.3.5 were triggered by reflecting on the approach and findings of the case study and by revisiting the literature on embodiment. It led to an overall feeling that the focus on the sensori-motor embodiment of conceptualising of self at least needed to be contextualised in relation to other forms of embodiment and that a research approach that combined several lenses of embodiment deserved consideration. The three questions are:

- 1/ How to understand the interrelation between conceptualising and interacting in the world from a perspective of embodiment? (1.3.4)
- 2/ How to understand self conceptualisations and the direction of change from a perspective of embodiment? (1.3.5)

3/ Are there other forms of embodiment that play a role in conceptualising of self? (1.3.3)

As Lakoff and Johnson's theory had directed my attention to the neurological dimension of embodiment, I chose to explore the questions first from a neurological perspective (see Chapter 2). This enabled not only the formulation of the research aim and main question but also resulted in five sub-questions and objectives (see Chapter 3).

Chapter 4 provides a more detailed exploration of the philosophical underpinnings of the research questions.

## 2. Neurological embodiment of self and thinking

Neurological science is not my field of training but the writings by authors who have made an effort to make the field accessible for other disciplines have helped me take forward the three questions above and have consequently inspired the way survivors' experiences of self vis-à-vis cancer have been explored in this study.

This chapter starts with a neurological explication of the relationship between self, brain, body and environment. This leads to distinguishing different stages of self, their link with different dimensions of embodiment and how these dimensions are at work when human beings conceptualise and express their experience of self.

Antonio Damasio, a neuro-scientist whose book 'Self comes to Mind' has informed this chapter, discusses the crucial role of the 'body-proper' as the linchpin between the brain and the world.

“... the representation of the world external to the body can come into the brain only via the body itself, namely via its surface. The body and the surrounding environment interact with each other, and the changes caused in the body by that interaction are mapped in the brain. It is certainly true that the mind learns of the outside world via the brain, but it is equally true that the brain can be informed only via the body” (Damasio 2012, p.91).

The interaction with the environment processed via the body-proper, is neurologically enabled and imprinted. In response to the first question about the interrelation between conceptualising and interacting in the world, it is the impact of the bodily changes in the brain caused by the interacting process that Damasio brings to the fore.

In the next section the relationship between the self and the brain is addressed. This is relevant as the topic of this study is the experience of self, the 'I' that comes to the fore in relation to survivors' experience of cancer at specific moments in time.

Damasio (2012, pp.20-24) explains how the self that can say 'I', which he calls the autobiographical self, from an *evolutionary perspective* has come into experience, by likening it to a conductor of an orchestra. The orchestra is used as a metaphor for the brain. In contrast to a real orchestra though, the self as conductor was not present at the start but came into existence as the performance of the orchestra, the brain, gradually unfolded over time. This means that the brain is seen as creating the self and not the other way around.

As the brain, from an evolutionary perspective, gradually evolved, two stages of self preceded the autobiographical self. The first stage of self, which Damasio (2012, p.202) calls the 'proto self', refers to a self that is limited to an elementary feeling of existence and having a living body. It is the stage where the self operates as an 'organism' that interacts 'bio-chemically' with the 'environment'. The proto-self evaluates what ongoing processes within the body, e.g. metabolism, basic reflexes, immune system, pain and pleasure behaviour, basic drives and motivations mean for its welfare and survival (Johnson 2007, pp.55-58). Imbalances in the bodily states trigger 'emotions'. In social and psychological sciences the word 'emotion' may be used as a synonym for 'feelings'. In this context the word 'emotion' refers to a chemical response.

Emotional responses to a distortion or threat trigger neuro-chemical changes which in turn affect the whole body and its musculature. These events change the proto-self. The overall feeling of existence changes into a feeling that differentiates and draws attention to particular objects. These events are non-verbal but they are happening to a protagonist, a self that is a proper self rather than a proto-self. It is an action-based self and Damasio calls it the stage of the core-self (p.203). By acting and behaving towards the world, be it just in the moment, structures of sensori-motor experience develop. These are often referred to as 'body schemas', as Thompson (2005, p.412) points out, not to be confused with 'body image':

“In the body image, the body is experienced as owned by the experiencing subject, and the image is typically a partial representation insofar as conscious awareness usually attends to only one part or area of the body at a time. The body schema, on the other hand, is neither an intentional object of consciousness nor a partial representation of the body, but rather an integrated set of dynamic sensorimotor principles that organize perception and action in a subpersonal and nonconscious manner.”

Body schemas are laid down in the brain as ‘image schemas’ (Johnson 2007). This ‘core self’ or ‘action-based self’ seems to resonate with what Shaun Gallagher calls the ‘minimal self’ which he describes as a self that is basic, immediate and devoid of temporal extension. It is limited to the momentary sense that it is my body that is moving (self-ownership) and that I am the initiator or source of the action (self-agency). It is a self-consciousness that is pre-conceptual and pre-language. Research shows that a human infant is already equipped with a minimal self that is embodied, enactive and ecologically tuned (Gallagher 2000).

The primitive, minimal, core self does not say ‘I’ yet. Further neurological developments are needed before that becomes possible. The self that can say “I”, is referred to as the ‘autobiographical self’ (Damasio 2012) or ‘narrative self’ (Gallagher 2000). The crucial difference with the previous stages of self lies in the fact that this self comes with a sense of personal identity and a sense of continuity across time. The conscious self could not hold all that constitutes its identity in its conscious mind. However the brain developed the capacity to hold a vast amount of memory records non-consciously. These are records of physical skills but especially of experiences of personal events and facts (Damasio 2012, p.289). The advanced brain also enables an integrated way of thinking and feeling which makes encompassing past and anticipating future experiences possible (Ibid., p.23). From an evolutionary perspective, the autobiographic self emerged to improve the effectiveness of the proto- and core action-based self (Ibid., p 270); the autobiographical self enabled a better life regulation, or what Damasio also calls homeostasis, in increasingly complex environments (Ibid., p 57).

These three stages of self do not only describe the evolutionary process of the brain. Cozolino's description of the development of self from childhood onwards echoes the same process:

“It is safe to assume that the self consists of many layers of neural processing that develop from the bottom up as we grow. The first systems of internal bodily sensations are joined by sensory-motor systems, added to be emotional and cognitive processing, and later topped off with abstract ideas and beliefs. This entire multilayered experience is then described in a co-constructed life story and labelled with the term ‘I’ (Cozolino 2006, p. 338).

What is especially relevant for this study is that according to Damasio (2012) not only the evolutionary self but also the self of the present day adult human being is not independent from but rather constituted by brain activity. In that sense it seems more correct to consider the self as a ‘process’. This contrasts with how lay people refer to the self as if it were an ‘entity’ or even a brain independent entity.

The view of the self as a ‘process’ seems to tip over in debates about the realness of self. Damasio (Ibid., p.24) does not hesitate to say that once the self gained the status of conductor of the orchestra, even if that still means that it is “cobbed together by feelings and a narrative brain device”, “this fact does not make the conductor any less real.” He adds: “The conductor undeniably exists in our minds, and nothing is gained by dismissing it as an illusion.” Other neuro-scientists, e.g. Varela et al. (1991) conclude from the neurological findings that ‘there is no self’ and refer to Buddhist philosophy where the self is rather seen as a metaphor and one that is better left alone:

“Self, it turns out, is a metaphor for a process we do not understand, a metaphor for that which *knows*. The insight practices reveal that such a metaphor is unnecessary, even disruptive. It is enough, these practices reveal, to open to the ongoing process of knowing without imputing *someone* behind it all” (Epstein 1996, pp.154-155).

The focus of this study is on the understanding of self from a perspective that any understanding of self is by definition metaphorical. I find it important to hold in awareness these different views on whether there is an ontological

self behind the metaphor but it is not necessary for this study to take a position in this debate.

The higher cortex conceptualising from where the self in the contemporary adult human being springs, is also ongoingly embedded in the pre-conceptual, non-conscious and lower cortex neurological processes that are linked with the body-proper processes (Damasio 2012, p.275). This means that cognition is underpinned by emotion (Damasio 1994). Johnson (2007) explains that the brain developed through evolution by adding to rather than replacing existing brain structures. The result is that the brain uses both core limbic and higher cortical shell structures and that the processes that through evolution led to less developed stages of self are now integrated in the workings of the higher cortex.

According to Johnson (2007, p.100) “structures in the core regions are massively interconnected, whereas structures in the shell are more sparsely interconnected.” Johnson points out that cognition moves from core to shell. Consequently experience always starts with a pervasive unifying quality of a whole situation as it stems from the dense core limbic system that is mainly responsible for body monitoring, motivation, emotions and feelings (Ibid.; see proto-self described above). But after the situation is given as a whole, objects, properties and relations are discriminated (Ibid., p.75). They are not ‘givens’ but ‘takings’. They emerge through the involvement of the shell cortical structure that enables perception, body movement (see core self) and the features of the autobiographic self such as action planning, reasoning, values and history (Ibid., p.100). These objects are still saturated with the meaning already present in the early ‘whole situation’ experience (Ibid., p.76). This process sheds light on the second question about the direction of conceptual changes.

Feldman describes the involvement of lower cortex processes in higher cortex functions such as language:

“... any approach to an embodied theory of language requires mechanisms of neural computation used for other purposes and adapted to thought and language – detailed structures in the visual system, the motor system, and basic learning mechanisms” (Feldman 2008, p.8).

He confirms that metaphor is, as is also the core statement in Lakoff and Johnson’s Conceptual Metaphor Theory, the neurological mechanism that brings embodied knowing into conceptual and linguistic knowing:

“There is now very strong evidence that essentially all of our cultural, abstract, and theoretical concepts derive their meanings by mapping, through metaphor, to the embodied experiential concepts...” (Feldman 2008, p.199).

Based on what has been discussed so far, and as an answer to the third question, I distinguished five levels of embodiment that underpin conceptualising and the emergence of self. These will be summarized below and are presented in relation to the different types of self in Figure 1:

1/ Equipped with a brain and body-proper, a person’s engagements with the environment take the form of actions and interactions. In this thesis this will be indicated with the term transactions (details in Chapter 4). They in turn trigger reactions in the body-proper which are also laid down in the brain. This process I will refer to as ‘transactional embodiment’ (see the grey box in Figure 1).

2/ The body-proper reactions exist on the level of organs, chemical and biological processes which I will refer to as ‘bio-chemical embodiment’. These body responses are laid down in the brain as neuro-chemical responses. In isolation this does not generate a proper self but rather a proto-self (see the blue box and above in Figure 1).

3/ The body-proper also reacts as a sensori-motor entity with its specific shape, limbs and posture which I will call ‘sensori-motor embodiment’. These patterns of action are laid down in the brain as image-schemas. The self that

lives on the level of action in the moment is indicated with the terms action-based self and minimal self (see the pink box and above in Figure 1).

4/ The interactive engagement with the world also generates an internally felt experience in the body-proper which will be referred to as 'experiential embodiment'. This resonates with a capacity in the brain to store vast amounts of memories of experience which forms a building block for a sense of identity and continuation from past to future. This was necessary for the emergence of the autobiographical self. Also, the lower dimensions of body-proper and neurological embodiment and self are used to conceptualise where the fully narrative autobiographic self emerges from (see the green box and above in Figure 1).

5/ The automatic drive towards survival, both in evolutionary terms and in any actual human being, seems to have led to an advanced brain structure that results in a process of creating increasingly sophisticated discriminations within an initially undefined experience. These neuro-biological drives which lead conceptualisings of experiencing to change in a standard direction, I will call 'developmental embodiment' (see the purple box in Figure 1).

Higher-level neurological processes like conceptualising and language occur from the brain and as the brain is considered to be a form of body, are in themselves embodied forces. The attention in this thesis is really towards lower-level neurological embodied processes and their body-proper counterparts and how these impact on conceptualising, language and the self.

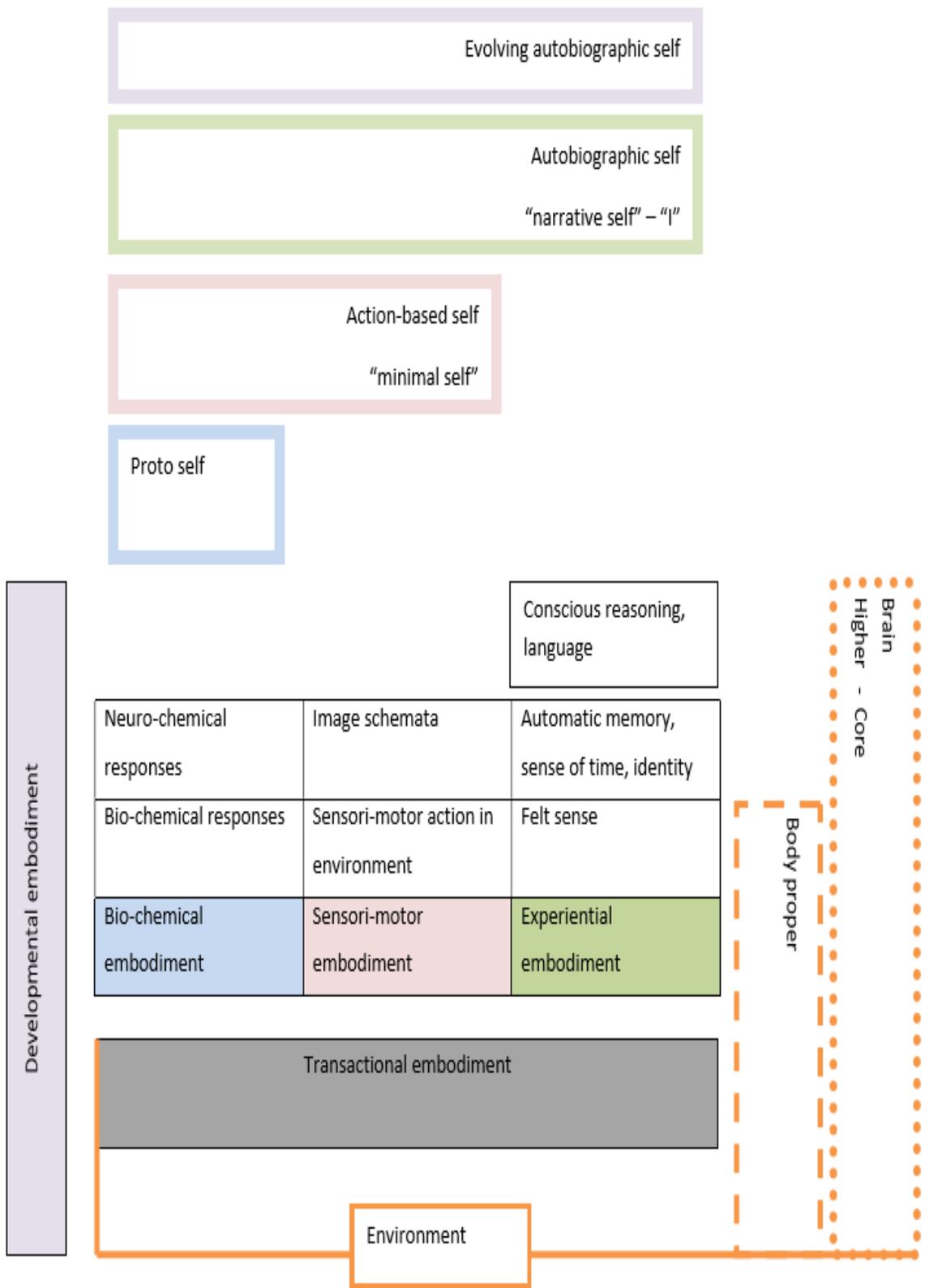


Figure 1: Five levels of embodiment and their impact on self

In conclusion, the neurological reflections have brought to the fore five dimensions (some authors use the term 'aspects') of embodiment involved with conceptualising and the emergence of self. I call them transactional, biochemical, sensori-motor, experiential and developmental embodiment. In Chapter 4 these dimensions will be further explored separately and as elements that constitute the concept of 'enactive cognition'.

Considering self as emerging from an interplay of such a range of dimensions of being and the specific consideration that self is co-constituted but cannot be reduced to brain activity, has been labelled by Gallagher (2013) as a "pattern theory of self". The role or weight of these aspects is likely to vary given individual circumstances (Gallagher and Daly 2018). In other words the coming together of the different aspects or dimensions is a dynamic 'process' and 'result'. If the word 'pattern' conjured up an image of 'patchwork', I rather think of it as a 'kaleidoscopic pattern', capturing that all the embodied dimensions simultaneously but in varying assemblages enable and mould self and thinking.

In the next chapter these five dimensions of embodiment will be taken forward in the design of the research aim, questions and objectives.

### 3. Research aim, questions, approach and objectives

In chapter 1 the topic of this study was described as the experienced, (metaphorically) conceptualised and expressed self that emerges vis-à-vis cancer for bowel cancer survivors who are at different times post treatment. In chapter 2 this self was described as a process rooted in and shaped by several dimensions of embodiment of which five were delineated. In the next section I will lay out how this has been taken forward into the research questions, aim, approach and objectives.

#### 3.1 Research question and aim

The **basic research question** I endeavour to answer is “How are survivors of bowel cancer *experiencing* their self vis-à-vis cancer post-treatment?”

I need to add that the way I intend to explore survivors’ ‘experiencing’ is by *exploring their expressions and conceptualisations of their experiencing* of self. This is symbolised below in Figure 2 by putting ‘experiencing’ in a thought or talk bubble. The thought and spoken ‘self experiencing’ expressed in dark green, the non-conceptual and non-linguistic ‘self experiencing’ coloured lightly.



Figure 2: The expressing and conceptualising of the experiencing of self

In Chapter 2 (and 4) I indicate how embodiment causes experiencing, conceptualising and language to be closely intertwined. Therefore it felt appropriate to capture these three concepts with the term 'comprehending'. The word 'comprehending' has been chosen deliberately. As a synonym for 'understanding' it refers to the cognitive and experiential dimension of an individual's knowing of their self. In this thesis the terms 'cognitive' and 'cognition' will be used in a broad sense, including both conscious intellectual activities such as thinking and talking and non-conscious mental operations and structures, e.g. visual and auditory processing, memory and attention, mental imagery, emotions, etc. This is the meaning used in cognitive science whereas in philosophy the terms may only refer to conscious conceptual systems (Lakoff and Johnson 1999, pp. 11-12). The word 'comprehending' was preferred over the word 'understanding' for two reasons. First 'to comprehend' is defined in the Oxford English Dictionary (2019) as "to include, comprise, encompass" which resonates with a consideration of understanding as a conflation of experiencing, conceptualising and language. Secondly, it expresses better the meaning of understanding as 'grasping mentally'. Since the kinaesthetic embodied dimension of thinking, talking and experiencing is at the core of this study, I appreciate how the word 'comprehending' also brings this dimension to the fore.

The **aim** is to build an understanding of survivors' *comprehending* of their self, but more specifically to do this by *exploring the embodied non-conscious processes* at work within their conscious experiencing, conceptualising and expressing. The five dimensions of embodiment that were delineated in Chapter 2 have been used as lenses to shed light on participants' comprehending of self. They will be refined into specific research sub-questions later but in Figure 3 below they are just briefly indicated.

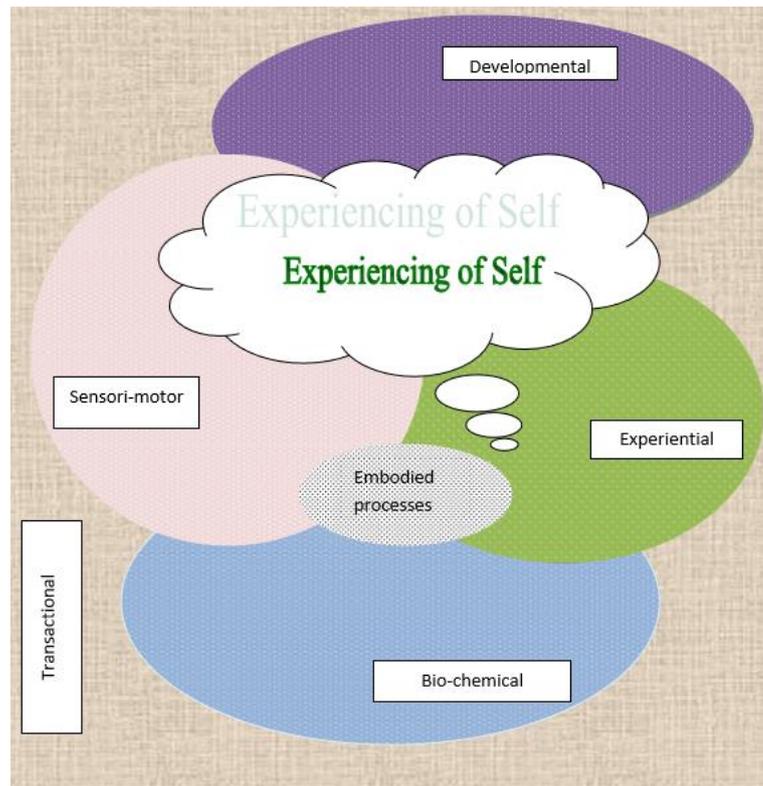


Figure 3: Five embodied lenses used to shed light on comprehending of self

When both the non-conscious embodied and conscious linguistic-conceptual angles of this research are taken into account, the **expanded research question** reads as follows: “What do post-treatment bowel cancer survivors’ ‘comprehendings of self vis-à-vis cancer’ look like when explored through the non-conscious bodily processes that shape their expressing and conceptualising?”

In this thesis I want to stay engaged with the process character of mental and bodily experiences and therefore from this point onwards I will only use the continuous form to refer to these processes. This means I will use the terms X is ‘experiencing / conceptualising / expressing / comprehending’, and X shares ‘experiencings / conceptualisings / expressings / comprehendings’.

Whereas the original exploration of the on-the-job case study evolved around the sensori-motor embodiment of the conceptual metaphors, for this research the decision was made to use all five dimensions.

Before exploring what this meant for the development of further research questions and objectives, in the following section an explication is given of the research approach implied in the above.

## 3.2 Research approach

With an interest in *exploring* survivors' subjective experiencing at the core of the research, this study sits within the broad family of *phenomenological* studies. In consolidating this choice I consciously put aside the option to test hypotheses that I could have formulated based on the case study. Furthermore I stepped back from considering or presenting what emerged from my explorations as 'explanations' or building blocks of a grounded theory. I aligned my researcher stance with my stance in person-centred counselling where I also endeavour to gain a feel for clients' subjective experiencing of the issues they bring. This choice not only generated a sense of congruence but it also gave me confidence that as a novice researcher I would be able to draw on skills that I had developed as a practitioner (Lees 2010; Finlay 2011).

However, the extended research question implies that the inability to attend directly to people's experiencing led me to consciously focus on the way participants were *conceptualising* and *expressing* their self-experiencing. This makes this study akin to the type of phenomenological studies that explore *how* people's experience arises in their consciousness (Finlay 2011). But, as indicated in Chapters 1 and 2, I have also drawn on embodied and enactive cognitive science to explore participants' thinking and communicating about their experiencing of self. In other words I made an attempt to *integrate a form of exploration, based in cognitive and biological science, into an overall phenomenological approach*. I believe this has been fruitful for the development of understanding the psychological experience of cancer survivorship. Traditionally a phenomenological study would not address the sub-personal mechanisms that enable us to experience in the way we do, but

that does not exclude that neighbouring disciplines can provide descriptions that have phenomenological relevance (Zahavi 2009) and vice versa (Gallagher 2004). In this study I aim to acknowledge and use insights from cognitive and biological science but considered in dialogue with phenomenological thinking. This approach may reside under what Zahavi (2009) describes as a modest form of Naturalised Phenomenology.

### **3.3 Research objectives and sub-questions**

The aim to look at survivors' comprehending of self through five lenses of embodiment, first resulted in the need to develop a better understanding of the dimensions of embodiment. This was realised through the study of five intertwined theoretical perspectives which then respectively informed the formulation of five research sub-questions.

Although the exploration of the theoretical perspectives is the topic of Chapter 4, they are summarized in the next section and the corresponding Figure 4 to enable the reader to make sense of the connected research sub-questions.

#### **Objective 1:**

The first research objective is to shed light on the conceptualised self by looking through the lens of sensori-motor embodiment of conceptualising. This is a repeat of the case study approach and was informed by revisiting Lakoff and Johnson's Conceptual Metaphor Theory (1999). This theory presents 'metaphors' as the neurological mechanism that embeds sensori-motor logic in conceptualising. Consequently the research question that guided this exploration can be formulated as: "What is the body schematic structure embedded in the metaphorical comprehending of the self vis-à-vis cancer?" *Or in short: what is the body-schematic structure of self?*

**Objective 2:**

The second research objective is to shed light on the conceptualised self by looking through the lens of experiential embodiment of conceptualising. This lens has been informed by Eugene Gendlin's process model (2018) which, rather than seeking meaning within the metaphors, states that it is in the very process of finding a metaphor that the meaning of a present situation in relation to the wider life context emerges. The uttering of the metaphor consequently carries the wider meanings forward. This has led me to appeal to participants' 'automatic memory' to generate life experiences that are felt to be meaningful in relation to their present metaphorical expressing of self. The guiding research question has been phrased as "What aspects of the wider self are noticeably involved in the process of comprehending the present self vis-à-vis cancer?" *Or in short: which self does the self vis-à-vis cancer carry forward?*

**Objective 3:**

The third research objective is to shed light on the conceptualised self by looking at the body schematic structures of self through the lens of the biochemical embodiment of conceptualising, and specifically on the impact of an organismic drive for survival and well-being. This has been inspired by Varela, Thompson and Rosch's theory of 'natural drift' (1991) which focuses on what is 'viable', feasible or possible, rather than what is ideal. This has been translated in the following research question: "Are there any body schematic structures that appear as impossible for the comprehending of self vis-à-vis cancer?" *Or in short: what is the body schematic boundary of self?*

**Objective 4:**

The fourth research objective is to shed light on the conceptualised self by looking through the lens of the transactional embodiment of conceptualising. This objective is based in Maurice Merleau-Ponty's (1968) embodied existential phenomenology, Varela et al.'s (1991) Theory of Enactive

Cognition and James Gibson's (1986) concept of 'affordances'. From a non-dualistic perspective events are not conceptualised as 'out there' and impacting on the self but as rather brought forward as actions and transactions of self in and with the environment. In this study I will focus on the transactions between survivors and their consultant. The research question posed is: "How do transactions during medical consultations function as affordances for the comprehending of 'self vis-à-vis cancer'?" *Or in short: which self does the transaction with consultants afford?*

**Objective 5:**

The fifth research objective is to deepen the comprehending of the individual experiencings and the overall cancer survivorship journey by comparing the comprehendings based on their body-schematic structure and ordering them according to a developmental sensori-motor logic. The research question posed is: "What does comparing the body schematic differences and similarities reveal about the self comprehendings?" *In short: do varying structures speak of changing selves?*

The exploration of the findings will be guided by the above research sub-questions. The exploration of the first and fifth objective has taken up most space and in that sense can be considered to be the most important objectives. Nevertheless, attending to the second, third and fourth objectives has been crucial in gaining an understanding of participants' self vis-à-vis cancer from a holistic and dynamic perspective.

The next chapter starts with a theoretical exploration of non-dualism and enactivism. These two philosophical concepts ground the theories that underpin the five research questions. These theories will be discussed in the second part of the chapter.

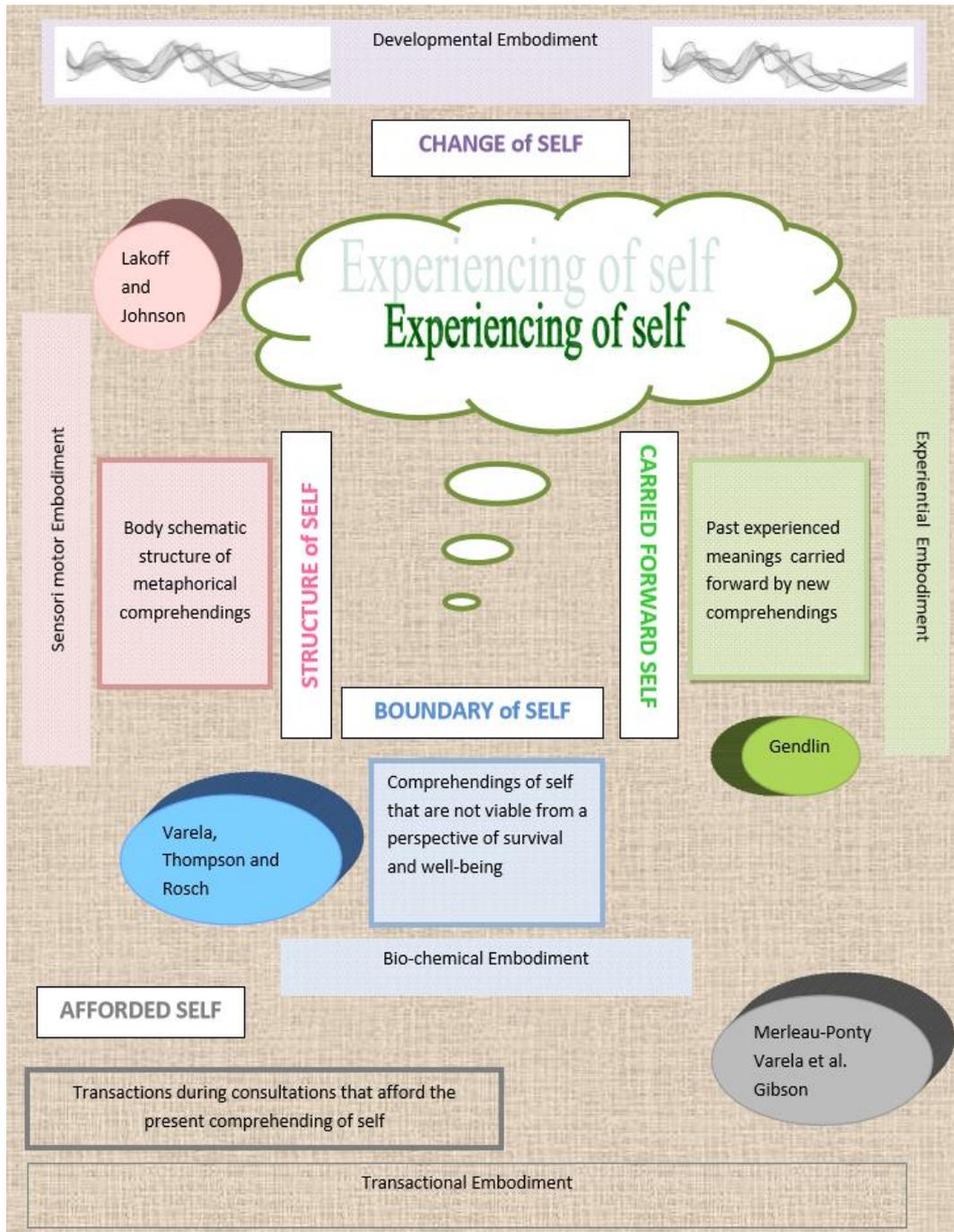


Figure 4: Five embodied processes impacting on the comprehending of self

## 4. Phenomenological embodiment of self and thinking

In this Chapter 'embodiment' will be explored from a philosophical angle in two steps:

First the focus is on the role of the body in the concept of 'non-dualism'. The brief exploration of the neuro-biological perspective on self in Chapter 2 did not only put forward the view that the brain constitutes the self and the conceptualising of self, but also the intertwinedness of the relationship between self/mind, brain, body and environment. This 'intertwinedness' has in philosophical terms been referred to as a *non-dualistic* perspective on mind and brain and implies a non-dualistic perspective on brain and body, and body and world. Consequently mind and world are seen as intertwined. As neurological findings increasingly supported this non-dualistic perspective, it has been applied in cognitive science where the term 'enactivism' was coined by Varela et al. (1991) to denote this non-dualism. These perspectives may be easily accepted in a neurological context but in lay thinking about cognition a dualistic perspective that considers mind, body and world as separate entities is probably more prominent. A dualistic perspective is also still upheld and defended by many theorists and researchers in both philosophy and science.

In the second section of this Chapter theories that further detail the five dimensions of embodiment encapsulated in 'enactive embodiment', and which have informed the research questions of this study, will be further discussed.

### 4.1 Non-dualism and Enactivism

Both in philosophy and cognitive science the *non-dualistic* viewpoint has gradually evolved over time. To clarify the implications of this perspective, I will start with a description of the *dualistic* mind-body perspective or what has

been called representational realism. I will then move onto phenomenological philosophy as this, within modern philosophy, seems to be the cradle of the consideration of the body from a non-dualistic perspective. I will describe how the role of embodiment has been understood respectively by Husserl, Heidegger and Merleau-Ponty. This will include the implications of the non-dualistic embodied perspective for the relationship between experiencing, thinking and language. In the last part the focus is on 'enactive cognition' as defined by Varela et al. (1991).

In summarizing the different philosophical perspectives on the embodiment of subjective experience and cognition I have been guided by the following ontological and epistemological questions:

- What is the nature of and relationship between 'mind', 'world' and 'subject'?
- What is the role of the 'body' in experiencing and understanding the world?
- Where and how does meaning and the consequent sense of self occur?
- Do objects and experiences have an essence?
- What is the relationship between meaning and language?
- What is the relationship between Subject and self?

#### **4.1.1 Representational Realism.**

According to Lakoff and Johnson (1999, pp.94-95), from a representational realist perspective, the meaning and essence of things in the world is considered to be in the things themselves rather than being defined internally in the mind. There is a gap between mind and world/body. Consequently the mind has no direct knowledge of the world. Instead the mind internally 'represents', 'copies' the outside world. This representation is therefore considered as absolute and as objective knowledge of the world. This 'representational realism' was introduced by Descartes. Lakoff and Johnson (1999, pp.553-554) outline their view on Descartes' perspective as follows:

Descartes challenged the earlier 'metaphysical realists' who also thought of the essence of things to belong to the things but who perceived the mind capable of absolute knowledge of the world through 'directly' grasping the essence of things in the world; they did not conceive of a gap between mind and world. Within the Cartesian perspective the mind uses human reason to represent the world internally. Human reason is believed to use some portion of Universal Reason, which is considered to have an objective 'existence' and characterises the rational structure of the world. In the first generation of cognitive science, informed by Descartes, the argument was that the world is structured mathematically by God. Yet mathematical symbols *are* different from the objects themselves but *represent* the world and objects most truly and precisely (in:

*Representational Realism:  
An independent Subject  
learns the meaning of the  
world through the use of  
the objective reasoning  
facility of their brain.*

Nagataki and Hirose 2007, p.221). Human reason is performed by the brain but is not shaped by the features of the brain (or body); it is disembodied reason, it is a 'faculty' of the brain. Lakoff and Johnson (1999, p.12) point out that within a representational realist perspective meaning is perceived as only having a conceptual and propositional (true/false) structure. Meaning is rational and conscious. Meaning is only 'cognitive' and cognitive in this view only relates to a conscious conceptual system. Non-conscious cognition does not exist. Meaning and cognition are considered as separate from emotions and feelings. Varela et al. (1991) summarises that in representational realism it is assumed that we inhabit a world with particular properties, and that we pick up these properties by internally representing them in our mind, but he also brings to our attention that it entails an assumption that there is a subjective 'we' (a self) that does this inhabiting of a world and the taking things up into our mind all the while being separate from the world and from the ideas. Merleau-Ponty (1968, p. 138) described this view as seeing the World as a box, with the body in it as another box and the 'see-er' in the body as a third box. In the context of this research, the word

'see-er' could be replaced with the word 'subject' or the word 'self'. The brain is seen as 'housed' in the body.

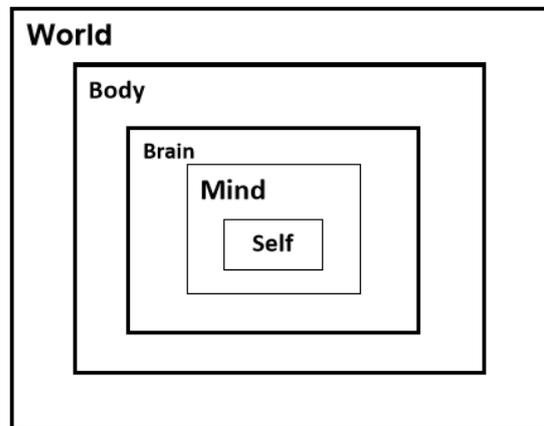


Figure 5: Traditional perspective on world, body, brain, mind and self

#### 4.1.2 Transcendental Idealism

In this second perspective, a phenomenological perspective, ideas and meanings come to us directly through our subjective experiencing of the world. Bullington (2013a,p.19-22) writes that Husserl, as the founder of phenomenology, drew attention to the fact that in addition to studying the world of objects from the objective view of the natural sciences, the world can also be investigated through our subjective experience of it. Through this subjective experience the world appears or shows itself to consciousness. The gap between mind and world is bridged through consciousness as this always flows to something outside of itself. This is referred to with the term 'intentionality'. Consequently that which appears in consciousness, appears because our consciousness has 'intended' it. It is consciousness, the intentional relationship with the world that constitutes the meaning of that which appears. To investigate the meaning of the human subjective world, one needs to turn to what people are conscious of. By describing both the manner of being aware (noesis) and the objects of awareness (noema) Husserl, in Bullington's reading, aims to reveal the 'essence' or the 'essential

general meaning structures' of a phenomenon. Finlay (2011) clarifies this by pointing out that focusing on description and avoiding interpretation does not amount to denying subjectivity. On the contrary, it is subjectivity that achieves objectivity. In the methods chapter this will be explored when addressing concepts like empathy and reflexivity (6.2.7). According to Dahlberg (2006, p.16) Husserl talks about universal essences, but in relation to understanding the lifeworld talks of essences as infinite, leaving open possibilities for further exploration; in other words open essences.

In a phenomenological perspective, Lakoff and Johnson (1999, pp.95-96) argue, knowledge of the world is not about gaining an absolute objective knowing, but about a knowing that is conducive to surviving, flourishing and achieving our ends. The world that is noticed is constituted by the subjective mind. What the mind notices is shaped by what part of the world we are engaged with. In other words the extreme Cartesian dualism between Mind and World is challenged.

For Husserl the body is 'inserted' between the material world and the 'subjective' sphere. The body is not 'in space', it 'inhabits' space. Human beings are not in the world like in a container, they are 'towards' the world through bodily tasks and engagements; they are 'situated' (in: Bullington 2013a, p.31). Carman (1999, pp.206-212) explores further how Husserl's view on consciousness relates to his view on the body. He describes how the body for Husserl is a 'lived body', a 'unity of body and soul'. It is not a thing like objects in the material world. It is a quasi-objective thing. The body can feel itself feeling and this creates an immediate sense of embodied agency. Husserl calls this 'bodily intentionality'. Through its immediacy it is different from knowing external objects, including one's own body in its external objective aspect. People identify with their quasi-objective body thanks to the localisation of their subjective sensations in the body. People have a sense of body as a bearer of sensations. But for Husserl the 'unity of body and soul' in the 'lived body' does not mean that consciousness in its connection to body loses anything of its own essence or that it takes up anything foreign to its

essence. In other words subjectivity may challenge the dualism between mind and world but nevertheless with Husserl the dualism continues as consciousness is conceived as prior to and therefore separate from embodiment and consequently from the world. Carman (1999, pp.214-224) argues that locating our sensations in parts of our own body means that we already understand the body in which we locate them as our own. In other words there is a sense of body but there is a prior sense of self. Husserl's sense of self, Carman argues, awareness of our self is the 'pure' or 'transcendental I' that stands at the centre of all our intentional acts and is independent of anything outside our consciousness, including our body. The body is not itself constitutive of intentionality. The body as quasi-object, as a lived body, is an achievement of transcendental subjectivity of an essentially disembodied transcendental ego. This ego has or owns the body as the locus of its subjective sensations. As meaning resides in consciousness and consciousness is achieved by a transcendental ego, this perspective is referred to as 'transcendental idealism'.

*Transcendental Idealism: An independent Subject experiences as meaningful those aspects of the world that it turns to subjectively with its disembodied consciousness.*

#### 4.1.3 Existentialism

From Inwood's (1999) reading of Husserl and Heidegger I understand that Heidegger agreed with Husserl that how things are is not independent of us but strongly depends on what we contribute to them but he does not share Husserl's view that we are pure consciousness. In contrast, as founder of Existentialism, he emphasises that we are concrete, existing human beings rather than pure consciousness. It is

*Existentialism: The essence of the Subject is in its ongoing changing 'Being-in-the-world-with-others' and consequently meaning changes as it emerges from such being.*

our being-in-the-world, our 'Dasein' that is essential (in: Inwood 1999, p.237). Dasein is essentially 'with others' from the start. The self is always also a 'they-self'. We do not first exist as isolated (conscious) subjects and then acquire knowledge and relate to others (Ibid., p.238).

The essence of 'Dasein' does not lie in there being a fixed nature but lies in "its always having its being to be, and having it as its own"(Ibid., p.236). It is part of Dasein to systematically misinterpret itself and its world (Ibid., p.237). Heidegger wrote that the meaning of names and words always changes according to the predominance of a specific line of vision toward the thing somehow named by the name (Ibid., p.239).

#### **4.1.4 Embodied Existentialism**

Building on Husserl and Heidegger, Merleau-Ponty focuses explicitly on the role of the body in our engagement in and knowing of the world. I have formed an understanding of what this means from his last book 'The Visible and the Invisible' (1968) and from interpretations of his work by Carman (1999), Marratto (2012) and Bullington (2013a). Merleau-Ponty's 'phenomenology of the body' expands on what it means to see the body not only as material but as an experiential structure, as a 'lived body' (body-subject) (Bullington 2013a, p.26). This results in questioning that consciousness is a distinct phenomenal region that mediates our bodily intentional orientation in the world as was proposed by Husserl (Carman 1999, p.206). Merleau-Ponty demands that we recognize that in embodied existentialism, consciousness and reality occupy the same conceptual space in the body. Mind and world are one in the body (Ibid., p.209). Merleau-Ponty (1968) describes what it means for the body to be simultaneously object and subject as follows:

"We say therefore that our body is a being of two leaves, from one side a thing among things and otherwise what sees them and touches them; we say, because it is evident, that it unites these two properties within itself, and its double belongingness to the order of the 'object'

and to the order of the 'subject' reveals to us quite unexpected relations between the two orders" (Merleau-Ponty 1968, p.137).

But then he corrects himself and moves further towards a non-dualistic view on the object and subject aspect of the lived body:

"To speak of leaves or of layers is still to flatten and to juxtapose, under the reflective gaze, what coexists in the living and upright body. If one wants metaphors, it would be better to say that the body sensed and the body sentient are as the obverse and the reverse, or again, as two segments of one sole circular course which goes above from left to right and below from right to left, but which is but one sole movement in its two phases" (Merleau-Ponty 1968, p.138).

In the last paragraph Merleau-Ponty moves from 'embodied consciousness' to 'intercorporeal being' (Finlay 2011, p.56). Instead of thinking of the World as a box, with the body in it as another box and the see-er in the body as a third box (Merleau-Ponty 1968, p.138), any separations are broken down when he conceptualises body as flesh. The relationship between the world and the body is like flesh applied to a flesh. The world neither surrounds the body nor is surrounded by it (Ibid., p.138), and there is no separation between body (body-object) and see-er (body-subject / mind) either.

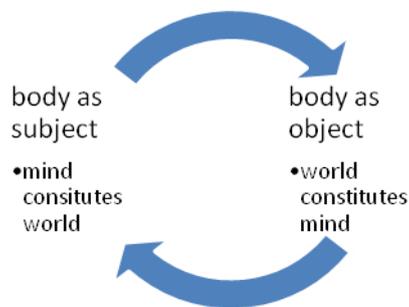


Figure 6: Body as subject and object

Carman (1999, p.224) concludes that for Merleau-Ponty the body in its perceptual capacity just is the I in its most fundamental aspect. Rather than having a body, we are a body. The body is a natural self and it is with our body that we perceive the world. This, Bullington (2013a, p.23) argues, implies that Merleau-Ponty suggested that we need to find another way to investigate the human world than through consciousness.

Marratto (2012) nuances this further. According to him Merleau-Ponty avoids the reification of a subject either as mind or as body. Subjectivity itself emerges in the living movement. It emerges together with meaning. Subjectivity emerges from a dynamic that happens before subjective consciousness. The subject only “inherits, takes up and transforms meanings that are generated in living movement, meanings of which it is not itself the ultimate source or ground, and which are thus never absolutely transparent to it” (Marratto 2012, p.2). And “Like subjectivity meaning also emerges in the living moment ” (Ibid., p.2).

For Merleau-Ponty (1968) meaning is neither in the mind, in the world nor in the body. It is in the ‘in-between’, the ‘entre-deux’. Or as Bullington (2013a) explains, meaning is that which emerges from the concrete encounter between the world and the tasks, interests and attentions that the subject brings to the scene. For Merleau-Ponty, meaning is not real, like a thing, nor ideal, like a thought.

*Embodied Existentialism: self and meaning are there in the fabric of the lived relationship between world, body and mind before appearing in the form of thoughts and language.*

It emerges as the world and the subject carve out each other ‘somewhere in the middle’ (Ibid., p.32). Whether Heidegger saw this differently is open to debate. Where my initial understanding was that for Heidegger meaning emerged within the subjective-being-in-the-world, it has been argued that in his later thinking mediation and relationality (Mitchell 2015) took centre stage and meaning was also considered to emerge in between mind, world and body.

In contrast to Husserl, for Merleau-Ponty it is not with a disembodied consciousness but with our bodies that we mediate the world. Bodies are constantly tacitly adjusting themselves in order to integrate experience and maintain an effective grip on things. He uses the concept ‘motivation’ to describe how one phenomenon releases another by the meaning it offers,

e.g. the movements of our body are naturally invested with a certain perceptual significance. In other words how we turn our body to the world is significant for what we notice. In doing so, ongoingly and non-consciously, a balance or gestalt in our bodily orientation in the world is preserved. This non-cognitive, pre-conceptual 'motor intentionality', Merleau-Ponty calls 'habit' (Bullington 2013, p.30-32).

Merleau-Ponty's insight was to put this pre-conceptual perception at the centre of the mystery of human existence. This perception is not an act, a deliberate taking up of a position; it is the background from which all acts stand out, and is presupposed by them (in: Bullington 2013a, p.29). This integrated set of skills, a body schema, poised and ready to anticipate and incorporate a world, is there prior to the application of concepts and the formation of thoughts and judgements (in: Carman 1999, pp.217-219). By putting forward the embodied condition of cognition Merleau-Ponty does not doubt or deny the existence of mental phenomena, but rather insists that thought and sensation as such occur only against a background of perceptual activity that we – by engaging in it - always already understand in bodily terms (Ibid., p.206).

Merleau-Ponty also philosophises about the relationship between pre-conceptual knowing and conceptual thinking and language. In 'The Visible and the Invisible' Merleau-Ponty (1968) describes the relationship between language, thinking and body (flesh) as follows. The body as 'flesh' is the condition of 'thought' (p.152). The Flesh is midway between the spatio-temporal individual and the idea (p.139). Our ideas are only accessible and knowable through our body (p.150). Thought must be brought to 'appear' – not given birth to – because it is already implicated directly in the infrastructure of vision (p.145). The explication of an idea does not give us the idea itself, it is but a second version of it (p.150). With the first version, there is initiation as an opening of a dimension. The idea is this dimension (p.151). The 'idea' is a sublimation of the flesh which will be mind or thought (p.145). Merleau-Ponty refers to Proust to say that idea is not the contrary of

the sensible, but its lining and depth (p.149). 'Pure ideality' is changing flesh. It abandons the flesh of the body for that of language (p.153). Language is the voice of the things (p.155).

Merleau Ponty (1968) preceded his conclusion, i.e. that "Language is the voice of the things", by pointing out that

"Already as seers (...) and especially our existence as sonorous beings for others and for ourselves contain everything required for there to be speech from one to the other, speech about the world. And, in a sense, to understand a phrase is nothing else than to fully welcome it in its sonorous being, or, as we put it so well, to hear what it says (l'entendre). The meaning is not on the phrase like the butter on the bread, like a second layer of "physical reality" spread over the sound; it is the totality of what is said, the integral of all the differentiations of the verbal chain; it is given with the words for those who have ears to hear" (p.155).

"... if my words have meaning, it is not because they present the systematic organization the linguist will disclose, it is because that organization, like the look, refers back to itself" ... "the signification is what comes to seal, to close, to gather up the multiplicity of the physical, physiological, linguistic means of elocution, to contract them in one sole act, as the vision comes to complete the aesthesiological body" (p.155).

At this point I want to refer back to the figure introduced in Chapter 3, emphasising this time how the relationship between experiencing, thinking and talking is one of integration, of one movement, which only strengthens my argument in Chapter 3 for using the term 'comprehending' instead of 'understanding'.



Figure 7: Concepts and language as second version of experience

Merleau-Ponty's philosophical view on thinking and language could not be more in contrast to the disembodied philosophy that underpins traditional cognitive science. When cognitive scientists did engage with Merleau-Ponty's thinking, it brought about a completely different outlook on cognition. It is this embodied understanding of cognition that is accepted in this thesis, and will be discussed in the next section.

#### **4.1.5 Enactive Cognition**

Traditional cognitive science and psychology was and to a large extent still is based on a representational view of thinking (see 4.1.1). This view has been critiqued for its neglect of the impact of emotions, consciousness, embodiment, the role of the physical environment and the dynamic and social character of thinking. One response to these challenges, called the Connectionist perspective, considers how networks of especially neural units explain cognition in a more dynamic way but without challenging the ontological and epistemological assumptions of the Cartesian dualistic perspective (Thagard 2014). In other words cognition remains restricted to brain activity and only refers to conscious and conceptual systems. Representations are still seen as pivotal in human cognition (Nagataki and Hirose 2007, p.220).

However, many cognitive scientists are now beginning to follow a very different path and new views that consider cognition as Embodied, Embedded, Extended and Enactive, and that have become known as the 4Es, have developed. Since the 1970s experimental neuro-scientific research has established that the sensori-motor system is involved in the conceptualising system. This means that concepts cannot be a direct reflection of an external mind-free reality as is presumed by representational realism (Lakoff and Johnson 1999, p.44). Instead, these findings strongly suggest that cognition significantly depends on aspects of our body other than the brain, in other words it makes sense to talk about 'Embodied Cognition'. I

will expand on this below. Another approach, defined as 'Embedded Cognition', explores how cognitive activity is distributed across agents and their physical, social and cultural environment. If the environment is considered as not only distributing but also constituting people's cognitive system the term 'Extended Cognition' is used. These three ways of embodiment come under the umbrella of 'Situated Cognition' (Wilson and Foglia 2016).

It was Varela, Thompson and Rosh (1991) who added an experiential dimension to 'situated cognition' and in so doing brought a phenomenological perspective, one especially inspired by Merleau-Ponty, into cognitive science. Varela et al. consider and understand bodies as physical structures and in that sense milieu or context of cognitive mechanisms. But they follow Merleau-Ponty in his concept of double embodiment and emphasise the need to consider bodies simultaneously as lived, experiential structures. Bodies are both biological and phenomenological. Merleau-Ponty called it the two 'leaves of embodiment' between which we continuously circulate back and forth, and certainly in his later work emphasised that the circulation was to be understood as one movement (see above). Understanding this circulation comes down to understanding the embodiment of knowledge, cognition and experience (Varela et al. 1991, p. xvi). When Varela et al. define cognition as 'embodied action' they mean that our cognition is rooted in our practical activity in the world (Wilson and Foglia 2016) or in more detail it means:

"First, that cognition depends upon the kinds of experience that come from having a body with various sensori-motor capacities, and second, that these individual sensori-motor capacities are themselves embedded in a more encompassing biological, psychological, and cultural context" (Varela et al. 1991, p.173).

They introduced the term 'enaction' and 'enactive cognition' to describe that cognitive agents 'bring forth a world' by the activities of their 'situated living bodies'. In more detail:

"We propose as a name the term enactive to emphasize the growing conviction that cognition is not the representation of a pre-given world by a pre-given mind but is rather the enactment of a world and a mind

on the basis of a history of the variety of actions that a being in the world performs” (Varela et al. 1991, p.9).

and:

“In a nutshell, the enactive approach consists of two points: (1) perception consists in perceptually guided action and (2) cognitive structures emerge from the recurrent sensori-motor patterns that enable action to be perceptually guided” (Ibid., p.173).

Examples of these sensori-motor patterns are our experience of up-down, front-back, near-far, in-out, on-under. Varela et al. (1991) call them “enactions” while Lakoff and Johnson (1999) (see 4.2.1) refer to them as “image schemas”.

There is a risk that ‘enaction’ is reduced to bodily action but within a body-independent world. For example, Piaget understood cognition as emerging from sensori-motor activity, but within a framework of a given world and a given mind. In other words cognition was not understood as bringing forth the world, it was accommodating and assimilating a given world with sensori-motor activity (Varela et al. 1991, p.176). Nevertheless, the fact that Piaget considered pre-verbal, sensori-motor actions as the source of a child’s cognitive development rather than language (Schwebel and Raph 1974, p.23), makes his theory not entirely alien to enactive cognitive theories. That, in a nutshell, a child attends to manipulations, then to itself and later searches for explanations and seeks to share these with others, portrays a developmental process that perhaps is not restricted to childhood cognitive development. Fisher (1980) applies a similar developmental process (i.e. from sensori-motor to representations to abstraction) to his theory of cognitive skills development in adulthood. Piaget himself already suggested that there may be general parallels between the way scientists develop their theories and childhood cognitive development (Schwebel and Raph 1974; Fisher 1980).

Both Enactive and Extended cognition consider cognition to be distributed across brain, body and environment but Gallagher (2017) points out that

Enactive Cognition, unlike Extended Cognition, sees no role for representation and functionalism. Gallagher clarifies that in the enactivist view, it is the relationship between brain, body and environment, not a representation of it in the brain, that 'constitutes' cognition. His description also emphasises the holistic character of the brain – body – environment connection:

“Brain, body, and environment are said to be dynamically coupled in a way that forms a system, and the coupling is not equivalent to identity of material parts; rather it involves physical relational processes. Significant changes in one part of the system will cause changes or adjustments in the other parts. For the enactivist just these dynamical causal relations constitute the system” (Ibid., p.8).

Whereas these definitions on the one hand make sense rationally, it is on the other hand difficult to grasp the meaning fully. Many, myself included, are used to only think of cognition as what Varela et al. (1991, p. 27) call a “reflection on experience” rather than also as an “experience of reflection”. Attempts have been made to make the concept more tangible with evocative words and pictures. Thompson (2007a, p.13) recalls how Varela drew on the words of the poet Antonio Machado to describe enaction as a “laying down of a path in the walking” or as the poet said “Wanderer the road is your footsteps, nothing else; you lay down a path in walking”. This metaphor has been visualised by Richard Long’s photo “A line made by walking” (Figure 8).



Figure 8: A line made by walking by Richard Long  
(Long 1967)

The advantage of using walking metaphors for our engagement in the world is that it brings home the dynamic character of our being-in-the-world, first by referring to our body in motion and secondly by suggesting an experience of a landscape or environment that does not stand still. In addition to this embodied and temporal aspect of perceiving, it also brings home that self and place are in a reciprocal process of becoming (Harvey 2014). No

wonder that in visual art the link is made with Merleau-Ponty's (2004 cited by Harvey 2014) description of a subject as "a being who can only get to the truth of things because its body is, as it were, embedded in those things."

In parallel with Merleau-Ponty, Varela et al. do not consider the self to be an existing separate entity that creates meaning. The self rather emerges together with meaning from the enacting of a world. As mentioned in Chapter 2, Varela et al. (1991) point out the contradiction between our everyday sense that we have an identity, a coherent centre from where we live, an ego-self that is constantly dealing with the flux and ups and downs of our experience, and the fact that no reflective tradition has ever discovered an independent, fixed or unitary self within the world of experience. This latter fact, they say, is then either ignored or 'solved' by postulating a transcendental self that can never be known by experience. According to Varela et al. (1991) it is only in mindfulness/awareness meditation as practiced in Buddhism that the groundlessness of self and our attachment to the idea of self is openly addressed.

*Enactive cognition means that cognition is rooted in our practical activity in the world. The sensori-motor and spatial patterns that emerge from the embodied interactions with the world we live in constitute our cognitive structures.*

*In enactive cognition subjective, phenomenological processes and objective, cognitive processes come together.*

In Chapter 3 this study was situated within the broader family of phenomenological studies but with a specific focus on *how* people's thinking emerges from their experiencing. It was stipulated that I would seek understanding of this process by studying developments in phenomenological philosophy and in embodied cognitive science, which has been the content of Chapter 4 so far. In the next section the core principles addressed in the above explorations will be brought together as they form the foundation for the research methodology (Chapter 6). The section will be concluded with some related reflections on the research questions and title.

#### 4.1.6 Research approach, questions and title revisited

In order to detail the initial brief description of the research approach, I want to draw attention to the embodied, existential and interpretive aspect of the intertwined movement of experience, understanding and language in Merleau-Ponty's philosophy of the body.

First, Merleau-Ponty, like Heidegger, turned away from a transcendental view of consciousness by seeing consciousness as "existence in and toward the world", but important to add is his emphasis that it is an "existence in and toward the world *through the body*". His focus is on "the embodied human being in the concrete world" (van Manen 2011). Within this Phenomenology of Embodiment, it is first of all the **embodied aspect** of understanding that comes to the fore.

Secondly, this means that, in contrast to Husserl, Heidegger and Merleau-Ponty saw understanding in ontological rather than epistemological terms. Understanding is a way of being. They also see understanding and language as inseparable and subsequently language, just like understanding, is 'a second version' (Merleau-Ponty 1968, p.150) of experience. Meaning does not reside in the structures of language but in understanding that in itself is already present pre-linguistically and pre-conceptually in experiencing. This

points to the **existential aspect** of understanding and language. In other words, human beings and the world are, in contrast to previous views, no longer seen as fixed (Crowell 2017).

Thirdly, Heidegger and Merleau-Ponty argue that experience and understanding is always in relation to the world. There is always a **relational aspect** to understanding. This viewpoint also means that understanding is 'positioned'. Positioned-ness implies that there is an **interpretive aspect** to experiencing, understanding and language. It has given rise to the term 'interpretive phenomenology'. This is put in contrast to 'descriptive phenomenology' associated with Husserl, who also acknowledges the general positioned character of experience but nevertheless believes in an ability to grasp the essence of experience rather than an interpretation of it.

Often used as a synonym for 'interpretive phenomenology' is the term '**hermeneutic phenomenology**' (for example, Finlay 2011, p.110). Yet for a correct understanding of this term it is helpful to refer to its origin. 'Hermeneutics' is older than 'phenomenology' and before the 20<sup>th</sup> century it was concerned with the prescription of questions that would enable a proper interpretation of literary, sacred and legal texts (Gallagher 2004). When Heidegger in 1927, in his work 'Being and Time', used the term 'hermeneutic of Dasein' to indicate that 'understanding' and 'interpretation' constitute man's being, the term 'hermeneutic' became, in one movement, connected with an understanding of interpretation as 'positioned-ness' and with the ontological character of understanding (Palmer 1969, p.42).

'Hermeneutics' was further developed by Gadamer who took it into the philosophical realm and away from its original focus on methods of interpretation. He emphasised the historical and linguistic character of understanding (Palmer 1969, p.42). In this study I have not focused on Gadamer's hermeneutic philosophy. Engaging with enactive cognition instead, my focus on embodiment rather than a focus on language, strengthened.

The 'embodied' aspect of understanding, brought forward by hermeneutic phenomenology, is in 'enactive cognitive science' captured by qualifying 'understanding' as 'enactive'. With the term 'enactive', 'enactive cognitive science' draws attention to the fact that cognition is seen as shaped by inter-subjective and situated lived experience. In other words from a cognitive science perspective, 'enactive' refers to a phenomenological turn within cognitive science. Cognitive 'enactivism' attends to the multiplicity of embodiment and its role in cognition. This also entails a specific attention for the sensori-motor aspect of engagement in the world and its neurological imprint which brings a **metaphorical aspect** to thinking and understanding. This neurological angle differentiates 'enactive cognitive science' from 'hermeneutic phenomenology'.

In this study I bring both viewpoints together. However, ultimately this is a hermeneutic phenomenological study. The methodology has been titled as '**enactive hermeneutic phenomenology**' (Chapter 6). 'Enactive' here draws attention to the fact that subjective comprehending is shaped by sub-personal dimensions of embodiment that are neurologically laid down. In other words it points to the bridge made with the neurological dimension of experiencing and thinking. If, from a phenomenological perspective, 'hermeneutic' referred to a cognitive turn, then 'enactive' refers to a neuro-cognitive turn.

In Chapter 3 the general research question was defined as "How are survivors of bowel cancer experiencing / comprehending their self vis-à-cancer post-treatment?" In reflecting on the implications of enactivism for what is traditionally considered a phenomenological question, Gallagher suggests that the description or exploration of experience is not a search for "what it is like" (or how people experience X), but "what I am like as I experience X – where "I" means the embodied agent engaged in the world, rather than anything like pure consciousness" (2011, p. 13). This means that the general research question in this study could be rephrased as "What are bowel cancer survivors like as they experience their Self vis-à-vis cancer post-treatment?"

The five dimensions of embodiment that have informed the research sub-questions resonate with the components of Varela et al.'s definition of enactive cognition. The inter-subjective and sensori-motor interaction (objective 4) and how this is neurologically laid down in body schemas (objective 1) forms the core of the definition of enactive cognition. They also spell out that sensori-motor capacities are embedded in biological (objective 3), cultural and psychological contexts (objective 2). The role of body self-regulation in their approach to enactive cognition (Thompson 2005) is also specified (objective 5).

From their definition it is clear that Varela et al.'s approach considers affectivity and inter-subjectivity as part of enactive cognition (Gallagher 2017, p.150). However, the term 'enaction' itself mainly suggests a concern with 'action'. This can be misleading if one is not familiar with the full meaning of 'enaction'. In this study I deliberately go beyond the sensori-motor approach and attend to the felt and affective layer of embodied cognition (see section 4.2.2). Therefore, to avoid too narrow an understanding, I have, in the title, described my approach as an 'embodied', rather than an 'enactive' interpretation.

Theories that have made the import of the five dimensions of embodiment for self and conceptualising more tangible will be discussed in the next section.

## **4.2 Five dimensions of embodiment**

### **4.2.1 Sensori-motor embodiment and 'conceptual metaphor'**

In this chapter Lakoff and Johnson's Conceptual Metaphor Theory, which was briefly introduced in the first chapter, and which informed the definition and exploration of the first research objective and question ("What is the body-schematic structure embedded in the metaphorical comprehending of the self vis-à-vis cancer?"), is further explored. The following topics will be

covered: (1) assessment of Lakoff and Johnson's 'embodied' cognition in relation to Varela et al.'s 'enactive' cognition; (2) how the embodied nature of thinking by definition means that thinking is metaphorical and how this is rooted in early childhood experiences; (3) the meaning and function of 'primary metaphors'; (4) what it means to 'bodily' understand, including the meaning of the terms 'conceptual' and 'experiential' metaphors; (5) the function of metaphorical conceptualising; (6) an outlook on the discrepancy between the ontological view of self as an embodied process and the way (the) self is conceptualised; (7) some critiques on Lakoff and Johnson's theory.

As said above Lakoff and Johnson's Conceptual Metaphor Theory is rooted in what they refer to as Embodied Cognition Theory. Varela et al. conclude that Lakoff and Johnson's understanding of 'embodied cognition' is similar to their own concept of 'enactive cognition':

“... the central theme of Lakoff and Johnson's (experiential) approach (is) that meaningful conceptual structures arise from two sources. (1) from the structured nature of bodily and social experiences and (2) from our innate capacity to imaginatively project from certain well-structured aspects of bodily and interactional experience to abstract conceptual structures. Rational thought is the application of very general cognitive processes – focusing, scanning, superimposition, figure-ground reversal, etc. – to such structures. This statement would seem consonant with the view of cognition as enaction which we are arguing” (Varela et al. 1991, p.178).

In this research I use the word 'embodied cognition' in the way it is used by Lakoff and Johnson, i.e. as a synonym for 'enactive cognition'.

When Lakoff and Johnson explain the origins of the embodied and metaphorical nature of human understanding they refer to four sub-theories that come together in their Conceptual Metaphor Theory (Lakoff and Johnson 1999, pp. 46-47).

The first sub-theory, a *Theory of conflation*, explains how for a young child subjective experience (e.g. experience of affection) is not differentiated from

the co-occurring sensori-motor experience (e.g. the warmth of being held). These experiences of conflation are laid down in the brain as an automatic association between two separate domains. Later on children are able to differentiate the subjective and sensori-motor component of their experience and at that point the sensori-motor information is used metaphorically. They argue that without the earlier conflation this would not happen. For example, the metaphor “I see the importance of your statement”, only has the meaning “I *know* the importance of your statement” because there has, in childhood, been a stage of conflation where seeing and knowing happened together; the child knew what was in the box by looking into the box.

The second sub-theory is referred to as a *Neural theory of metaphor* and specifies that the cross domain associations that are first established in early childhood (first theory) persist and form the anatomical basis of metaphors. This means that the anatomical connection between domains in the brain that regulate sensori-motor functioning and domains that process subjective experiences, forms the structure of metaphors, i.e. “I experience learning a new theory (subjective experience) like walking uphill (sensori-motor).” It is by creating this connection that I create and consequently share an understanding of my experience.

A third sub-theory, *Theory of primary metaphor*, argues that the neural connections are activated through our everyday experiences and give automatically, naturally and non-consciously rise to ‘primary metaphor’. ‘Primary metaphors’ are connections between basic spatial sensory motor experiences and subjective experiences (see below). Primary metaphors are the building blocks for our at times more extensive metaphorical conceptualisations. E.g. when Edward uses the metaphorical expression ‘letting go of dying’, Lakoff and Johnson’s work draws my attention to two primary metaphors, i.e. movement captures a subjective experience of change’ and ‘closeness captures an experience of intimacy’ (letting go of undoes closeness).

The fourth sub-theory, a *Theory of conceptual blending*, states that several primary metaphors can be activated together and blend into an extended complex metaphor. But, also wholly original blends are possible.

Lakoff and Johnson conclude that simply by functioning in the most ordinary of ways every day from our earliest years, we acquire a large system of primary metaphors that operates automatically and non-consciously. This means that also the conceptualisings of self vis-à-vis cancer will be rooted in everyday experiences. These experiences they broadly categorise as (Lakoff and Johnson 1999, p. 269):

- a. Manipulating, taking possession of or exerting force onto objects;
- b. Being located in space;
- c. Entering into social relationship;
- d. Empathic projection;
- e. A real self (essence) that is compatible with the Essence that is part of the Subject.

Hundreds of primary metaphors populate our thinking. Lakoff and Johnson made a long list of 'primary metaphors' (see appxs.B0-B1 for illustrations). It would be very difficult not to use metaphors to reason, especially about new subjective experiences. But what is more, without the use of metaphor and therefore the use of sensori-motor inferential structure our thinking is impoverished. Imagine we needed to reflect on an experience of 'love' without using any metaphors (Ibid., pp.57-59), or on an experience of 'self' or 'cancer'. Conceptual metaphors can not only be manifested in words but also in grammar, gestures, art or ritual (Ibid., p.57).

The metaphorical and embodied nature of thinking has specific implications. A metaphorical description of a subjective experience is an act of "grounding" the newly experienced state of mind in a known physical experience which is neurologically captured in an image schema (Lakoff and Johnson 1980. p.59). Through this "grounding" we tap into a bodily logic that creates understanding and meaning in two ways (Johnson 2007, p.139): First, image schemas make

it possible for our bodily experiences to have meaning. For example, human beings know what it means to be 'in' something without having to think or reflect on the word 'in'. Non-consciously the word triggers a 'container' image schema with its specific possibilities for interaction. Secondly, the logic of image-schematic structure makes it possible to make sense of and act intelligently in everyday life situations. For example, it is part of the container image-schema logic that I understand that when I have my car keys in my hand and place my hand in my pocket, that my car keys are now in my pocket.

It also means that the occurrence of the metaphor in that moment creates the understanding rather than describes an understanding that has happened before the use of the metaphor. In other words metaphors are more than just 'words'. They are conceptualising language. Hence the term 'conceptual metaphors'. Johnson (1987, p.98) describes it as follows:

“... metaphors do not merely report pre-existing, independent experience; rather, they contribute to the process by which our experience and our understanding are structured in a coherent and meaningful fashion.”

The term 'conceptual metaphors' has led to misinterpretations though, as the word 'conceptual' is often understood from a disembodied cognitive perspective where it only refers to an abstract, formal, propositional structure. As in Lakoff and Johnson's view metaphors depend on non-propositional embodied experience they thought it might be more accurate to call them 'experiential metaphors':

“This captures the fact they are not intellectual forms, but rather are the very stuff of our world as we experience, conceptualize, and reason about it” (Johnson 1997, p.157).

This goes back to the intertwinedness of conceptualising and experiencing that is implicit in an embodied understanding of cognition and that was addressed by Merleau-Ponty and Varela et al. (see above). Lakoff and Johnson argue that this entails that living systems cannot not categorize and consequently not only categorize conceptually but also pre-conceptually or experientially:

“Since we are neural beings, our categories are formed through our embodiment. What that means is that the categories we form are part of our experience! They are the structures that differentiate aspects of our experience in discernible kinds. Categorization is thus not a purely intellectual matter, occurring after the fact of experience. It is part of what our bodies and brains are constantly engaged in. We cannot, as some meditative traditions suggest, “get beyond” our categories and have a purely uncategorized and unconceptualized experience. Neural beings cannot do that” (Lakoff and Johnson, 1999, p.19).

Metaphors also ground understandings culturally. When individuals are embedded in the same (linguistic) community, culture and historical context, their mental structures will be similar as they are based on similar embodied experiences from childhood onwards. It is this embodied nature of conceptualising that enables public, shared meaning (Lakoff and Johnson 1980, p.190). Moreover research shows that we do not only use sensorimotor experiences that we personally have had, but that there is a wealth of metaphorical concepts that make sense to all of us because they are part of our non-conscious cultural baggage, e.g. we have no problem reasoning about ‘arguing’ in terms of ‘war’ regardless of having personally been involved in a war or not. A lot of metaphors used by people to understand subjective new experiences are part of a “cultural metaphorical conceptual system” (Ibid., p.9, p.64).

Although the ontological realness of self is debatable (see Chapter 2 and 4.2.5 below), human linguistic being brings about a narrating of a self. Human beings constantly refer to themselves as subjects and selves, moreover – in contrast to the non-dualistic perspective portrayed in this thesis – as selves that relate to the world as if they have an existence separate from that world and separate from their body, (e.g. it feels natural to say ‘I feel on top of the world’, ‘she is distancing herself from the world’, ‘I was beside myself’, ‘I feel like jumping out of my skin, out of my body’, etc.) Lakoff and Johnson (1999, p.563) point out that it is, paradoxically, through the embodiment of our phenomenological experiences that we end up with the illusion that we have disembodied minds. When as human beings we look

with our eyes, listen with our ears, touch with our hands, etc. we tend not to attend to them and consequently experience our mental acts as independent of our body which leads to the experience of a disembodied mind including a disembodied self.

Lakoff and Johnson's (1999, p.269) study of the conceptualisation of Subject and self also gives a detailed account of how human beings do not only experience their Subject-self as split from their body and the world, but how the Subject-self itself is also experienced as split. There is not one Subject-self but a complex structure containing one Subject and many selves. The Subject stands for the locus of consciousness, subjective experience, reason, will and by its nature exists only in the present, it is the "I". The Subject is also the locus of a person's essence, of the 'real self', of everything that makes us who we uniquely are. The selves on the other hand consist of everything else about us, that which is not picked up by the Subject – our bodies, our social roles, our histories etc. There are many contradictions between the selves.

In metaphors the Subject will always be person-like and exist independent of the self, while the self can be referred to as an object or a location (Ibid., pp.267-269), or even a combination of an object and location, e.g. at the most difficult time of this doctorate I (subject / person) would have described my self (one of many selves) as 'an empty vessel on a wide ocean' (object in location).

Metaphors are not chosen at random. They have a specific function. They are purposeful. First, metaphors make it possible 'to get a handle on' (expression used by Lakoff and Johnson) a specific – in that moment for the person relevant – aspect of an experience (Lakoff and Johnson 1980, p.97). A metaphorical statement works when it feels like a statement that is true given that situation and purpose. Each individual metaphor enables one to think about certain aspects of an experience but is also limited in so far that it does not provide a handle on other aspects of that experience. Metaphors

only capture an experience partially. When people introduce new metaphors they are trying to grasp another aspect of their experience. People move on to new metaphors when these explain and help them to move on from the frustrations or limitations of the previous metaphor (Ibid., p.179).

Emotions and feelings are part of experiencing and rather than being separate from, they underpin thinking (see Chapter 2). Cameron (2010) argues that it is important not to overlook the role of emotions as they are often the non-conceptual driving force behind the occurring of metaphors. This connects with Gendlin's outlook (see the next section). Research shows that emotions are mainly conceptualised as forces. An example that will be discussed in this research is: controlling with anger is 'batting down'. It also shows that cultural differences play an important role in the conceptualising of emotions (Kovecses 2000).

As metaphors structure our thoughts, they also structure our actions. They are 'systematic' (Lakoff and Johnson 1980, p.36). When primary metaphors are triggered, the neural circuitry that simulates the physical actions also makes the behaviour more likely (Lakoff 2012). For example, by conceptualising "letting go of dying" Edward's brain gets primed for behaviour in the direction of reengaging with life.

Four decades ago, Lakoff and Johnson's work was at the origin of 'conceptual metaphor theory'. Since then, more linguistic and cognitive scientists have presented complementary or contradictory views and findings. Except for the occasional reference, e.g. in relation to emotion (see above), these have not been included here as priority was given to building a multi-disciplinary theoretical framework.

However, as Lakoff and Johnson's Conceptual Metaphor Theory largely refers to sub-personal aspects of human being and reasoning, it is to be expected that critical voices will question whether individual and cultural differences have not more impact than acknowledged by Lakoff and Johnson.

El Refaie (2014) suggests that the same sensori-motor and spatial gestures may have different meanings across different cultures. Lakoff (1993, p.245) acknowledges that “metaphorical mappings vary in universality; some seem to be universal, others are widespread, and some seem to be culture-specific” and they report that their research suggests that more general metaphors, e.g. the conceptualisation of ‘events’ is very widespread, whereas the conceptualising of specific experiences like life, love and careers is culturally more restricted (Lakoff 1993, p.225). The conceptualisation of time also differs from place to place and certainly in places where it is not conceptualised as a resource like in Western society (Lakoff and Johnson, 1999, p. 141, p.165). Studying metaphorical expressions of e.g. self, Moser (2007, p.152) argues, is like studying the “symbolic environment” of self because of the cultural and social beliefs that are embedded in the metaphors. In this study all participants come from a white British background and subsequently the findings will need to be understood within this context.

One can imagine that Lakoff and Johnson’s point that neural beings cannot not categorise and consequently can only experience self, world and body, despite neurological and philosophical counter-indications, as separate entities, may be challenged by those who practice an uncategorised state of mind. On the other hand the struggle, if not the impossibility, to reach this state is often reported as part of the meditative experience, as is the conclusion that language brings our categorising into awareness. For example, in research conducted by Mojsa (2012) the struggle to experience non-dualism was expressed as follows: “a state where there is no subject, object or experience, but how rare is that” (p.182), “there is no one sensing, ... but actually it is me that is sensing” (p.189). It is perhaps just about possible to talk *from* a minimally categorised experience, but as we speak *about* that experience, the experience becomes further categorised and the sense of non-dualism disappears (p.190).

The link between meaning and sensori-motor spatial experience is, according to Lakoff and Johnson, initially formed in childhood and strengthened through

life. El Refaie (2014) argues that the present experience of the 'lived body' must also have an impact on the conceptual metaphor used. As this study focuses on the experience of cancer survivors who have gone through intrusive surgery, often including temporary or permanent colostomies, it was important to take this criticism seriously. El Refaie (2014) gives an example of a visual metaphor, i.e. a drawing in which a patient with breast cancer has replaced the eyes with breasts. She argues that this brings about a new conceptual metaphor, "Eyes are Breasts", as an alternative for "Seeing is Understanding". In my opinion however, the drawing is more a specification of the Seeing than an alternative for the metaphor: Through the cancer experience this client seems to be saying that her experience of breasts has become the lens through which she sees and consequently understands the world. Gibbs's research (2002) showed that although cancer patients have disruptive bodily experiences, they use metaphors that are based on ordinary embodied experience. They still refer to the healthy body when trying to understand their experience of illness. El Refaie (2014) refers to this research but does not give it the weight that I am inclined to give it. It does trigger the question though whether people who are physically different or disabled from birth metaphorically conceptualise their experiences differently. A case study by ter Horst et al. (2012) showed that long-term loss of kinaesthetic stimuli to the brain, leads to an inability to imagine those movements. This could suggest that people with such conditions may not think with metaphors based in movements that they have not experienced. It prompts the question whether such serious body schematic differences impact on and are compensated by other cognitive or linguistic processes. Gallagher's (2005) work is of interest here but as none of the research participants were in this situation, this has not been pursued.

Whether the specific embodied experience in the moment has an influence on the metaphorical conceptualising is another concern. This questions the impact of the media used to express the experiencing. For example, drawing may trigger metaphors related to vision, dance to movement (El Refaie 2014).

In this study I also invited participants to express experience with sheets of paper by positioning these in relation to the body and the room.

Another layer of critiques suggests that the meaning of metaphors should not just be explored in terms of the embedded sensori-motor logic, in other words in their conceptual function. Semino et al. (2018a) suggest exploring metaphors also from a 'discourse' and from a 'practice based' perspective. From a discourse perspective, Cameron and Deignan (2006) argue that e.g. the metaphor 'baggage' (used to express emotional burden) is not just an activation of the conceptual metaphor 'Difficulties are Burdens' but emerges in the dynamic interaction and communication between people. From a practice based perspective it is researched how and what type of metaphors are useful, e.g. in institutional communications such as the health care sector (Reisfield and Wilson 2004; Miller 2010; Semino et al. 2017). These communicative and contextual perspectives are not at the core of this study but are not ignored either. They are reflected in considerations of the role of participants' transactions with medical consultants (objective 4).

Gendlin (1995) warns cognitive scientists to be aware of the risk of projecting the structure and pattern of metaphors and concepts onto the experience they are believed to capture and, in doing so, forgetting that meanings that are experienced in a non-conceptual manner are also at play in the occurrence of metaphors. Based on Gendlin's critique I have widened the theoretical framework of this study by including an experiential dimension of embodiment. It is this dimension that is addressed in the next section. There I will draw on Gendlin to shed light on how metaphors are chosen in a specific situation, as well as on the dimension of meaning that precedes and goes beyond the meaning that emerges through conceptualising.

In conclusion, informed by Lakoff and Johnson's Conceptual Metaphor Theory, metaphors (understood as 'embodied thinking based in experiencing') have been chosen as the core data in this thesis. The research question put forward in Chapter 3, 'What is the body-schematic structure embedded in the

comprehending of the self vis-à-vis cancer?', will be explored with reference to comprehensive lists of Primary Metaphors as those are structured by specific body-schematic forms. This will be explained in more detail in the methods chapter.

#### **4.2.2 Experiential embodiment and 'felt sense'**

In this section Gendlin's process model is brought in dialogue with Lakoff and Johnson's Conceptual Metaphor Theory. First, this entails a more detailed exploration of what it may mean to say that conceptual meaning is rooted in pre-conceptual meaning and that conceptualising and experiencing are intertwined. Secondly, Gendlin's (2004, p.127) concept of the "more", by which he means "more than categories", is introduced. The role of the wider experiencing in conceptualising of the present, is reflected in the third research question: 'What aspects of the wider self are noticeably involved in the process of comprehending the present self vis-à-vis cancer?'

In a debate with Johnson, Gendlin (1995) argued that cognitive scientists, including embodied cognitive scientists, have a tendency to think that conceptual structures, e.g. metaphors, work because they are a 'fit' to the situation and that by being a fit the conceptual structure brings meaning and process to the experience. In Gendlin's view (1995) though, metaphors are *not* chosen because of a correspondence between their pattern and the pattern of an experience. Pre-conceptualised experience, Gendlin (1973) argues, is unpatterned, unstructured. However, he also points out that the moment experience is studied, it becomes organised (patterned) through the way the body is involved and the way language makes distinctions in the situations that are experienced. Nevertheless, when this elementary organised experiencing is then further and more explicitly organized with language, e.g. by using metaphors, the original organisation still plays a role, but it is not the original, existing pattern of the experience that is further organised.

According to Gendlin (1995) when specific metaphors are used it is because they are the ones that work. This means that they make it possible for the experience to be carried forward, for a situation that is experienced as 'stuck' to become 'unstuck', for an experience to continue to flow. An example used by Gendlin (1995) to explain stuckness that becomes unstuck is when we have a sense that we forgot something but cannot remember what. As we think of a range of things, perhaps retrace our steps etc. suddenly we 'know' what it was and our whole felt sense shifts and the sense of stuckness is released. Gendlin states that when metaphors connect with experience, it is after a whole range of possible uses of the metaphors have 'crossed with' the whole range of possible next steps for the experience. It is non-conscious, bodily knowing – which Gendlin (2004, p.133) calls “a felt knowing” and a knowing of what is “implicit” - that very precisely 'knows' which metaphor connects with the experience and thus creates flow.

So metaphors are not “occurring” (Ibid., p.136) randomly but rather than emerging from a match with the pattern or organisation of the experience, they occur in resonance with the felt sense. This means that new meanings come into existence on both the metaphorical and the experiential sides. For Gendlin (1995) all words have the potential to function that way. He argues that if there were something truly specific to a specific pattern of a metaphor this would mean that we cannot understand something that we do not already know.

Johnson (1997) replies by pointing out that in embodied cognitive science conceptual meaning is considered as sitting on the top of a mountain of non-conscious implicit meanings. He comments that Gendlin has wrongly lumped the term 'structure' together with the term 'form', and has distinguished them from 'felt sense'. Johnson agrees with Gendlin that felt sense is full of possibilities that are not yet realised. But he also points out that this means that it is also full of embodied structure that is not yet realised (Johnson 2007, pp.82-83).

It can be argued that this resonates with both Lakoff and Johnson's and Gendlin's acknowledgment that the moment an experience is attended to, categorising (organizing, patterning) is happening. The very fact that there is a felt sense of a demarcated situation, based on an overall quality, seems to be a categorisation in which is discerned that which is part of the quality, and that which is not. As experiencing is always embodied, it seems inevitable that it also comes with a felt sense of the potential for spatial and sensori-motor structuring.

This potential felt structure is not rigid, it is lively, agile. This is how I understand Johnson's point that the felt sense is full with implicit embodied structure. I accept Gendlin's point that there is a myriad of words or metaphors that can take the experiencing forward and that it is not the words or the structures alone that enable the processing, but that this taking forward demands a coupling between felt knowing and words, and that meaning springs from this coupling rather than residing in either side. Yet, I struggle to see how the structure of the metaphor would have no relevance for its 'working' towards this flow. I wonder whether the qualitative felt sense is experienced as much in its implicit structural potential as in its absence of structure. I reason that from all the personal or universal experiences that people know and that can potentially function as 'metaphors' for the present situation, it is those that in some aspect correspond with the implied structure of the experiencing which come to the fore and which enable the experience to flow. In other words metaphors are not chosen for their specific meaning in another situation but for the extent to which their bodily structure resonates with the implicitly felt structure of the present situation and therefore has the capacity to function as a hook that picks up the present experiencing and carries it forward.

The meaning embedded in the structures is not the full story. There is always a 'more' that falls outside the conceptualisation (Johnson 1997, p.153). Words and concepts only refer to what is experienced as form, structure,

pattern (Ibid., pp.149-150). Gendlin (2004) explores what this 'more' is, what it is not and how it can be accessed.

Gendlin (2004) writes that the 'more' is not like a 'halo' around concepts, nor is it a mere feeling about a situation. It is an experiencing of an implicit cluster of thought. This implicit intricacy is more finely organised, ordered and demanding than any conceptual form. It is not language but understands language and its organised preciseness shows when it does not permit you to say things that do not resonate or when it rejects words. It is a "responsive order" (Gendlin 1997, p.XiX).

Gendlin (2004) states that although the implicit cannot be captured by words it is possible to attend to this pre-conceptual meaning by speaking from and with it rather than about it. This means a tuning in with the felt sense of a situation and allowing the body to speak, allowing a 'physical' coming of the words. These words may have specific cultural meanings, yet when spoken from the implicit they go beyond the old meanings. They are spoken afresh; they are spoken in a new and more sophisticated manner.

The sense that words "match" the felt sense is misleading; it does not mean that the words "copy" the felt intricacy (Ibid., p.133). The implying never becomes explicit. The non-formal never becomes formal. It cannot be represented; it can only be taken along in the process of thinking.

The concepts and categories do not control the intricacy. As soon as categories are spoken or applied, the intricacy changes and further differentiations in the concept may already be required. Nevertheless, speaking from and with the intricate is experienced as valuable as it is comes with a sense of giving expression to oneself (Gendlin 2004).

The explicit does not capture the implicit, yet it is through the explicit that the implicit is found. In other words the implicit and explicit are not independent. Meaning does not belong to either the implicit or the explicit. It does not

belong to the implicit but it 'comes from' the implicit. Meaning develops in the interweaving of the implicit and explicit. As Johnson (2007, pp.82-84), in line with Gendlin, puts it, meaning resides in the situational relation between the implicit (the felt sense, the non-formal, the subjective side) and the explicit (the patterned, formal, objective side) as that relation develops and changes. The meaning is carried forward by the body. To use a word from Lakoff and Johnson (1980, p.97), the words or metaphors are a 'handle' on an aspect of experience. It is a handle that makes it possible for the implying to be carried forward.

Implying and occurring, as one movement, are continuously repeated. What occurs goes into the implying where it gives rise to new occurring and so on. Consequently experiencing is always a sequence that generates itself (Gendlin 2004, p.146); or what has been called the "spontaneity of inner process" (Olsen 1999, p.2). Where Lakoff and Johnson's reminder that metaphors serve a specific purpose, and are therefore limited in their use, already drew my attention to the changing character of meaning, Gendlin's Process Model brings this to the fore. Moreover Gendlin draws attention to the life-enhancing, moving-forward character of experiential implying. This, he says, refers to the body's organic direction which is prior to any externally defined direction (Gendlin 2004, p.136). Implying is not the same as that which will occur (in action, language or thoughts). The implied only happens if it is possible in the environment. Gendlin (2018, p.11-12) emphasises that occurring is a body-environment interaction. The role of the interaction with the environment will be further addressed in section 4.2.4, while the role of organic life-enhancing drives will be discussed in the next section, 4.2.3.

The viewpoints addressed in this section have strongly influenced the research part of this thesis. First, the data generation has been conducted in a manner which aimed to enable a 'talking from the implicit'. Secondly, relying on the working of the non-consciously held memory of the wider self (see Chapter 2), the explorative conversations with participants were guided by the second research objective: 'What aspects of the wider self are

noticeably involved (read: carried forward) in the process of comprehending the present self vis-à-vis cancer?'. This means that the embodied patterns or structures of the metaphorical conceptualisings were not only, as Todres (2007, p.20) puts it, explored for what they 'say' (first research objective) about an experience, but also as 'messengers of the unsaid' (second research objective).

### **4.2.3 Bio-chemical embodiment and 'viability'**

As discussed in the first section of this chapter, in Varela et al.'s 'enactive cognitive science', in contrast to 'cognitivism', mind and environment are no longer seen as static, separate and pre-given entities. Cognition has become understood as enacted, embodied and embedded. Varela et al. (1991), who were also biologists, explain that adhering to 'evolutionary adaption thinking in neo-darwinism' is the equivalent of cognitivism as it also starts from the assumption that organisms adapt to a pre-given world. What it means to let go of adaptational thinking in biology and what that may mean for this thesis will be briefly explored below.

At a basic level 'human beings' are living systems and with this comes the possibility of dying. The implication is that living *systems* organise themselves towards the avoidance of dying and towards survival (Froese and Stewart 2012). In biology survival may be seen as a result of a mechanistic employment of physiological processes which by an observer may look as *if* purposefully intended by the organism (Weber and Varela 2002). Others adhere to a viewpoint akin to that introduced by Maturana and Varela (1980, pp.78-79), and expressed with the concept of 'autopoiesis', which they define as:

"An autopoietic machine is a machine organized (defined as a unity) as a network of processes of production (transformation and destruction) of components that produces the components which: (i) through their interactions and transformations continuously regenerate and realize the network of processes (relations) that produced them and (ii) constitute it (the machine) as a concrete unity

in the space in which they (the components) exist by specifying the topological domain of its realization as such a network.”

Considering living systems as autopoietic implies understanding them as *really* having an intrinsic teleology, i.e. an internal purposiveness. It is in this self-organized process towards survival that human beings’ subjective concern for survival and their valuation of and intention towards continuation and realisation of life is rooted (Weber and Varela 2002). As mentioned in Chapter 2, Damasio calls this process of life regulation *homeostasis* and discusses how brain evolution and the emerging self are based in this biological value. If life wants to continue then it has a value for itself and the world acquires meaning as either supporting or hindering this life continuation (Ibid., p.118-119).

The link between the self-organised drive towards survival and the orientation towards the environment, Di Paolo and Thompson (2014, pp.69-73) further specify as follows. They explain that body survival does not occur through bio-chemical or physiological processes alone. These processes are insufficient because of the “precarious” nature of organisms. By that, they mean that although organic processes may be conceived as being positively life sustaining, in reality organic processes have intrinsic tendencies towards internal imbalance. To counteract the negative tendencies of its own parts, it is crucial that a system has relations with the outside world. A system is not only self-enabling and self-organising but will also out of necessity be spontaneously drawn towards interacting with the environment.

Varela et al. (1991, p.196) point out that this coupling of a ‘being’ with ‘complex environments’ generates cognitive abilities that *far outweigh* their relevance for survival. They define evolution as

“bricolage, the putting together of parts and items in complicated arrays, not because they fulfil some ideal design but simply because they are possible.”

In other words, from a non-dualistic biological perspective, natural selection towards survival is not seen as an adaptive process that guides towards an

ideal, an optimal fit, following a prescriptive logic. Instead, natural selection is seen as following a proscriptive logic which means it operates in a much more moderate sense and merely accepts all actions as long as they do not go against the integrity of the system (Ibid., p.205). Only that which is not viable and not compatible with survival and reproduction, is discarded (Ibid., p.196). Varela et al. call this process of evolution a process of 'natural drift' and it allows for much more variation and biological flexibility than the adaptation explanation does.

The idea that a living organism reacts, not only physiologically but also psychologically, as a whole with a continuous organismic valuing process at work towards the maintenance of the organism is also at the core of Roger's Personality Theory (1951). It is what the person-centred therapist relies upon (Ibid., p.489). This has been called the 'self actualizing tendency'. Carl Rogers argued that it is not through externally acquired knowledge, but through their experience, their own senses, their own physiological equipment that people are able to discover what is satisfying and enhancing (Ibid., p.513). The goal of the organism Rogers specifies as

"... to maintain itself, ... to move in the direction of maturation, ... to actualize itself in the direction of greater differentiation of organs and of function, ... to expansion, ... to greater independence or self-responsibility, ... self-government, self-regulation, and autonomy, and away from control by external forces and ... finally in the direction of socialization (p.488)".

This process is not expected to happen smoothly but rather through struggle and pain (Ibid., p.490). This principle has been taken further by Joseph and Linley (2005), in their Posttraumatic Growth Theory (see the literature review). Rogers (1951) also refers to other conditions. Sensory and visceral experiences and feelings need to be admitted into awareness through accurate symbolisation and need to be felt and accepted by the whole person for the self-enhancing process fully to unfold (Rogers 1956). Childhood relationships are seen as potentially causing a disconnection from the organismic valuing process, and resulting in external values being imposed. This can be restored when new relational experiences enable a rediscovery of the organismic values (Ibid., p.517).

Although person-centred theorists and practitioners would share the view that the self is a process or, as Rogers (1967, p.122) phrased it, “a stream of becoming, not a finished product”, they differ in the interpretation of the actualizing tendency. Possible interpretations are that in addition to 1/ working towards organismic maintenance and enhancement, it is 2/ a formative process that integrates all aspects involved into coherent forms and it is 3/ a process of actualizing all that one potentially can be. Some, e.g. Greenberg and Van Balen (1998), object to the actualizing-of-potential view, while e.g. Bazzano (2012) also resists the formative view. Both also put forward that the actualising tendency is highly interpersonal and warn for the temptation to understand actualizing in a static manner by narrowing it down to individualism, rather than acknowledging that others partake in the life of the organism (Mearns and Cooper 2005; Cooper 2019a). Or, as Cooper (2019b, p.43) puts it “there is place for wisdom without, as well as wisdom within.”

From the perspective of this thesis, understanding a person’s responses to others and to the world is essential, but seeing those responses as enactions is contrary to the idea that they somehow already exist, waiting inside the person as potentials to come out under the right circumstances. That a range of processes are at work where self continuously emerges from, has been described by Gallagher’s (2013) pattern theory of self. The different weights of the processes and the continuous changes seem to counter the idea of coherent forms, as does Varela’s concept of ‘natural drift’ that expresses the notion that what does not undermine the integrity of the organism, may occur.

Informed by the concepts of ‘natural drift’ and ‘actualizing tendency’ (understood in its minimal meaning, i.e. as a drive towards the maintenance and enhancement of life), I cannot but hear participants’ comprehendings of self at different times post-treatment as illustrations of an active or passive continuation of life and self. What I am specifically interested in though is what type of comprehending of self in relation to cancer may be considered as not viable, and therefore potentially organismically avoided, as such

comprehending would undermine a person's orientation towards survival or well-being. I have decided to concretise this by asking the sub-research question: "Are there any body schematic structures that appear as impossible for the comprehending of self vis-à-vis cancer?" I take this angle as I believe that although understanding what is not possible, is easily overlooked, it can deepen the understanding of an experience, in this case cancer survivorship. I will particularly explore the degree of closeness between self and cancer.

In the next section I focus on the fourth research objective, i.e. the consideration of the role of the transaction between survivors and their consultants.

#### **4.2.4 Transactional embodiment and 'affordances'**

In the discussion of Merleau-Ponty's and Varela et al.'s viewpoints it emerged that there are two dimensions to enactive cognition, albeit in one movement, i.e. a conceptual and a phenomenological dimension. I have chosen to use the term 'enaction' to refer to this totality.

The conceptual dimension is concerned with the interplay between the brain and the intercorporeal engagement in the environment, and focuses on 'sensori-motor embodiment' (Chapter 2). This gave rise to the research sub-question "What is the body schematic structure embedded in the metaphorical comprehending of the self vis-à-vis cancer?" and was further explored with Lakoff and Johnson's Conceptual Metaphor Theory (section 4.2.1).

The phenomenological dimension is concerned with the interplay between the embodied being and the environment, and focuses on what I call 'transactional embodiment' (see Chapter 2). In this study I attend to an aspect of this dimension with the research sub-question "How do transactions

during medical consultations function as affordances for the comprehending of ‘self vis-à-vis cancer’?” Below the term ‘affordances’ will be explained.

First I need to explain the choice of the term ‘transactional’. As said above, I wanted to preserve the term ‘enaction’ as a term that addresses the totality of the mind in the world and the world in the mind. When focusing on the role of the environment in the mind-body-environment coupling, I wanted to use another term yet one that was aligned with the concept of ‘enaction’. Johnson (2007) mentions that Dewey used the term ‘transactional’ in a similar way as Varela et al. used the term ‘enaction’. I chose to use the term ‘transactional’ to focus specifically on the role of the environment in the engagement. This is a deliberate choice in order to avoid the more familiar term ‘interactional’. The word ‘interaction’ somehow suggests a gap between subject and world (Johnson 2007, p.118), the very thing that Varela et al.’s ‘enaction’, in line with Merleau-Ponty’s thinking, contest. I aim to stay in tune with their effort to conceptually overcome the gap between mind and world

As indicated above the biological and sensori-motor loops with which living systems self-organise their continuity are coupled to the environment in a way that they “enact or bring forth what counts as information for them” (Thompson 2005, p.418). Or as Johnson (2007, pp.46-47) puts it, the sensori-motor capacities of the organism, the characteristics of the objects and the nature of the environment together determine what responses are possible for an organism, or what is ‘afforded’. The use of the terms ‘afford’ and ‘affordance’ in this context was introduced by Gibson who gives the following definition:

“The affordances of the environment are what it offers the animal, what it provides or furnishes, either for good or ill” (Gibson 1986 (1979), p.127).

This means that an object can be experienced as affording different things to different organisms, or to the same organism at different times. What counts as an object is also dependent on the organism. For human beings, other human beings are ‘objects’ that afford possibilities for communicating and

exchanging meaning (Johnson 2007). Gallagher et al. (2017, p.93) highlight that “situations and their meanings are relative to affordances that are physical (relative to individual motoric abilities / disabilities and skills), but also social and cultural”. As the research sub-question explores the affordances of participants’ transactions with medical consultants, social and cultural affordances are likely to weigh more than physical affordances.

Organisms perceive objects and environments as affording certain actions. Whether these actions are subsequently met with support or impediment will inform the next action and generate a continuous perception-action cycle (Gibson and Pick 2000, p.16). By acting, the context changes and the enactions of others, impact on the self. The other and the self “move in a mutual becoming”. (De Simone and Simoncini 2012, p.321). With cognitive acts such as speaking, perceiving, touching they generate each other on the condition that they acknowledge each other.

Varela et al. and Gibson agree that organisms and environments are coupled by perceptually guided action. But Varela et al. (1991, pp.202-204) also sharply address the difference in their views. Gibson (1986) sees the environment as independent and perceptually guided action means ‘picking up’ the affordance that is always there to be perceived regardless of whether the organism attends to it or not. In contrast, Varela et al. argue that perception is always sensori-motor enactment. The affordance only occurs through enactment. In this thesis I follow Varela et al.’s perspective, which means that the ‘affordances’ that seem to work for participants have not been understood as ‘picked up’ from the environment but as enacted through their engagement with the environment.

So far, embodiment was mainly discussed with the momentary comprehendings of self in mind. However, the potential impact of embodiment on the direction of a comprehending process is also important. In the next section each of the levels of embodiment will be revisited briefly from a developmental perspective.

#### 4.2.5 Developmental embodiment and ‘personal dynamics’

In this study, the focus is on exploring momentary comprehendings of self vis-à-vis cancer. One way of doing this, is by looking at those comprehendings through a developmental lens. This is done by comparing the comprehendings based on their body schematic structure and by ordering them according to a sensori-motor developmental logic (research objective 5). This might suggest that in this thesis development is only understood in these body schematic terms. This is not the case. On the contrary, embedded in the explorations of the embodied dimensions (above) is a multi-facetted view on development of thinking and self. In the following summary these facets are highlighted and brought together.

By using the term ‘developmental embodiment’ I first of all mean ‘an embodied process of *change over time*’. That change is inherent to enactive cognition, Varela et al. (1991, p.205) explain as follows:

“...cognition as embodied action is always about or directed toward something that is missing: on the one hand, there is always a next step for the system in its perceptually guided action; and on the other hand, the actions of the system are always directed toward situations that have yet to become actual.”

In other words by living in the world (what I have called transactional embodiment) there is an unavoidable need to respond. On the back of that, the self, with all its cognitive and other abilities, changes and develops (Hohwy 2007). In this acting, whether through actions or verbal expressions, that which ‘occurs’, Gendlin says, is one side of a self-generated process of implying and occurring. This experientially embodied process, on the one hand, draws attention to the push for *continuity*, while on the other hand pointing at the inevitable process of change. The ‘occurring’ carries forward the implied but in doing so it also changes the self. Gendlin refers to the *direction of change* by stipulating that the changes happen according to an organismic drive towards self maintenance and enhancement. By exploring bio-chemical embodiment through Varela et al.’s concept of ‘natural drift’, I now understand this teleological organismic drive as a wide road where life

maintenance and enhancement are the boundaries of the road, and where is *discarded that which is not viable*. The road discards what is not viable rather than dictates what is viable.

Turning to the neurological theories it is the *sequence of change* that comes to the fore. The structure of the human brain makes that initially new situations are experienced as undefined but then gradually *differentiate*. As discussed in Chapter 2, from an evolutionary perspective and from a child development perspective, this differentiation happens through bodily action in the environment. The sophistication of bodily action depends on the underlying sensori-motor skills. Sensori-motor development enables a child step by step first to look at objects, but then also to manipulate them, to walk away from them, take them into new spaces etc., in other words their sensori-motor development influences how they structurally experience the environment. As has been discussed, in embodied cognition, these sensori-motor schematic structures are considered to be the source of metaphorical thinking. In this study, the body schematic structures of the participants' metaphors will be highlighted but, as pointed out at the start of this section, they will also be ordered according to their position in the sensori-motor development process.

In summary, the different dimensions of embodiment highlight several facets of development. First, development entails a process of *change* which unfolds according to a *sequence* of steps and is *directed* towards increased *differentiation*. Secondly, development entails a taking forward of what already existed, i.e. it is a process of *self-continuation* and preservation. Thirdly, a developmental process allows for *personal variation*. Finally, all these facets mutually influence each other and impact on the total process, which makes a developmental process also a *dynamic* process (Gallagher 2017, p.21).

### 4.3 A quest for holism

In this thesis sub-personal processes are considered as enabling, but that means they are therefore also shaping or limiting, personal processes. However, personal dynamics are also impacting on the unfolding of the sub-personal processes. In the research inquiry this will be attended to by exploring the interplay between features of participants' wider self (objective 2), their particular medical transactions (objective 4) and the structure of their metaphorical comprehendings of self vis-à-vis cancer (objective 1).

As indicated at the end of Chapter 1, by taking into account different dimensions of embodiment and their interplay, and by considering both the momentary experience in its own right and through a lens of change over time, an attempt will be made to build an understanding that is not only comprehensive but also 'holistic'. I will now reflect on what this means within a framework of embodied thinking.

Bullington (2013b) argues that in health care the term 'holism' is used with very good intentions, i.e. to overcome a bio-medical view that reduces human being to our somatic part. But it is at risk of being just as reductionist by staying within a framework that assumes there are 'parts'. I have chosen to address the different dimensions of embodiment separately in order to explain my views. This is an artificial approach, but one that I hope to have counteracted by engaging with a theory that specifically conceptualises the relationship between mind, brain, body and environment as a Gestalt. As Gallagher (2017, p.10) reminds us, "in a gestalt the whole is said to add up to more than the sum of its parts". This is one reason why in this study the research findings have been taken forward into a painted format, i.e. a visual medium that has the capacity to communicate things that cannot be conveyed through words (Pink 2004; see Chapter 10).

On the other hand the focus on the embodied nature of human being also throws up a limitation. Self, in this study, is considered as a process that

emerges within the confines of embodied human being. It means that it is deemed impossible to experience a dimension of self that preceeds, exceeds or prolongs human being outside bodily being. Yet many people believe not only that there is such a state of being, i.e. a state of being that is not embodied, but also that there is a link between such a state and the human embodied state. This is usually referred to with terms such as 'spirit' or 'soul'. However, for Lakoff and Johnson, spirituality is restricted to 'embodied spirituality'. Gendlin's concept of the 'more', has a transcending and spiritual ring to it, but is theoretically also strongly embedded in embodiment.

When attempting to grasp experiencings in a holistic manner, the need to include a spiritual dimension presents itself. Somehow, spirituality that is described as confined by embodiment, conjures up the feeling that what it intends to include is excluded. The 'holistic' exploration of the experiencing of self vis-à-vis cancer in this study does not consider the *existence* of an experience of disembodied spiritual experiencings. This does however not mean that the exploration of participants' conceptualisings of experiencings they consider to be spiritual and disembodied have been excluded. Those conceptualisings too have to rely on references to body schemas and logic. Lakoff and Johnson (1999, p.567) argue that it is possible to feel passionate about disembodied entities exactly because of the metaphorical character of conceptualising which grounds them in embodied everyday experience, and which creates a sense of realness.

Having defined and explained the philosophical framework of this study and the research questions they underpin, the next chapter (Chapter 5) contains an exploration of how this study approach relates to the existing body of cancer survivorship literature. In Chapter 6, based on my theoretical framework, a set of methodological aspects are explicated. This in turn has guided the methods of data generation, inquiry and presentation as described in Chapter 7.

## **5. Embodied outlook on cancer survivorship research: literature review**

### **5.1 Aim and approach**

As mentioned in the introduction, a literature review at the start of this project established that a methodological perspective based on embodied cognition and conceptual metaphor theory had not been applied much to research on cancer survivors' comprehending of self and cancer. Six studies were found to be relevant for my research and will be discussed in section 5.1.5. Because of this relative dearth of research in this area, it seemed useful to inform the reader fairly early on of the methodological framework and the research objectives.

In addition to contributing to research informed by theories of embodied cognition in health psychology, I consider this study into bowel cancer survivors' comprehending of self vis-à-vis cancer worthwhile in relation to two further gaps. First, as long-term survivorship is a relatively recent possibility, it follows that there is scope for studies that include the experience of long and very long term survivors. Secondly, there is scope to extend the knowledge on cancer survivorship from a process and holistic perspective (conceptual, transactional, experiential, bio-chemical and developmental).

Although the following research review is presented partially to demonstrate the existence of the aforementioned gaps, the main purpose lies elsewhere. Reviewing research literature is a process of comprehending. I found it important to approach the review with the theoretical understanding of comprehending adhered to in this study. This means I deliberately considered some of the interpretive and embodied characteristics of the review process, which I hereby further concretise as follows:

First, congruent with interpretive methodology the main purpose of the research literature search has been to engage with the *context* against which the findings of this study need to be understood and thought through (Smythe and Spence 2012). To what extent the findings of this study may overlap with the findings of other studies informed by embodied cognitive thinking will be explored in section 5.2.5. However in the sections 5.2.1 to 5.2.4, the context is widened and the review discusses studies that were informed by other theoretical perspectives but that, in parallel with the research objectives of this study, research the structure and meaning of experiences, explore how experiences are embedded in survivors' psycho-social engagement in the world, and that unravel patterns, directions and dynamics of change.

Secondly, it is a given that each piece of research has limitations and that therefore its meaning and implications need to be considered cautiously and critically. However, by over-focusing on limitations, one may dismiss findings that can help forward the understanding of a phenomenon. I side with those who suggest an open and generous stance. I believe that it is through an ongoing weaving together of findings that we develop a richer understanding (Crouch and McKenzie 2006; Randolph 2009).

Thirdly, as Lakoff and Johnson (1999, p.338) have argued, all thinking is non-consciously metaphorically structured, and this is as much the case for everyday thinking, as it is for philosophy, or interpretive research including the literature review. After a first phase of general reading, I took time to reflect on the metaphorical roots of the spontaneous ordering that seemed to unfold. In the next section I provide an explication and discussion of the metaphorical structure that underpins the ordering of the studies.

From a practical point of view, cancer survivorship literature has been searched by using search engines, academic networking sites, internet browsers, and reference lists. Key words were used to include and exclude specific topics. Details of this search are included in appendix B2.

As cancer survivorship is a relatively new concept it is no surprise that the majority of studies are maximum 20 years old, with a steady increase in research publications from about 2006 onwards.

## 5.2 Metaphorical perspectives on cancer survivorship

Although conscious that cancer survivors conceptualise their life after a cancer diagnosis with metaphors that range from ‘fighting’ and ‘journeying’ to a multitude of more personal metaphors (Semino et al. 2018b), I became aware that in categorizing previous research I was drawing mainly on ‘journey’ and ‘movement’ metaphors. This might have been influenced by Varela et al’s (1991) metaphor for enactivism: ‘the path is in the walking’, but it is more likely that the thought of researching a long-term process was more predominant. The most prominent metaphor for long-term experiences is ‘Long-term activities are Journeys’ (Lakoff and Johnson 1999, p.193). Journeys are constituted by locations, destinations, movements and difficulties. It seemed that especially the interrelation between the two first features informed the way I distinguished previous research studies from each other:

In a first group of studies the implied location of cancer survivors seems to be described as one of psychological distress caused by physical and psycho-social problems. These studies also imply that the aimed for destination is a *return* to a distress-free place. In metaphorical terms I consider these studies to conceptualise cancer survivorship as a process of ‘getting back on track’.

Studies brought together in a second group describe the starting point for survivors as one of identity disruption, while the destination consists of finding a path that leads to a *new* identity. In metaphorical words, cancer survivorship seems to be conceptualised as: ‘walking a new path’.

A third group of studies considers survivors to be in a location where the adversity of the diagnosis needs to be processed. This processing, they argue, potentially leads to 'post traumatic *growth*'. Metaphorically I capture this as: 'taking the hurdle leads to a new track with unexpected heights'.

The fourth group of studies does engage less in linear thinking which presupposes movement from start to destination. Instead survivors are considered to be in two places (e.g. illness and health) and the emphasis is more on the continuous movement between the two places than on reaching a destination. Rather than walking a path, the emphasis is on moving about in a terrain. Metaphorically I understand the reasoning of these studies as a conceptualising of survivorship as 'moving between and betwixt angst and normalcy'.

The fifth group of studies is informed by conceptual metaphor theories and analyse which metaphors are used to understand cancer and illness experiences. Metaphorically 'understanding' is a process that is mainly expressed as 'seeing' or 'grasping', rather than through spatial or movement terms. I suggest that in these studies survivorship is explored as a process of 'framing cancer experiences'.

These metaphors need to be held lightly. They are intended to create transparency about my thinking at this moment in time. They are also only a partial handle on my understanding of survivorship albeit one that has been useful to think about the position of my own research approach in this wider survivorship research context.

In the next sections the studies that gave rise to each of the metaphorical conceptualisations are discussed.

### 5.2.1 Getting back on track

A diagnosis of cancer is in the first place a diagnosis of a physical illness. Consequently there is also, when it comes to the psychological experience of cancer survivorship, a body of research that focuses on this physical 'ill-being'. Within this perspective survivors' experiences tend to be described in terms of psychopathology or psychological problems. For example, experiencing a life-threatening illness was recognised as an event that could cause posttraumatic stress disorder (PTSD) in the DSM-IV in 1994 and it has been suggested that 5 to 35% of cancer patients suffer from PTSD (Sawyer et al. 2010). An overview of articles published between 2004 and 2015 shows that a significant proportion of colorectal cancer survivors experience clinically meaningful levels of anxiety and symptoms of depression, or reduced mental well-being across the trajectory of the illness (Mosher et al. 2016). This confirms findings in mixed cancer research revealing that anxiety and depression may fade after two years but that survivors' well-being is impeded well beyond that time (Stanton 2006). Fear of cancer recurrence (FCR) is one of the main problems reported by survivors (Deimling et al. 2006; Skaali et al. 2009; Greer et al. 2011; Mitchell et al. 2013). Based on an overview of 130 quantitative studies published between 1996 and 2011 Simard et al. (2013) concluded that survivors, although reporting low to moderate levels of FCR, considered it as one of the greatest concerns, and one that remained stable over time. 'Chronic Uncertainty' is another common experience during survivorship. Cancer survivors reported ruminating about their patient experiences and tend to question treatment decisions well beyond finishing their treatment (Miller 2012). Foster and Fenlon (2011) report loss of self-confidence in survivors after treatment. Others have made a point of the 'loss experience' that comes with survivorship: losses caused by the impact of cancer diagnosis or treatment on re-engagement with previous psycho-social roles (McGrath 2003) as well as loss due to moving away from the security and support from professionals and other patients (Armstrong-Coster 2004).

Knowledge about long and late physical effects of cancer increases steadily as more people live longer after a cancer diagnosis. Appleton et al. (2013) conclude from their review of the literature that the physical symptoms experienced by long-term survivors of colorectal cancer range from fatigue, bowel disturbance and problems related to living with a stoma, to pain, sexual dysfunction and weight loss. Drury et al.'s (2017) analysis of eighty-five studies of survivorship in the context of colorectal cancer published between 2006 and 2016, emphasises the physical but also psychological distress caused by bowel disturbances and stomas, often resulting in a sense of loss of control and hiding away.

Dunn et al. (2013) researched the level of psychological distress after colorectal cancer at six time points, i.e. from 6 months to 5 years post-diagnosis. They found that the prevalence of high overall distress ranged between 32 % and 44 %. Their findings also alert practitioners to be aware that their study showed men to be more vulnerable to distress than women, and that some survivors only experience high levels of distress later in the trajectory (and are therefore unlikely to be detected if the assessment of support need is limited to the early stages of survivorship). The prevalence of distress at the time of diagnosis seems to be generally expected and there is a body of research into the relationship between the way the 'bad news' is communicated and patients' distress (e.g. Shofield et al. 2003). Some studies point to advanced levels of cancer as a predictor of high levels of psychological distress (e.g. Kimman et al. 2017). No studies were found that explored the link between further nuances in grade of cancer and distress at the time of diagnosis. Foster et al. (2009) looked at the experience of survivors who were five years and longer post diagnosis. From a review of 43 studies published between 1960 and 2006 they concluded that 20 to 30 % of long-term cancer survivors report psycho-social problems. These problems included psychological distress, sexual problems, problems with social relationships, financial concerns in addition to poorer quality of life due to ongoing physical problems. Although these findings alert healthcare practitioners to a potential need for support, methodologically the above

studies do not allow insight into whether psychological distress is caused by cancer and its treatment, or by other factors. In long and very-long term survivorship especially the impact of other life crises becomes more likely.

In addition to the presentation of long-term physical problems as a cause of continuous psycho-social problems some researchers explored the impact of other contextual variables. For example lower levels of education and lower income levels have been found to inhibit adaptation for colorectal cancer survivors (Ramsey et al. 2002), while the presence of social support, and having a religious faith, in a study of female survivors of colorectal cancer shows to help adaptation (Sapp et al. 2003). Gordon et al. (2008) found that one year after a diagnosis of colorectal cancer the proportion of people who do not return to work is not entirely explained by increasing age, demands of therapy or concurrent health conditions, and suggest that further research in non-physical causes is needed. Appleton et al. (2013), who conducted an early qualitative study into the experience of colorectal cancer survivors who were between six months and five years post-treatment, point out that although they considered time since treatment to be an important characteristic, their data did not reveal temporal differences in experience. This resonates with findings by Ramsey et al. (2002) who studied the experience of people who were at least five years previously diagnosed with colorectal cancer. The implied aim of problem-focused research is for the 'psychopathology' or milder psychological problems to lift. Adjustment to cancer is understood as an "absence of psychological morbidity and return to pre-morbid functioning" (Brennan 2001, p.7). It may also mean making health behaviour changes in response to the health problems (Park et al. 2008).

In addition to illness and contextual factors, researchers have also explored the impact of personal differences in coping style, and found that those who appraise their situation as 'harm' or 'loss' are likely to use 'avoidance coping strategies', whereas a situation appraised as a 'threat' leads to 'problem-focused strategies', and a 'challenge' is linked with 'approach coping strategies' (Franks and Roesch 2006). Avoidance coping strategies have

been found to go hand in hand with higher levels of depression and anxiety (Donavan-Kicken and Caughlin 2011), less adaptive health behaviour (Park et al. 2008), less paired relations, less paid work, more fatigue and overall poorer psychological quality of life (Rutskij et al. 2010).

Long term (between 5 and 10 years post-diagnosis) and very long term (more than 10 years post-diagnosis) cancer survivors (in mixed group studies and colorectal cancer studies) are reported to have an “overall good to excellent Quality Of Life” (QoL) (Bloom et al. 2007), as good as the rest of the population (Arndt et al. 2017) or even better than age-matched populations (Ramsey et al. 2002). A first drawback of QoL studies is that the term QoL does not always refer to the same content. For example, Bloom et al. (2007) have specifically reviewed literature on multi-dimensional QoL. This meant that they excluded an abundance of literature on QoL that solely attends to the physical dimension. However, for an understanding of the QoL of survivors of bowel cancer who often live with problematic bowel functioning, these studies may, although one-dimensional, be greatly relevant. Another confusing aspect of QoL findings is how they relate to other explorations of well being. Arndt et al.’s (2017) research points out that despite a QoL that matches the population, ongoing social, emotional, cognitive and physical detriments are reported and especially affect patients under 50 years of age and very old survivors. When the spiritual and religious dimension of well-being was measured in survivors of colorectal and lung cancer who were maximum one year post-treatment this dimension scored high (Clay et al. 2010). Depression has been found to correlate negatively with spiritual well-being, at least in patients with advanced cancer (McCoubrie and Davies 2006).

The ‘positive psychology’ movement sets out to shift the focus from ill-being to subjective well-being and from adjustment as a lifting of negativity to positive adjustment. Well-being, when understood from a hedonistic philosophy, refers to feelings that are related to feeling happy (Lent 2007). Appleton et al.’s (2013, p.6) conclusion illustrates this:

“We found that having overcome adversity people who live beyond colorectal cancer do not just survive the cancer, they derive physical, social and psychological benefits from it.”

There is a “strong nature view of Subjective Well-Being” (Lent 2007, p.235) that states that, after a disruption of subjective well-being, in time people will automatically return to a generic disposition of well-being. Despite this, both Lent (2007) and Appleton et al. (2013) are cautious not to dismiss studies where colorectal survivors report ongoing physical and psycho-social problems. Appleton et al. wonder whether their participant group (which had a mean age of 67.2 years) had under-reported their problems. They refer to Bismark et al. (2006) who revealed an inverse relationship between age and propensity to complain about health care. We need to bear in mind, however, that Bismark et al.’s study focused on complaints about injuries caused by medical care. Foley et al. (2006) found that older survivors (in general) are also less likely to report personal growth and overall tend to minimize the impact on their lives. This was found in a study with survivors who were more than 15 years post diagnosis whereas Appleton et al.’s participants only ranged between 6 months and 5 years post treatment.

This focus on positive experiences as part of survivorship, seems to paint surviving as an active and interactive experience, rather than an experience of being victimised. Appleton et al. (2013) mention the role of survivors’ altruism and their wish to support others as a relevant factor in their sense of self. Survivors were found to be actively engaged in the management of their restrictions through interaction with family, friends and health carers, and by setting personal goals. Brennan (2001) specifies that adjusting to cancer does not only involve ‘coping’ but is also enabled by private reflection, worrying, talking to others, cognitive behaviour therapies, writing down traumatic experiences, resuming social roles and relationship. He argues that ‘coping’ theories and ‘cognitive theories’ tend to ignore the role of social context and do not appreciate the ongoing development of the adjustment process. He emphasises the mutual relationship between survivors and their contexts: “social context both modulates internal adjustment and is subjected to it”

(Brennan 2001, p.7). Simard et al. (2013, p.318), for example, report how relatives present at times higher levels of fear of recurrence than patients and also wonder about the mutual influence. Seiler and Jenewein (2019) also emphasise the contribution of social factors to survivors' 'resilience' or ability to adjust to cancer. Based on a large scale literature review they consider posttraumatic growth (see below) as an indirect path to increased resilience.

### **5.2.2 Walking a different track**

Researchers have explored, if and if so how, cancer impacts on patients' usual sense of self and identity, and how this in turn influences their quality of life. Based on a review of the cancer survivorship literature Zebrack (2000) posits that the experience of cancer leads to changes in social roles and identity. For example, Mathieson and Stam's (1995) research of the narratives of 27 cancer patients revealed cancer as a threat to self and identity. They describe how what they consider to be a universal drive to create meaning, triggers 'identity work'. This involves engaging the early disrupted feelings of fit, as well as biographical narrative work that incorporates the meaning of illness in older self-narratives, and then generates a space where identity is renegotiated. They noted that cancer initially is experienced in the 'foreground' while it later on becomes the 'background' to their self and life.

Naus et al. (2009) present their Cancer Survivor Adaptation Model as a model that looks behind the emotional and physical adjustment to diagnosis and treatment and instead focuses on the disruption of self and identity and a life-long adaptation process. Where Mathieson and Stam (1995, p.299), from a narrative perspective, write about "incorporating the meaning of illness" and refer to the engagement of "older self-narratives", in parallel, but from a cognitive perspective, Naus et al. (2009, p.1355) speak of the "construction of new goals and world assumptions", and how this depends on survivors' "autobiographical memory, which provides memories of personal meaning

and identity". Little et al. (2002, p.176) conclude from their research with three lay carers and twelve survivors of colon cancer, Hodgkin's lymphoma or hepatoblastoma, diagnosed between 6 months and 25 years previously, that "the survivor can be said to be surviving a radical challenge to continuity of identity". They mention the role of 'memory' and 'embodiment' in identity and describe how survivors' identity work consists of referring to stable anchor points in their beliefs and values, of reconstructing a new version of their pre-experienced identity, of using their experience of cancer to 'develop pre-established facets of identity', and of imbuing the cancer experience with meaning and recognising the 'enlarged identity' made possible by survival.

The meaning of the experience of disruption of roles and identity is considered to be dependent on the socio-cultural, biomedical and psychological context in which the disruption is experienced, e.g. a disruption in intimacy through cancer treatment will be experienced differently by a young survivor who needs to disclose this to a potential partner, than by an older adult in an established relationship (Zebrack 2000). Mathieson and Stam (1995) paid specific attention to how identity work emerged in interaction with the responses of family, society and the medical world. For example, patients may not have been given a voice in relation to their illness by their doctors, or friends may not be able to see 'them' behind the cancer. Little et al. (2002) mention the unhelpfulness of others who fail to understand the uniqueness of cancer survivorship. In an earlier article Little et al. (2000) describe how health care practitioners are just as vulnerable as their patients and employ similar coping strategies. Yet the denial of their own vulnerability and a negative framing of patients' vulnerability, they argue, causes the discordances between patients and health carers.

Karnilowicz (2011) also makes a point of how health practitioners can play a constructive role in the patient's identity renegotiation. He conducted an autoethnographic study in which he describes his own diagnosis of prostate cancer as a sudden disruption of self and loss of control: "the disease came to own me" (Karnilowicz 2011, p.8). He argues that the unexpectedness (he

was only 50, there were no symptoms) was the motor for a process of building psychological ownership of the illness. Ownership comes with a sense of control and responsibility. McGrath (2004) frames it as a key aspect of an individual spiritual journey after cancer, while Karnilowicz (2011) emphasises that a sense of ownership is, really, a psycho-social construct. These different frameworks could be a reflection of the time post-diagnosis of the survivorship experiences that were explored. Karnilowicz's reflections probably refer to his experience up to five years post-diagnosis, while McGrath's study includes six survivors who were diagnosed 5 to 8 years prior. Alternatively it may also be an example of framing similar experiences according to the preferred lens of the researcher. McGrath's study was specifically funded to research spirituality in cancer patients and survivors.

For Karnilowicz (2011) seeing ownership as a psycho-social construct means that the way health care practitioners relate to their patients is of crucial importance. He concludes that issuing directives (e.g. for the survivor to adopt new behaviours) bypasses the patients' need to 'own' their illness and health behaviour. Health and care practitioners need to take into account their patients' situation and assess whether they are ready, and then truly negotiate, through the use of education and information, any treatment options or recovery action plans. Drury et al. (2017) conclude from their recent research literature study that the navigation of systems and resources has become an inherent part of the cancer survivorship experience. They point out the lack of empirical research into the impact of healthcare experiences on cancer survivors' quality of life. Fiori (1990), writing as a psychologist and cancer survivor, points out how an active partnership with physicians mobilizes personal resources to combat cancer. Jorgensen et al. (2017) studied cancer patients' experience of empowerment during follow-up with a qualitative systematic review of literature written between 2000 and 2015. They concluded there was a distinct lack of attention for patients' own understanding of empowerment and highlight the need for an illness and stage specific study of patient empowerment. The body of research that explores the willingness or capability of relatives and health care

professionals to be supportive in survivors' identity work, suggests that the disruption of identity is embedded in a 'disruption of reciprocity' (Bury 1982, p.180). Despite the reported frustrations of cancer survivors with their families in their present real life relationships, Pascal (2010) looks into the role of memories of past family life as a source for restoring identity continuity. Her study of the experience of 15 self-defined cancer survivors shows how their past family relationships inspire them to cope with the present. The re-establishment of a future often happens with stories involving their children.

In a slightly different body of research into identity and survivorship, researchers explored how survivors identify their relationship to cancer. At five years post-diagnosis 55 % survivors of colorectal cancer identified as a 'cancer survivor', 39.4 % as a person who had (or has) cancer, 1.4 % as a cancer patient and 1.2 % as a cancer victim (Chambers et al. 2012). Similar results were found by Deimling et al. (2007) in their study with older long term survivors. Differences between survivors are associated with numerous psycho-social, clinical and demographic factors. Park et al. (2009) explored identity with a mixed cancer group of survivors who were diagnosed on to three years prior but allowed them to choose more than one identity. Again 'survivor' scored the highest, followed by 'had cancer', 'patient' and 'victim'. The main finding was that most survivors recognized different identities. Those identities point to the diversity of their experience. Finally, a large scale study by Thong et al. (2018) concluded that a significant number of survivors (e.g. 25 % of colorectal cancer survivors) 5 to 15 years post-diagnosis do not identify as 'survivors' but as 'patients'. Their methodological approach to present survivors with a dichotomized choice between 'patient' or 'survivor', can be seen as too simplified. On the other hand it may expose that the group of survivors who in the above studies might identify as 'a person who had or (has) cancer', when pressed, identify in equal measure as 'patients' and 'survivors'.

### 5.2.3 Taking the hurdle leads to a new track with unexpected heights

Above I indicated how 'positive psychology' has, within cancer survivorship research, broadened the focus from ill-being to well-being. The studies mentioned earlier (e.g. Appleton, Brennan) were informed by a hedonistic philosophical position, meaning that it is important to consider the possibility of 'happiness' even under distressing life conditions (Lent 2007, p.232). Within 'positive psychology' there is also an eudemonic philosophical position which states that not only 'happiness' but also 'growth and meaning' can spring from adversity. In cancer survivorship research literature this is discussed as 'Posttraumatic Growth' (PTG). The term was first used by Tedeshi and Calhoen (2004, p.1) and is defined as follows:

"Posttraumatic growth is the experience of positive change that occurs as a result of the struggle with highly challenging life crises. It is manifested in a variety of ways, including an increased appreciation for life in general, more meaningful interpersonal relationships, an increased sense of personal strength, changed priorities, and a richer existential and spiritual life."

Hefferon (2009) analysed 57 articles published before November 2007 which addressed posttraumatic growth following trauma related to physical illness, in contrast to other traumatic events. In line with the above definition she found change in perceptions of life and priorities, in the development of self, as well as existential re-evaluations, e.g. a changed perception of death. In addition she discovered that survivors tend to express a new awareness of the body, a theme that is unique to the "corporal nature of the illness related trauma and the process of reconnection with the body" (Ibid., p.344). Moreover, participants found that the diagnosis heightened their awareness of physical self identity and it was due to the overcoming of physical adversity that the PTG experience was propelled (Ibid., p.372). Surprisingly, no reference is made to the potential impact of surgery, chemo- and radiotherapy, in addition to the experience of diagnosis and physical disease, on survivors' changed body awareness.

Jansen et al. (2011, p.1158) differentiate between “posttraumatic growth” (PTG), which they define as benefits associated with changes in perspectives on life, relationships and self, and “benefit finding” (BF), defined as re-assigning positive value to the illness based on the identification of benefits. They explored the experience of 483 colorectal cancer survivors and found that five years after diagnosis almost all survivors experienced some degree of PTG and BF. Moderate to high levels of PTG were found with 46 % of survivors and 64 % reported BF. In a study by Salsman et al. (2009) colorectal cancer survivors reported less PTG than other cancer populations studied. This result could be caused by the fact that 85 % of the 55 colorectal cancer survivors in the study were diagnosed with an early stage cancer. This could explain lower levels of distress and subsequently lower PTG (see above).

Sawyer (2010), who studied PTG through a meta-analysis of research studies that explored the experience of survivors of cancer and HIV/AIDS up to 108 months post diagnosis/treatment, points out that PTG is at times noticed early and at times late in relation to the moment of diagnosis. This suggests that early PTG refers to a coping strategy aimed at reducing emotional distress, while later PTG refers to a more substantial life change (Sawyer et al. 2010). The early ‘use’ of PTG does not seem to include real growth. Maercker & Zoellner (2004) speak of the ‘self-deceptive illusionary side’ of PTG. They align this with Taylor’s (1983) concept of ‘positive illusions’ which refers to the phenomenon that when people are confronted with threatening events, they may respond with a somewhat distorted positive view of themselves, and with a naive optimism and overstated sense of personal control. According to Salander (2012) this transforming or reconstructing of some aspects of the threatening situation is often observed in cancer patients and is best captured by the word ‘disavowal’, a concept introduced by psychoanalyst Michael Basch. It is self-deception in the face of accurate perception, or a “playing with reality” so as to make it easier to cope (Salander 2012, p.543). Taylor (1983) described these ‘illusions’ as essential to normal cognitive functioning. It is only when these illusions continue beyond an early stage of dealing with

trauma that they change from “constructive optimism” to “naive optimism” and at that point they may have deteriorating effects on adjustment (Maercker and Zoellner 2004, p.47). The ‘positive illusions’ early on also explain why it is possible for cancer survivors to report ‘benefit finding’ from one year to another while presenting with increased psychological distress later on (Occhipinti et al. 2015).

When we focus on the ‘life-changing’ meaning rather than the ‘coping strategy’ meaning, of PTG, two components seem to be essential. First, the probability of PTG is dependent on having to overcome ‘adversity’. Jansen et al. (2011, p.1163-64) found indeed in their study of colorectal cancer survivors that

“the prevalence of moderate to high PTG was higher for cancer survivors who had a higher objective burden of their disease, such as a higher stage at diagnosis or higher intensity of therapy, or a higher self-reported burden of diagnosis”.

However, Joseph, like Tedeschi and Calhoen a prominent writer on PTG, reports that wider research on PTG shows that when posttraumatic stress levels are too high, the possibility of growth diminishes (Joseph 2011, p.92). The second essential component of PTG, then, is to do with how the experience is cognitively processed:

“Posttraumatic stress may well be the engine of posttraumatic growth, but survivors need to take control of the rudder and point themselves in the right direction” (Ibid., p.99).

Joseph (Ibid., p.118) emphasises that working through trauma requires the right balance between accommodation and assimilation. Assimilation means perceiving the stressor in a way that fits the existing way of being, while accommodation entails an acceptance of the stressor for what it is and an ability to alter the self to accommodate for it. Without accommodation growth is not possible (Ibid., p.114). Caspari’s (2011) study with 169 breast, prostate and colorectal cancer survivors confirms that a perceived threat and cognitive processing are good predictors of PTG. Abernathy (2009) researched the difference between cancer survivors who assimilate and those who accommodate their cancer experience and concludes the difference is due to

different identity structures which go hand in hand with different cognitive processing styles. Cancer studies show that posttraumatic growth is related to a better quality of life but this does not exclude the presence of distress (Sawyer et al. 2010; Joseph 2011, p.94-95). Salsman et al. (2009) suggest that early PTG may coincide more with distress than later PTG.

In general, social support seems to promote posttraumatic growth (Joseph 2011, p.121), while the impact of age and education is more cancer type specific. A younger age at diagnosis and lower education coincide with higher levels of PTG in survivors of colorectal cancer (Salsman et al. 2009).

Joseph and Linley (2005) specify PTG Theory as an 'organismic valuing theory of growth through adversity'. Their aim is to go beyond the more descriptive nature of other theories, e.g. Tedishi and Calhoen's Functional Descriptive Model. They explain why growth is possible by stating that people automatically evaluate what is inherently in their best interest. When this process does not unfold these authors work from the premise that something in people's past or present social context blocks this innate developmental trend and propensity towards growth.

#### **5.2.4 Moving betwixt and between Angst and Normalcy.**

PTG theories are strongly process orientated. Neither Tedishi and Calhoen (2004) nor Joseph and Linley (2005) suggest that people consciously aim for growth. PTG is, rather, a side-effect of their engagement with adversity. However it invites a focus on change and progress with the risk that experiences associated with slow or stationary movement get to be overlooked. Some studies into cancer survivorship have revealed in more depth the intricacy of the survivorship experience. Rather than focusing on the result of the disruption, these studies focus on the experience of the disruption. Rather than revealing how overcoming the disruption can lead people onto a track with new heights of meaning, these studies reveal how

experiencing the disruption opens up a space betwixt and between hard existential angst and a rocky version of normalcy.

Little et al. (1998) are important authors within this perspective. Their starting point is that cancer is an embodied experience. They point out that before diagnosis, the body is experienced as 'transparent'. Bodily experiences such as living with a colostomy bag, being breathless etc., undo the transparent nature of embodiment and instead make embodiment visible and problematic. Bleeker and Mulderij (1992), who research this bodily awareness in children with motor disabilities, draw on Merleau-Ponty's language when they define it as " (they) too often *have* their bodies and too rarely *are* their bodies" (p.16). Stroke patients, even one year after their stroke, express that "the body becomes something foreign and separate from the self" (Ellis-Hill et al. 2000, p.731). Cancer survivors' experience may differ from experiences of stroke and motor disability in that, the diagnosis first of all brings 'mortality' into their awareness. The body becomes unreliable in its ability to sustain life. It is all this that Little et al. bring together when they conclude:

"To perceive the limitations of the body, to experience the body as dread, as unfamiliarity, as the non-transparent, is to experience alienation of the self from the vehicle for self" (Little et al. 1998, p.1493).

Little et al. capture this experience with the idea of 'liminality'. Based on research with survivors of colon cancer who had surgery 3 months to 11 years prior, they characterise liminality as an experience of ongoing patientness, communicative alienation (not feeling understood by others) and boundedness (in space, time, roles, empowerment, future etc).

All this does not ignore that survivors may take positive action within ongoing constraints, e.g. when using their own experience to better inform recently diagnosed patients (Little et al. 1998, 1489) or that they may not be too overwhelmed by their patientness and, instead, insist that 'life goes on' (Little et al. 1998, p.1487). Little et al.'s view, however, is that, for cancer patients, liminality "can be coped with, it can be palliated. ... but it cannot be completely removed" (Little et al. 1998, p.1491). They write of early and late, acute and

sustained liminality to capture the variations in experiences expressed by survivors. Their study made manifest an ongoing oscillation between experiences of acute and sustained liminality as part of survivorship.

Blows et al. (2012) reviewed 10 articles published between 1985 and 2011 which used the framework of liminality to understand cancer experience, albeit in slightly different ways: the first is closely linked to how the concept was originally coined by the anthropologist Van Gennep. Liminality is then seen as a stage of transition, preceded by a stage of separation and followed by a stage of re-incorporation, i.e. a re-entry into a structure, into society. In other words it is the middle part of a tripartite 'rite of passage'. Turner (1967, p.97) described the experience of this part as a being "betwixt and between" all the recognized fixed points in space-time of structural classification". Being diagnosed with cancer at a young age may trigger specific experiences of liminality, e.g. uncertainty about having children (Rees 2017), or feeling bodily young and old at the same time (Hannum 2016). Blows et al. (2012) discuss cancer survivorship studies where this view on liminality was used to refer to survivors feeling in between health and illness, and prostate cancer patients feeling between gender identities. As these studies explored the experience of survivors who had not yet progressed beyond treatment, they are not really suitable to discover whether people move from a liminal stage to a non-liminal stage.

A second body of studies exceeds two year survivorship. All speak of the ongoing experience of liminality and challenge the idea that liminality in survivorship is inevitably followed by a stage of reincorporation. Little et al.'s study, which includes survivors over 10 years, is part of this body of research. According to Little et al. (1998) survivors do not move through the three stages of a rite of passage; they have a sense of liminality from the moment of suspected diagnosis and this sense continues for the rest of their life. Bruce et al. (2014) call this 'pervasive liminality' and from their research with survivors of cancer, renal disease and HIV/AIDS, suggest that people learn to live with the opposing and paradoxical experiences, rather than seek to move

on to a stage where these are resolved. Little et al. (1998) argue that living a 'liminal life' is living an 'existential life'. This resonates with Pascal (2010) who argues that existential 'angst' that is caused by the diagnosis, and is continuous throughout survivorship, also opens up a reflectiveness that appreciates the true nature of being-in-the-world. Based on her research of the experience of 15 self-defined cancer survivors (up to 15 years post-treatment) she concludes that the experience of cancer survivorship leads to a revision of 'normalcy', often with a stronger focus on the everyday here and now, but also with conscious reflections on the future possibility of death, triggered, for example, by illness anniversaries (Pascal et al. 2009). Little et al. (1998) add though that unlike our ancestors we have no heritage that has taught us how to live 'on the threshold'. The struggle to live 'on the threshold' has often been researched under labels such as 'spiritual pain' (McGrath 2002) or the 'existential plight of cancer' (Lee 2008).

Based on a third group of studies in Blows' review, some authors seem to try to combine the thought that survivorship both continues to be an experience of liminality and yet also re-anchors in a sense of normalcy. Thompson (2007b), who studied survivors up to two years post-diagnosis, agrees with Little et al. that liminality is a permanent state in survivorship, but finds that the liminal experience is not solely limiting or restricting, but is often generative in nature. Crouch and McKenzie (2006, p.495) suggest something similar when they propose to add to Little's acute and sustained phase a third liminal phase in which survivors transcend the sustained liminality. This they argue happens between 5 and 12 years past diagnosis, when survivors experience "some security and become more like 'ordinary' people". They call it a phase that not all reach but that most yearn for.

Scott (2014, née Blows) concluded from her own research with 13 cancer survivors (who were between 5 and 16 years post-treatment), that while the majority expressed a sense of sustained liminality, some made the transition out of the liminal stage, with the five year marker playing an important role. Within 'sustained liminality' Scott differentiates between 'physical liminality'

(experiencing ongoing consequences of treatment) and 'existential liminality' (experiencing ongoing fear of recurrence). Little et al.'s determined emphasis on the ongoing nature of liminality in survivorship on the one hand feels like a stubborn resistance to the acknowledgement of recovery, yet at the same time it is a finding that is echoed in later studies as well, e.g. in Koutri and Avdia (2016), who, based on their research with breast cancer patients, advocate the use of liminality as a lens to understand survivors' experience, especially as it is a 'non-preferred story-line' in society and in the health care sector.

McKenzie and Crouch (2004) deepen the understanding of liminality with their study of the experience of 22 cancer survivors (who were between 2 and 35 years post-treatment). They note that a specific feature of cancer survivorship is the life-long 'threat' of recurrence. They argue that this results in an 'anxiety-tinged mood' and in flashes of fear that well up at times throughout life. This anxiety based outlook sets survivors apart from others, especially in societies that do not tolerate expressions related to mortality. It is present in the fears of their relatives and friends, but also in their own fear and beliefs that negative affect contributes towards cancer. Consequently survivors (McKenzie et al. prefer the term post-patients) are highly motivated themselves to 'control' their negative mood and are encouraged and expected to do so both by relatives and health carers. The authors refer to research that says that emotions cannot really be controlled and therefore the 'control' achieved is more likely to be a 'control of expression' rather than a true control of their feelings. McKenzie and Crouch conclude that this mismatch between the way survivors interact and the way they feel creates an existential 'in between' state that characterises life-long survivorship.

More recent studies seem to explore more what it takes or means when survivors' experience goes beyond the full blown sense of liminality. Wake (2017), who explores 'continuous liminality' as wearing the 'Cancer Mask', suggests that it is through 'listening' to self and others that cancer survivors may be able to accept liminality, rather than being controlled by it. Sleight

(2016) on the other hand suggests the possibilities for cancer survivors to transcend liminality through ritual. Sibbett (2008), who questions a linear presentation of liminality, suggests both from her personal experience as a cancer survivor and her professional experience as an art therapist, that art therapy can offer an opening for the symbolic and metaphorical therapeutic expression of the experience of liminality in a ritualistic manner. Assing Hvidt (2017), informed by an existential-phenomenological framework, concludes from research with survivors in rehabilitation, that people 'arrive' at a new 'home world' that *integrates* the initial 'alien world' of cancer diagnosis. This resonates with what Sleight (2016, p.58) describes as a "post-liminal identity that holds space for the experience of illness."

### **5.2.5 Framing cancer experiences**

The following studies explore, like the research in this thesis, how people conceptualise their experience of cancer or cancer treatment, from a framework that understands conceptualising as embodied. This means they explicitly explore the metaphorical character of the way cancer patients and/or survivors think about their self and cancer. The use of metaphors in coping with illness and cancer has been researched for a long time. Although it is difficult to ignore work by e.g. Sontag (1979) who is known for taking a critical stance against the use of military metaphors to capture the experience of cancer, in this literature review the focus has been on studies that specifically explore metaphor as *thinking*. These studies are only emerging recently, in parallel with a growing interest in embodied cognition theory.

The role of metaphor in psychotherapy has also been intensely researched. This includes studies which consider metaphor as thinking. As a counsellor I find these research studies, as well as the therapeutic approaches that proactively engage with conceptual metaphor theory, for example Lawley and Tompkins (2000), to be highly relevant. However, in this thesis I am not researching cancer survivors' metaphors or potential variations in survivors'

metaphors over time as they occur within a counselling context. I suffice here to refer to Tay (2017) who gives a detailed description of the different angles which the use of conceptual metaphors within the therapist-client relationship has been researched from.

Below I present studies that are by content or approach particularly relatable to the research in this thesis.

Both small qualitative and large mixed method studies, first of all, bring to the fore the vast number of metaphors that populate people's conversations. In the following studies the analysis of the data consists of pointing out metaphorical differences in the way patients or survivors conceptualise their cancer experience. The criteria used to differentiate the data are related but unique to each study:

Gibbs Jr and Franks (2002) analysed the metaphors in six women's narratives of their recovery of cancer. In addition to 'creative idiosyncratic metaphors', e.g. 'living with cancer is like being at war, participants' 'conventional metaphors' were also explored. These are metaphors that are part of everyday expressions, e.g. 'it took me a long time to get back on my feet'. The inquiry consisted in categorizing the metaphors according to the embedded metaphorical concept, or what Lakoff and Johnson (1999) also call 'primary metaphors', e.g. 'Understanding is Seeing' is the metaphorical concept underpinning the linguistic metaphors 'cancer allowed me to see life in a different way', 'it was like putting on a new pair of glasses' and similar expressions. A total of 796 linguistic metaphors (on average 132 per person) were reduced to only 23 primary metaphorical concepts.

A recent study presented by Semino et al. (2017; 2018b) studied the creative and conventional metaphors used by patients with advanced cancer, relatives and health care practitioners. This included the narratives of 56 patients who between 2007 and 2012 contributed to a UK online forum for people with cancer. The metaphors deducted from 500,134 words, were categorized

according to 10 types of metaphors. The journey and violence-related metaphors were most frequently used. Health care practitioners were found to use these metaphors as well but with a lower frequency.

Teucher (2003) conducted a quantitative and qualitative cross-cultural study of metaphors in the cancer discourse of people with and without cancer. He elicited 184 different cancer and 145 different cancer treatment metaphors. In four steps he presents them in 11 clusters based on an intuitive understanding of the meaning of the metaphors, and positions these clusters in relation to each other in a three dimensional space with the following three axes: intangible to tangible, static to dynamic, and internal to external. For example, when cancer is metaphorically conceptualised as an intruder, it is tangible, dynamic and goes towards the internal pole.

Each of the above studies also acknowledge the transformative power of metaphorical conceptualising, which forms the specific focus of a study by Hoggan (2014). The 18 breast cancer survivors in his study had been in remission for three to seven years and believed their disease brought positive benefits. Nine of the survivors used conceptual metaphors to transform their way of thinking, i.e. to uncover tacit ways of making meaning, to imagine new possibilities, and to name their experiences. Despite expressing strong emotions, the participants in this study did not seem to use conceptual metaphors to express their emotions.

Although the above studies acknowledged the transformation that occurs through patients' metaphorical conceptualising, none explored a potential sequence in the occurrence of the different metaphor types, nor queried time or place of their occurring in relation to the overall cancer survivorship process. Only one study was found to focus specifically on the change of metaphors. Yet, this study by Boylstein (2007) does not explore the experience of patients after a cancer diagnosis, but after a stroke. Boylstein (2007) comments on how much in metaphor research seems to focus on bringing forth the variety of metaphors used to express the experience of

illness. In contrast he is interested in exploring how metaphors shift throughout a person's recovery and to that end compares the metaphors used by stroke patients at the onset of stroke, as well as one month and six months later. An interesting finding was that a severe impact of the stroke on functionality not only leads patients to conceptualise stroke as a 'disaster' at the onset but to conceptualise themselves one month later as a 'survivor', while six months later more negative feelings returned.

Some of the above studies take the analysis of the metaphors beyond the conceptual perspective.

Teucher (2003) used the framework he generated from a conceptual analysis of the metaphors (see above) to analyse (a sample of) the literature on the experience of cancer. His literature analysis addresses the function of the spoken metaphors in the personal and social context of the patient and/or the impact of personality disorder on people's ability to frame their experience with 'helpful' metaphors.

Boylstein (2007) explored whether changes in patients' metaphors corresponded with any shifts in their sense of self, levels of depression and functional ability. He explains how patients changed their metaphorical description from 'disaster' to 'survivor', and then back to expressions of negativity, in physical terms. He argues that when it becomes apparent that the physical recovery is not what patients hoped for, the positivity disappears and the new reality needs to be accommodated for before any sustained posttraumatic growth becomes possible.

Semino et al. (2018) emphasise how metaphors are context and usage dependent and encourage further research into individual variations. They also argue strongly for an approach that combines a conceptual perspective with a discourse and practice based perspective (Semino et al. 2018a). This shows in their work as they expand on the first layer of analysis which points to the dominance of journey and violence related metaphors. Further inquiry

concluded that there were meaningful differences within those metaphors related to the expressed sense of agency and emotion. Those differences determine whether the journey metaphors and violence-related metaphors are a positive or negative frame of survivors' experience. Subsequently Semino et al. (2018a) concluded that in communicating with individuals or small groups neither "a blanket rejection of Violence metaphors" nor "an uncritical promotion of Journey metaphors" is recommended. Instead healthcare practitioners are encouraged to raise their awareness of the specific function of the metaphors for their patients. On the other hand, based on the more general analysis, they recommend avoiding violence related metaphors when communicating to the general public as this may harm patients who do not conceptualise their illness in such terms. This also underpins UK policy and the use, in public documents, of the 'cancer journey' metaphor.

How patients' conceptualising of their illness experience relates to their behaviour in a health care setting has been the focus of a study by Gotzmann et al. (2007). Using interview and a questionnaire (which contained various standardized test instruments to assess anxiety, depression, self-esteem, health perceptions and personality factors) they explored how 20 patients after lung-transplantation mentally represented the relationship between self on the one hand and lung, donor and medical staff on the other hand. The researchers did not specifically generate patients' metaphors but deduced the spatial structure of the way they talked about their experience, which makes this study relevant in this thesis. They found that patients who felt more distant to the lung, close to the donor but not close to their medical staff showed low to middle compliance with the medical regime after transplantation while this was the opposite for patients who showed high compliance.

Finally, the aforementioned study by Gibbs Jr and Franks (2002) also investigated some theoretical aspects of Conceptual Metaphor Theory. An important conclusion was that despite disruptive bodily experiences, the

cancer patients in their study used metaphors that refer to the healthy body to understand their experience.

### **5.3 Discussion and conclusion**

First of all the study in this thesis relates to the work by Semino et al. (2018), Teucher (2003) and Gibbs Jr and Franks (2002) as I too seek to point out the 'primary metaphor' that speaks from participants' metaphorical comprehending. My work differs from those studies in so far as it specifically explores the relationship between self and cancer rather than a more general conceptualisation of life after cancer. Secondly, in this study the primary metaphors are used as an in-between step to raise awareness of the basic spatial and kinaesthetic structure of participants' comprehendings.

The metaphorical studies above mainly draw attention to the impact of individual contexts on the occurring metaphors but do not explore potential patterns of change over time. In this thesis, as in Boylstein's (2007) research, the potential link between metaphorical comprehendings of experiences at different times is considered to be of interest. Boylstein has been able to compare changes within individual participants. This has not been possible in this study, but by considering participants' momentary expressions as a step within an assumed developmental bodily process (my research objective 5), an additional frame of meaning has been added.

Boylstein (2007) and Gibbs Jr and Franks (2002) respectively explain changes in conceptualisings as responses to changed illness realities, or as transformations caused by narration. They do not consider the impact of bio-chemical developmental processes. It is in the work of Joseph and Linley (2005) on posttraumatic growth, and in the underpinning organismic valuing theory, that I find support for the inclusion of an exploration of participants' data from a bio-chemical perspective (research objective 3).

Both in the review of metaphorical studies (Semino et al. 2018, Gotzman 2007) and the wider literature review (e.g. Karnilowicz 2011, Drury et al. 2017), interactions with healthcare practitioners are brought forward as an important part of the experience of cancer survivors that needs further research. This resonates with my research objective 4 which guides an exploration of the transaction between participants and their medical consultant.

It is no surprise that in metaphorical studies informed by embodied cognitive science, emotional, relational and functional aspects of the experience come to the fore. Those aspects shape the metaphors and that they are consequently integrated in the overall analysis (Semino et al. 2018, Teucher 2003, Boylstein 2007). In this study I specifically attend to the impact of the wider self on patients' conceptualising of their cancer experience (research objective 2). This makes the research literature on identity disruption and restoration (e.g. Little et al. 2002, Mathieson and Stam 1995, Naus 2009), and on resilience (Seiler and Jenewein 2019) relevant for this study.

In conclusion, I would like to revisit the claims made in the first chapter about the relevance and originality of this study.

First, the need for further research into long-term cancer survivorship has been confirmed in recent systematic literature review studies (Jorgensen et al. 2017, Drury et al. 2017). This is not so much because of a dearth of studies but because the survivorship experience keeps evolving and new issues are still emerging.

Secondly, in the metaphorical studies discussed above, different aspects of the cancer survivorship experience are brought to the fore as participants' cancer related conceptual metaphors are lifted from their conversations. I believe this supports my claim that the exploration of metaphors can be an effective tool to open up a more detailed understanding of broad experiences such as cancer survivorship.

Thirdly, by using a holistic framework of interpretation, this study builds on previous research which points out the need for such an approach. In relation to the existing research literature in the embodied cognitive approach, the addition, specifically, of a developmental and bio-chemical approach, is what adds originality to the research study at hand.

Fourthly, although the wider research literature review suggests that a bio-psycho-social research model is prominent in health psychology, it is important to keep in mind that in many studies this model is understood from a dualistic perspective on body and mind. Ghane and Sweeney (2013) promote the use of a non-dualistic embodied perspective in health psychology research as a means to explore how deliberate physical actions can 'improve' patients' health behaviour or physician-patient communication. I suggest that health psychology can gain from the non-dualistic embodied perspective in two other ways. First, the explication of the embodiment of patients' conceptualising gives us data that speaks directly to our own bodily understanding of their experience. Secondly, I believe that by taking embodiment as a starting point in this study, a range of experiences of cancer survivorship can be understood all at once, in one movement.

In the next chapter I explore how this will be done. Based on the philosophical principles of embodied understanding outlined in Chapter 4, the methodological consequences will be discussed.

## **6. Enactive Hermeneutic Phenomenology: Methodology**

In this chapter two questions are explored. First, how can an enactive hermeneutic phenomenological philosophy of 'understanding' be carried forward into methodological aspects and subsequently inform the methods? Secondly, can interpretation guided by those methodological aspects be considered as rigorous?

### **6.1 From theory to methodological aspects**

In Chapter 4 I concluded that for the methodology of this study to be in tune with an embodied existential phenomenological paradigm participants' comprehending of self and my comprehending of their comprehending must be addressed as embodied, thus mediating the relational, interpretive and existential character of comprehending. In enactive cognitive science the view on comprehending is aligned with these characteristics but its specificity has led to the following adjustments. First, in enactive cognitive science the 'embodied' is understood as 'enactive' which gives more explicit weight to the sensori-motor dimension of embodiment. Secondly, the neurological dimension of comprehending is addressed and specifies comprehending as metaphorical, a characteristic that will be included in the methodological framework.

As indicated before I refer to the methodology of this study as 'Enactive Hermeneutic Phenomenology' (EHP). In the next section the characteristics of comprehending will be concretized and presented as: enactive existential, enactive interpretive, and metaphorical and multiple embodied.

There are no specific rules or pre-given methods of interpretation in (enactive) hermeneutic phenomenology. Drawing up such rules would ignore the philosophical view that 'understanding' is first and foremost a way of being

before it leads to knowing. However it is recommended to aim for a tangible consistency between theory and research methodology and methods (Holloway and Todres 2003). Rather than creating a rigid method it has been suggested to outline “key aspects” (Laverty 2003) or “a set of disciplining understandings” of the philosophical underpinnings (Todres and Wheeler 2001, p.6) or as McManus Holroyd (2007, p.1) puts, to clarify the “conditions of understanding” rather than construct a procedure.

A list of key aspects has been created and is discussed in this chapter. These aspects have guided the research methods. This list is not considered to be exhaustive but is sufficiently comprehensive to function as an effective bridge between the research theory of this study and the research practice. The key aspects are based in the literature on hermeneutic phenomenology and enactive hermeneutics, and on how I envisaged their meaning in this particular study. Most of the aspects can be understood in relation to more than one of the above mentioned characteristics of comprehending. However, in Table 1 the aspects are ordered according to the characteristic that they best concretize.

Table 1: Aspects of Enactive Hermeneutic Phenomenology (EHP)

“Key aspects” of Enactive Hermeneutic Phenomenology:	Enactive existential comprehending	Enactive interpretive comprehending	Multiple embodied and metaphorical comprehending
1/ Pointing to what is really expressed			
1.a. Attending to multiple embodiment of comprehending			X
1.b. Hermeneutic imagination	X		
1.c. Experience near thinking and talking	X		
1.d. Fundamental existential categories	X		
1.e. The ‘more’	X		
2/ Hermeneutic ‘dance’			
2.a. Starting with pre-understandings		X	
2.b. Looking through research interpretive frameworks		X	
2.c. Moving from parts to whole and back again		X	
3/ Richness of description and expression	X		
4/ Awareness that understanding is an ongoing process	X		
5/ Relationality and Empathic Openness		X	
6/ Comprehensive reflexivity		X	
7/ Active engagement of metaphorical understanding			X

### 6.1.1 'Pointing to' what is really expressed

Phenomenological studies aim to grasp participants' experience as it is lived and are especially "concerned with unveiling hidden meanings of lived experience" (Finlay 2011, p.112). In this study that has been carried out in two ways. First, the research objectives specify **multiple 'hidden' embodied dimensions** (as detailed in Chapter 4) that will be attended to in order to grasp participants' comprehending of self vis-à-vis cancer. Secondly, research interventions are conducted according to the following methodological principles which will be explained below: inviting experience-near thinking and talking, hermeneutic imagination, understanding in terms of fundamental existential categories and attending to the 'more'.

Within the theoretical framework of this study, what is said and thought is seen as rooted in and shaped by an embodied experiential base. Subsequently the methods of data generation and inquiry of this study have been chosen for their capacity to generate "**near-experience**" **thinking and talking** (Todres and Holloway 2004, p.59).

Listening to participants' stories is more than listening to their words. In order to really capture what is said it is important to go beyond the words and ask oneself "what is at work in particular ways of speaking and acting? This has been described as '**hermeneutic imagination**' (Smith 1991, p.197).

In aiming to shed light on human conceptualising as rooted in experiencing an exploration of the **fundamental existential categories** that are implied in human experience in the world seems very relevant (Todres & Wheeler, 2001). In this study it appeared that the research approach lent itself best to an exploration of the experience of body, space, time and relationship to self and others, embedded in the participants' comprehendings of self and cancer.

As addressed in 4.2.3 Gendlin (2004) has repeatedly pointed out that words and thoughts cannot capture an experience completely. While listening to

participants, the aim was not to interpret thoughts and words as a “summation of experience” but as an “invitation to experience more” (Todres, 2007, p.25). The body is considered to play a central role in understanding the ‘more than can be said’ (Todres, 2007, p.20). In this study **the ‘more’** has been attended to with an ‘embodied inquiry’ into the data.

When ‘interpretation’ goes hand in hand with a conscious attempt to stay as close as possible to what is expressed by participants, ‘interpretation’ has been described by van Manen (1997, p.26), drawing on Gadamer, as “pointing *to* something’. It is this type of ‘interpreting’ that has been employed when exploring the first four research questions: pointing to the body-schematic structure of participants’ metaphors (objective 1) and to those that seem not possible (objective 3), pointing to the ‘carried forward’ self processes (objective 2) and to the medical transactions involved in the self-enaction (objective 4).

### **6.1.2 Hermeneutic ‘dance’**

In order to emphasise that comprehending is a continuous process that neither starts nor ends with the presentation of the findings, that it is rather an ‘always being on the way’, has been indicated by the term ‘hermeneutic circle or cycle’. At the end of this chapter I argue that the term ‘hermeneutic dance’ captures more accurately the principles of interpretation in EHP than the term ‘circle or cycle’. In the next section I discuss how the hermeneutic ‘circle’ or ‘dance’ of interpretation starts with pre-understandings, including external interpretive frameworks, and as a process that goes backwards and forwards between the whole and the parts (Laverty 2003).

#### **6.1.2.1 Starting with pre-understandings**

The position from where the data are explored changes throughout the interpretation process but the data interpretation cannot but start with what is

already known (Todres, & Wheeler, 2001, p.4). In the context of this study, pre-understandings based on the case-study (appx.A0) were at play in the early stages of the interpretation of research participants' data. It has been important to keep this in *reflexive awareness*. Yet the initial understanding also made it possible to hear 'new' aspects which were taken on board and further enriched the way of thinking about the phenomenon. From a hermeneutic viewpoint there is value in knowing 'differently' rather than knowing 'more' (McManus Holroyd 2007, p.3).

### **6.1.2.2 Looking through research interpretive frameworks**

It is part of a hermeneutic approach that both empirical and theoretical lenses can be used to explore the meaning of data (Finlay, 2011, p.110). As with any pre-understandings it is important to keep in *reflexive awareness* that the study findings are directly shaped by the lenses employed. In the research part of this work the emphasis is on exploring the data through theories of neuro-cognitive and phenomenological embodiment. In the practice part the data has been taken forward into artistic expression involving a colleague practitioner whose 'interpretation' has inevitably co-influenced the ongoing stream of interpretation, and has been experienced as an additional 'empirical lens' that sheds another light on the data (see Chapters 7 and 8).

Lakoff and Johnson's Conceptual Metaphor Theory was used to 'point to' the body schematic structure of metaphors, Gendlin's Process Model to 'point to' carried forward aspects of self, Varela, Thompson and Rosch's theory of 'natural drift' to 'point to' body-schematic metaphorical structures that seem impossible and theories of non-dualism and 'affordances' to 'point to' the role of medical transaction. But the developmental perspective used for the exploration of objective 5 enabled an interpretation which is more directive than a 'pointing to'. It is a perspective that in itself is an interpretation. It suggests that sensori-motor changes happen according to a given sequence. Rather than saying that the meanings that emerge after ordering the research

data according to this perspective are 'pointed to', it may be more accurate to say that they are 'pointed *out*' (Van Manen 1997).

### **6.1.2.3 Moving from parts to whole and back again**

This refers to the circularity of interpretation, i.e. in order to understand the whole of texts or experiences, researchers look into the parts of these texts and experiences; to understand the parts they look at the whole (Lavery 2003). Repeating this movement from whole to parts and back again deepens understanding. What is considered a 'whole' and the 'parts of that whole' varies. The first to fourth objectives of this study focus on the individual experiencing and therefore the totality of each participant's expressions is considered as a 'whole' consisting of a range of parts, e.g. conceptualised themes, body schematic form of different metaphors, a range of implicit meanings, etc. The fifth objective considers the totality of all participants' expressions as the 'whole' with the individual variations as parts.

### **6.1.3 Richness of description and expression**

By embedding conceptual and linguistic understanding in ever changing experiencing, the idea that understanding may be absolute or definite becomes untenable. From the existential viewpoint that human understanding is 'indeterminate' it follows that the stories that capture thoughts and interpretations are "transitional phenomena" (Todres 2007, p.44). Todres argues that one must aim to keep the indeterminacy tangible by *leaving gaps* which draw people in thus making engagement an almost spontaneous embodied response. This allows for the emergence of "personal insights not explicitly provided by the writer's description" (2007, p.57). Todres (2007) has described how the method that serves this purpose best is to engage in *different modes of understanding, some structural, some textural and where possible a combination of both.*

Different modes of understanding are *reflected in different types of language* (Todres 2007, p.8-13): *A general and abstract language*, e.g. 'Sadness arises from a person's emotional dimension of being' expresses that the findings outreach the particular and are if not universal, at least applicable within similar contexts. Language that describes the texture of phenomena on the other hand communicates of the "thickness" of experience (Todres, 2007, p.47). Todres (2007) suggests this can be done by adding *descriptions of the concrete and individual occasions* and by engaging in an 'embodied inquiry', a tuning in with the felt sense and mood of participants' stories. Understandings from embodied inquiries will rather take *an aesthetic form*.

Separately these modes of language do not achieve a balanced understanding, which made Todres (2007, p. 48) suggest that a search for methods that *harmonise texture and structure without splitting* them is worthwhile.

#### **6.1.4 Awareness that understanding is an ongoing process**

On a practical level the closure of data inquiry is no doubt influenced by imposed time frames, yet there is more. Kvale (1996) points out that if phenomena are considered to have an essence then a sense of 'coherence' tends to indicate that the inquiry can be halted. He contrasts this with studies conducted from a framework that sees experiences as constructed in interaction. In this study the idea of experiencing and comprehending as an ongoing flow is prominent and this has shaped how the 'findings' of the data inquiry have been presented in this study (see Chapter 7). As a phenomenological researcher I want "to be open to the phenomenon that we investigate and careful not make definite what is indefinite" (Dahlberg et al., 2008, p.94). Yet the ending of the research inquiry and presentation of the findings has not been arbitrary. The ending, rather, was reached on a sense of satisfaction on a cognitive, ethical and experiential level. The interpretation meanders around the research question. The cognitive

commitment to formulate an answer to the research question has been an important factor in finding a point of rest. But this also depended on a conscientious knowing that the data and information had been explored systematically and thoroughly. When this combined cognitive and ethical appreciation became tangible as a felt sense of accuracy and honesty I could genuinely say that the study had been brought to a closure rather than a halt, albeit that the closure is like a door that remains inevitably, ajar.

### **6.1.5 Relationality and empathic openness**

First of all it is worth noting the vast number of people who influence any research project. In this study I consider the findings to have emerged in dialogue with participants, in dialogue with myself but also in dialogue with so many other people with whom occasionally I discussed my thoughts and feelings evoked by the research. Given my professional background there has also been an internal imagined dialogue with cancer survivors and health care practitioners for whom I hope my work will be useful. Before starting a doctorate, there was the search for the 'right' university department and supervisors, again because of an intuitive understanding that the relationship can help as well as hinder the development of our understanding, and that without any actual 'relating' the process of understanding is less likely to flourish. Formulating the research question, aim and objectives in relation to the professional background, research literature and paradigmatic and methodological frameworks, entailed an engagement with the views of a vast number of people. I have come to realise that my understanding of theoretical views is often enhanced by reading reflections by other scholars. Their interpretations, agreements and disagreements brought me to take a position. Interpretation thus becomes a relational experience. Bringing this into awareness brought it home to me that interpreting is both within and beyond us (Todres, 2007, p.32). These social engagements and the realisation that it is important to hold them in awareness when reflecting on the achievements and limits of this study, can be seen as part of a specific

contemporary research culture in which I got involved through a background of study and practice that resonates with this culture. But, as Gallagher and colleagues (2017) point out, one should not underestimate the physical and pragmatic affordances. In this case distance and cost could easily have prevented my engagement with the university research community that has significantly influenced the development of the theoretical framework of this study.

In addition, if the relationship with participants is considered as influential in the generation of data, then it is important to engage in a manner that is methodologically informed. In general, phenomenological schools proclaim to aim for an 'open' attitude towards participants. The 'relational openness' that underpins phenomenologically inspired research is embedded in related humanistic values, e.g. total acceptance of what participants express as their experience and a willingness in researchers to change their own pre-understandings of the phenomenon (Finlay 2011, p.77).

In order to clarify my own research relational approach I compared some of the phenomenological attitudes that are considered conducive to achieving openness and reflexivity based on the body schematic structure of their descriptions. The first stage of this exercise included a body schematic exploration of bracketing, bridling, reflexivity and empathy. The findings are included in appendix C0. Below I present some *personal notes* to explain how my understanding and practice of 'relational openness' with research participants gradually developed and is best described as a combination of empathy, reflexivity and bridling (see also appx.D16).

*After about three research sessions I started to wonder how I conceptualised my own approach in these explorative sessions. I had a sense that my approach was subtly changing as I became more familiar with the task. I did not understand how it changed though. I wanted to make sense of what I felt not in the least because I wanted to assess whether the change was congruent with my methodology.*

*A first reflection brought to my awareness that I experienced the interviews as a process of taking down music notes on a music sheet, with the notes symbolising participants' metaphors. Yet, the next day, this image felt unsatisfactory and from there developed a sense that I was much more hands on and I likened my subsequent research experiences to a gardening experience. I likened the generated data to flowers on a plant and the communication with the participants as "hands that jointly kneaded the soil from where the flowers on their plant appeared".*



Figure 9: Metaphorical expression of interviewing

*The first metaphor did not express an awareness of a reflexive involvement in the data generation while the second metaphor did. In the second metaphor my hands are continuously there and they are not still; they need to move together with the participants' hands as it is their joint dynamic that generates the data. This suggests that I am not concerned with actively putting any pre-understandings aside, but they potentially come into awareness in response to the working of the hands of the participants, and may be used in a way that is conducive to the emerging of the participants' flowers. Based on this reflection I am inclined to argue that it has been part of my approach not to bracket my pre-understandings but to have them there in the working relationship in order to have them impacted on and changed by the participants' approach. If willingness to change pre-understandings is part of the test of real openness to participants' experiencing, then a stance of bridling, and bracketing is difficult to rhyme with this, at least not in the moment.*

*Where Finlay points to a tango-like relationship between bracketing and reflexivity/openness (appx.C0), the kinaesthetic experience that underpins my gardening metaphor draws more on fine motor skills and is not so much an experience of moving forwards and backwards but an experience of understanding that metaphorically would rather be expressed as 'grasping'. I wonder to what extent this has been influenced by conducting a piece of research that involves the use of material, like paper, shells and stones, as well as an experiencing of empathy with participants manipulating these objects. With this in mind I believe this section gives a partial expression of the way I have 'lived' openness during my research.*

*The question I am pondering at the moment is whether there is an experience of ‘bracketing’ and ‘bridling’ within an empathic encounter. Conceptualising this, first of all entails looking into the meaning of the moving hands. My sense of the above metaphor is that the hands are moving but not in a controlling or manipulative way but rather in a way that tunes in with the movements of the participant. This is a responsiveness that goes with and supports the participants’ flow. Within this context there is space for an empathic ‘bridling’ if it is conceptualised as being like a ‘sounding board’. In other words when it is conceptualised by drawing on sensory rather than spatial kinaesthetic bodily experiences. ‘Bracketing’ within empathic relating I feel conjures up a stance of ‘observing’ and therefore can be understood by drawing on visual rather than spatial experiences.*

### **6.1.6 Comprehensive reflexivity**

#### Reflexivity as a research method

“appreciates that the researcher actively constructs the collection, selection and interpretation of data and that any results are co-constituted – a joint product of the participants, research and the social context” (Finlay, 2011, p.80).

A more extensive reflection on the meaning and implications of ‘reflexivity’ has been included in appendix C1. From an enactive perspective it is emphasised that in addition to pre-understandings and interpretive frameworks (see 6.2), biological, social, cultural, psychological and pragmatic characteristics of the people involved influence what type of understanding is

'afforded' (Varela et al. 1991, Gallagher et al. 2017). Below this difference between epistemological and more comprehensive reflexivity is addressed.

In 'reflexivity' literature detailed pointers are set out to help researchers to raise their awareness for the myriad of ways they impact on the research. The self-evident way is of course through the research question, the data generation and analysis methods and the ontological and epistemological beliefs that underpin the study. Although the research approach is intended, "epistemological" (Willig, 2001, p.10) or "strategic" (Finlay, 2011, p.84), reflexivity aims to make clear that the findings are not only enabled but also limited by these choices. Reflexivity also entails an awareness of pre-understandings about the topic of investigation. For example the sampling and recruitment strategy of this study focused on recruiting participants that could challenge the pre-understandings based on the case-study and professional practice. "Personal reflexivity" entails a reflection on the impact of our own values, beliefs, experiences, and other social-political-cultural aspects (Willig 2001, p.10). I would like to specify here that this also incorporates more visible features such as age, gender, language and the mannerisms that come with professional roles. Finlay, who categorises reflexivity in terms of the level on which it is experienced, captures these factors under "relational reflexivity" and "embodied reflexivity". The latter also draws attention to the impact of the researcher's felt sense and gestures (Finlay, 2011, p.84). Reflexivity also addresses the ethical issues and power relations between researcher and researched (Etherington, 2006, p.37; Finlay, 2011, p.84). "Ethical reflexivity" is probably best incorporated in the way research is organised and conducted. For example counteracting or carefully attending to vulnerability in participants potentially caused by the research topic, method and venue, is usually (and also in this study) the first methodological task during data generation (see Chapter 7). Counteracting may consist of protective actions (e.g. confidentiality, anonymity), support (e.g. in distress), empowering actions (e.g. informed consent, information letter for GP, right to withdraw) and basic respect for humanity (e.g. prioritise attending to need over following planned research schedule and methods).

As it was my aim to take a consistent reflexive stance, also during the sessions and afterwards, I looked out for unintended relational dynamics and how they might impact on the results.

### **6.1.7 Active engagement of metaphorical understanding**

This key aspect has been addressed in two ways. First with an 'embodied enquiry' of the data I have actively generated a metaphorical understanding of participants' comprehendings. Secondly, in this section I present a metaphorical understanding of EHP itself.

Aiming to develop an embodied and enactive comprehending of 'enactive hermeneutic phenomenology' I have engaged with the body-schematic structure of some related metaphors, e.g. hermeneutic circle, cycle, shuttlecock movement (dixit Dilthey cited by Todres and Wheeler 2001, p.4) etc. This exercise is described in appendix C2. As a result, rather than using the term 'hermeneutic circle or cycle', I propose the metaphor of 'hermeneutic dance'. How this metaphor, in my opinion, captures the spirit of EHP, is described below.

In search of a more apt metaphor than 'hermeneutic circle', I came across a picture (Figure 10), called 'Flamenco' by Camille Kleinman, which, so far, for me best expresses my understanding of enactive hermeneutic phenomenology.



Figure 10: Flamenco – courtesy @ Camille Kleinman  
Metaphor for enactive hermeneutic phenomenology

First of all by representing the 'dance' metaphor with a picture of a person, interpretation is presented as a process that is generated in and with a 'lived body' and as an embodied experience.

The movement of the person (researcher) through a sea of yet unexplored data (blue), touches parts of data one by one and brings out their aliveness (the person leaves behind a trail of coloured pieces which one could see as fruits or flowers or blood vessels). Together the thus enlivened data take, the shape of wings and spur the researcher into further movement, which in turn leads to wings that further gain in beauty, muscle and span. Different lenses are like different paths which the researcher follows in moving through the surrounding data, resulting in different colourings being activated in the data. In my view the imagery of 'circle' and 'shuttle-cock movement' conjures up the search for depth, as in a grinding down movement, an aiming to 'grasp' rather than to 'evoke' and 'open up a space'. The 'dance' metaphor offers an image of a path which implies an opening up of an ever widening space. With this one may miss out the message of 'depth'. However, in the metaphorical picture (Figure 10) the emerging colouring and wing muscle in a way suggest both depth and space.

In hermeneutic methodology there is no set system of interpreting. How one explores the data, emerges from previous findings. The enactive view of understanding echoes this in an embodied way by saying that 'the path is in the walking'. In other words interpreting creates the next step of interpreting. As the person in the picture is a dancer (a metaphor for the hermeneutic researcher also used by Finlay, 2011, p 109), the metaphorical equivalent is that the next dance movement is informed by the previous one and its results. Dancing also captures a view of phenomenological research as responding both to intuitive and felt understandings in the moment, whilst also being guided by rational understanding and knowledge of research steps and movements.

## 6.2 From methodological aspects to rigour

I am now turning to the second question: can interpretation guided by the above methodological principles be considered as rigorous?

There has been a lot of debate about which criteria should be used to evaluate the rigour of hermeneutic phenomenology and qualitative research. In positivistic scientific research, research methods are evaluated for their ability to capture precisely, objectively and consistently a reality that is presumed to be out there. In hermeneutic phenomenological studies, findings are not seen as 'exact' but as indefinite, temporal and contextual. Over decades numerous sets of criteria have been put forward to evaluate rigour of the interpretive methods that generate that type of findings. Some sets either 'replicate' or 'parallel' the criteria upheld in scientific research, but other sets aim to correspond directly with the characteristics of interpretive research (Rashotte and Jensen 2007). It is to the latter that I have turned to evaluate the rigour of the 'key aspects' which have formed the methodological guide in this study and were discussed above. I mainly use the criteria put forward by Madison (1988, pp.29-30), but have included additional criteria suggested by Rashotte and Jensen (2007) and Meleis (1996).

Madison (1988) focuses on the interpretation of 'text', yet his criteria are easily transferable to data that is conversationally gathered from participants. Rashotte and Jensen (2007) focus on the relational aspect of interpretive phenomenology and suggest that good interpretation needs to look into the relationship between the researcher and their participants, their data and their readers. Meleis (1996) overall presents eight criteria to support culturally sensitive research. Two of those, 'power dynamics' and 'disclosure', I have added to the list below as they add rigour to inter-personal relating in general, and complement what Madison puts forward.

The following criteria, proposed by Madison, seem specifically pertinent for the rigour of *data generation*:

Interpretation is evaluated as showing '**appropriateness**' if the research questions have emerged from the researched experience. In the first chapter of this study, it was explained how the focus on self vis-à-vis cancer, on the body-schematic structure of metaphors and other embodied dimensions emerged from observing and listening to survivors in counselling, during a case study and in the wider health care sector.

A second principle, '**contextuality**', refers to the importance of understanding *participants* 'in their context'. This is reflected in the research objectives, where the role of participants' wider self experience and medical transactions are actively invited in order to contextualise their metaphorical expressions of self vis-à-vis cancer. Awareness of the contextuality of the *researcher* is part of the key aspect called 'comprehensive reflexivity'. The possible impact of being a hospice worker, counsellor, and novice researcher, on the data gathering process will be discussed in Chapter 7.

A good interpretation needs to be '**penetrating**' or searching for what is intended. In this study this happens by enabling 'near-experience' thinking. Todres (2007, pp.37-38) has argued that such "faithful presencing", i.e. participants being faithful to the bodily felt sense of their experiencings, contributes to what according to another set of criteria of rigour could be called the 'truth value' of qualitative research.

The next three criteria are about evolve the importance of not ignoring 'what does not fit' during the *data inquiry* process:

Both Madison and Meleis find rigour in the interpreters' ability to stay with the data and with what participants really say. Madison calls this principle: '**agreement**'. This I believe is served by what was described above as 'pointing to' what is said, but also by the demand for an awareness of pre-understandings. In this study it has been important not to over-attach to the earlier case study findings and remain open-minded with regards to new data, especially when this challenged pre-understandings. Madison also urges to

understand texts in line with how authors usually communicate. Transferred to participants' stories this poses new questions: at some point the case study participant, for example, spoke in contradictory ways. It was a point of judgment whether it was more rigorous and informative to reveal the contradiction or to frame it in a way that created coherence. In this study staying with what participants really said, entailed a conscientious selecting and exploring of those metaphorical expressions which best captured how I understood the overall experience of self that was conveyed. The focus has been on a rigorous *understanding* of participants' metaphors. This is different from metaphorical research conducted by linguists whose inquiry is about *analysing* metaphors, and where rigour also refers to the quality of their technical exploration, e.g. of types of metaphors, or of the linguistic and/or conceptual character of specific metaphors (Semino et al. 2004).

Good interpretation is expected to show '**comprehensiveness**' and '**thoroughness**'. This means not ignoring parts of the data and dealing with all the questions posed. This is partially addressed with the hermeneutic 'dance' of repeatedly attending to the whole and the parts.

A third group of criteria relate to the rigour of *data presentation and dissemination*:

'**Coherence**', or an integration of parts, which does not exclude that data may have contradictions, is also put forward as a quality of good interpretation. This resonates with Todres' (2007, p.48) suggestion for a harmonious bringing together of textural and structural ways of understanding. In this study working towards 'coherence' has been a stepwise process, culminating in capturing the understandings in painted format.

Whether the interpretations in this study have '**potential**' to be extended beyond the research context is something that, as the researcher, I hope for. This will be tested by using the findings in future health care practice and academic work.

In the process of interpretation, other options for research have opened up and are referred to in the conclusion. This corresponds to the criterion of '**suggestiveness**' of good interpretation.

A final group of criteria which has been gathered from Rashotte and Jensen and Meleis, refers specifically to the *inter-personal relationship between researcher and participant*:

It is important to be cognizant about '**power** differences' between researcher and participant, and for the researcher to invite 'participants' **trust**' so they feel safe to reveal their authentic self. These issues are overall guided by the key aspect of 'relationality and empathy'. They have been addressed throughout but specifically at the start of the explorative interviews.

Rashotte and Jensen encourage attending to the **relationality between the research and the reader**. In this study this came to the fore when writing up the findings. I realised that I wanted and needed to ask the reader to engage with the findings not just rationally but also by imagining the described body schematic structures. This corresponds with seeing the 'enactive' aspect of interpretation in EHP through into the dissemination of the research findings.

In conclusion, there is a close link between the presented criteria of rigour and the key aspects of this research as discussed in 6.1. I set out to conduct the research in line with the key aspects and the criteria of rigour. The 'key methodological aspects' described in this chapter and their relation with the existential, interpretive or metaphorical character of enactive comprehending, have been included in a 'master Table' (see appx.C3). In this Table the methodological approach is presented in relation to the theoretical framework and the aims and objectives of this study. In the following chapters, the elements of data generation, inquiry and presentation will be presented using a colour coding which shows which methodological aspects they reflect.

## **7. Research methods**

In this chapter the participant recruitment process, the methods of data generation and inquiry, and procedural aspects including the adherence to ethical requirements are addressed while the alignment with the methodological aspects of EHP will be pointed out.

### **7.1 Sampling and Recruitment**

After a brief outline of the background of the sampling size, in this section I will explain how initial sampling criteria led to a first recruitment stage. I will also give a rationale for the type of variation I was envisaging and how this was achieved by a purposive second recruitment stage. I will describe my rationale for ending the recruitment. This section is concluded with some reflective notes in relation to the recruitment process.

#### **7.1.1 Sampling size**

For qualitative research small numbers, varying between 5 and 20, are considered sufficient (Crouch and McKenzie 2006; Finlay 2011). In order to come to a nuanced understanding as aimed for in qualitative research variation is important (Dahlberg et al. 2008). This can be expected to push the size of the sample up. Nevertheless, as explained in the methodological chapter the method of analysis in this study consists of empathic reflection and detailed comparison of the data. This meant that the size of the sample could not exceed what I could hold in mind as a whole, as a totality. This resonates with the view that, in addition to variation, the quality of qualitative research is dependent on the quality of the engagement with the data (Crouch and McKenzie 2006). When data of 12 participants had been

generated and analysed I felt that a satisfactory level of variation had been reached.

### **7.1.2 Initial sampling criteria**

In line with the boundaries of the research domain of this study (1.) the initial criteria for inclusion were for participants to have a past diagnosis of bowel cancer, have finished treatment, have no active disease up to participation and be 18 years or over. Initially I envisaged exploring 'long term survivorship' by recruiting participants up to 15 years post-treatment but this was extended when a participant who was 20 years post-treatment came forward. Gaining insight in the experience of survivorship two decades post-diagnosis I considered useful as indeed increasing numbers of people survive cancer, including bowel cancer, for a considerable number of years (see 1.1.; Cancer Research UK 2019a).

Within the group of bowel cancer survivors who met the inclusion criteria it was my aim to sample a group of participants that would enable me to generate and explore as many diverse post-treatment experiencings of cancer as possible. As explained in Chapter 3, I understand experiencing as emerging from an enactive relationship between persons and their life context. Consequently, as Crouch and McKenzie (2006, p.493) put it

“ ...if anything is being 'sampled', it is not so much individual persons 'of a kind', but rather variants of a particular social setting and of the experiences arising in it. ... respondents embody and represent meaningful experience-structure links.... (they) are 'cases', or instances of states, rather than (just) individuals who are bearers of certain designated properties (or 'variables').”

Based on this methodological view, underpinned also by an ethical stance of inclusion, minimal exclusion was aimed for. I set out not to exclude participants based on their sexual orientation, religion or world view, race, ethnic origin, nationality, language, disabilities or any concurrent life crisis. I was, however, willing to adjust the provision of information to accommodate

specific needs and support fully informed consent. An introductory screening meeting was set up to assess whether other life circumstances were preoccupying participants' mind to the extent that it would severely interfere with the generation of rich data about their survivorship experiencing. In practice it was difficult to determine this and no one was excluded for this reason (see below). I excluded cancer survivors if I was currently seeing them for counselling. Researching clients in one's care can easily lead to power inequalities (Holloway and Wheeler 2002) or to unnecessary confusion through a blurring of the boundaries between the counsellor and researcher role. It is not that such concerns must unavoidably lead to unethical research, it is rather that there is a lack of consensus, not in the least in the professional world, about the ramifications of such issues (McLeod 2010).

Since this is a qualitative study, I do not aim to draw conclusions about the prevalence of the experiencings that emerge from my sample in the overall population. The search for diversity in the sample is not to be understood as an intention to create a group of participants that could be seen as representative of a wider population. The aim is to take the understanding of cancer survivorship further by embracing a variety of experiencings and, in doing so, enable a critical assessment of existing insights and open up new questions.

Not knowing how easy or difficult it would be to recruit a sufficient number of participants, at the start I did not want to add to the initial inclusion criteria. Nevertheless I felt it was important to think through the life contexts in which I hoped the participants would vary.

First, I hoped to recruit a group of participants who were up until 15 years of life post-treatment. It is part of my practice based understanding of the cancer survivorship journey that different times after treatment do not necessarily lead to variations in experiencing, but certain ways of conceptualising may potentially only become available in time. In addition to exploring a multitude of varying cancer survivorship experiences, the fifth

objective of this study lies in exploring potential developmental patterns between experiences over time. This meant that ideally participants would not all randomly fall within the 15 years post-treatment group but would be spread out over that time period in some balanced way. Based on the longitudinal case study findings and on my general professional understanding of psychological processes of change, five time zones were defined: completed treatment less than 1.5 years ago, between 1.5 and 3 years, between 3 and 5 years, between 5 to 10 years and over 10 years ago. With five time zones defined, a minimum of five participants were needed.

Secondly, in the research literature variations in experiences have been linked to differences in terms of age, gender, medical severity of illness and treatment, and the subjective psychological impact at the time of diagnosis (see Chapter 5). Aiming to increase the heterogeneity of the participant sample I decided to aim for up to 10 participants, preferably evenly spread across the five time zones.

Thirdly, the relationship between the data of the on-the-job case study and the research data needed to be considered. The findings of the case study are precious to me, especially as they so often prove useful in understanding the experiencings of other survivors who I meet in my hospice counselling practice. Nevertheless, and even more, specifically because I experience them as precious, from the start of this research I understood that it was important to recruit a group of participants that had the potential to improve the quality of my practice-based understanding of cancer survivorship. One way to conduct good psychological qualitative research is to employ 'theoretical sampling' which seeks for cases that have the potential to extend understanding but also to look for cases that are unlikely to fit with the already explored experiences, and that therefore have the potential to modify previous understandings (Willig 2001). In other words I was not only hoping to recruit a heterogeneous participant group but also to achieve heterogeneity across research and case study data. The latter captured experiences up to five years post-treatment. The eight metaphorical conceptualisings generated

by the case study emerged as follows: two metaphors emerged within 1.5 year of finishing treatment, four between 1.5 and 3 years, and another two between 3 and 5 years. In order to maximise the variety of the combined data (research and case study) generated in the first five years of survivorship, I looked out for participants to be at similar times post treatment but for a minority to resemble the case study participant and the majority to be different (appx.A0), i.e. to be outside the 55 – 64 age range (younger or older) at the time of diagnosis and research, female, not having needed treatment additional to surgery and not having a permanent stoma, and the impact at diagnosis not being all overwhelming. This variety would allow for a comparison with the case study data and considerations whether the new data brought about a modification or extension of my pre-understandings.

### **7.1.3 Recruitment sites**

Following ethical approval from a NHS research ethics committee, the Research and Development Office of the participating Hospital, and from Bournemouth University (appx.A2), the research participants were recruited via two recruitment sites: 1/ a bowel cancer survivorship support group organised by the hospital and 2/ a hospice social media platform which reaches a group of people who are supportive of the hospice, usually following a family member's experience with cancer. The flow chart in appendix D7 gives a general overview of the participant recruitment steps and research contacts.

Although I work as a counsellor I decided not to recruit participants through a counselling service. In this study I aim to explore survivorship experiences of people who vary in terms of the severity of the diagnosis and treatment, in terms of age and gender. In my experience a myriad of factors are at play when cancer survivors attend counselling but one of those is that the cancer experience may be particularly traumatic because of the severity of the diagnosis. This may include having to adjust to a permanent colostomy bag,

and having gone through the full set of treatment. Older people and men may be less likely to access counselling (Mahalik et al. 2003; NHS England 2019). By recruiting through a medical setting and through social media I wanted to avoid implicit exclusions in terms of severity of illness, age or gender.

The decision to recruit via a survivorship support group run at the local hospital was made after explorative conversations with my research supervisors, employer, and nursing and research leads at the Hospital NHS Foundation Trust. I was informed that follow-up cancer clinics in the hospital were too busy to guarantee efficient participant recruitment. Recruiting via local GP practices would have meant recruiting via several NHS trusts. This was deemed to be too time consuming. The hospital only functioned as a Participant Identification Centre by allowing me access to their support group, while the actual recruitment was my responsibility.

I decided to recruit in steps and to start by attending one of the monthly gatherings of the bowel cancer survivorship group at the hospital.

#### **7.1.4 First recruitment stage**

This hospital support group is on average attended by 30 people. Attendees are mainly up to five years post treatment but some attend for longer. With a letter of agreement from the Colorectal Macmillan Nurse Specialist who facilitated the support group I was given permission to give a brief verbal presentation about the research and to hand out participant information sheets (appx.D0) at the group session on the 2<sup>nd</sup> November 2015. Attendees had been informed about the aim of my attendance by the group facilitator (appx.D1).

Six people were interested and were given a participant information sheet which gave them the option to express their interest at any time by returning

the reply slip. All of them preferred to give their contact details immediately and were contacted within a week for an initial conversation over the phone (see schedule in appx.D9) to establish provisional inclusion, and to explain the next steps. Two more people who were unable to attend the presentation had expressed an interest via the facilitator and were contacted as well. During the initial conversation it transpired that one person could not be included as she had just been diagnosed with a recurrence. One person lost his wife only three months earlier but it was not clear whether his bereavement would hinder the generation of data in relation to his cancer experience and he was included in the sample.

In total seven participants were invited to an introductory screening meeting to establish definite participant inclusion. The invitation letter outlined the aims of the screening meeting and included a Health and Care questionnaire asking for details about their illness and responsible health professionals (appx.D10).

#### **7.1.5 Ongoing sampling**

The variation described above formed the benchmark against which I assessed the variation of participants that came forward as the recruitment process unfolded. As will be described below, this led to the decision to alter the recruitment strategy midway and to purposively recruit for specific variation in the participant sample.

The group of seven participants demonstrated many variations in age, gender, time post-diagnosis and treatment, treatment regime and severity of the psychological impact at the time of diagnosis. However, I wanted to broaden the final selection of participants to optimize the variation in the experiencing of survivorship. Comparison of the features of the seven participants against the variations I hoped for (see above), led to the following conclusions:

a/ Four participants fell in the 1.5 - 3 year time zone post-treatment, one in the 3 – 5 year zone and two in the 5 – 10 year zone. To improve the spread over time I concluded to purposively recruit according to time post-treatment. This meant searching at least for one participant to be less than 1 year post-treatment, for one to have finished treatment about one year previously and for one to be more than 10 years post-treatment.

b/ Two out of the seven participants acknowledged deep emotional and cognitive distress at the time of diagnosis. They were 1 year 9 months and 6 years 6 months post-treatment and were the only participants who had a permanent stoma. As the case study participant expressed severe psychological impact at diagnosis, I was not looking for a predominance of research participants scoring high on this criterion, but I felt that it would be helpful to further recruit participants who were psychologically deeply affected at the time of diagnosis but who were at different time zones than the case study participant. Common sense suggests that the more severe the diagnosis, the more severe the psychological distress. Rather than purposively recruiting for specific diagnostic cancer grades, which felt too confrontational, I decided to purposively recruit participants based on the treatment they received, i.e. surgery only or surgery combined with radiotherapy and/or chemotherapy.

c/ The five participants who expressed that at the time of diagnosis they were only moderately affected in their sense of equilibrium and needed less medical interventions were now between 1 year 10 months and 7 years 4 months post-treatment. It made me wonder about the subjective experience of a less severe diagnosis nearer the time of diagnosis and decided to purposively recruit for a participant in that situation.

Combining the time criterion (point a) and the level of treatment received (points b and c), in the second recruitment round I purposively searched for participants in one of three situations with specific inclusion and exclusion criteria (see the recruitment poster in appx.D3). Figure 11 gives an overview

of the initial criteria (purple boxes) which guided the first recruitment stage and the three sets of inclusion and exclusion criteria (red, blue and green box) which guided the second recruitment stage, and which emerged from the comparison of the first sample of seven participants with the hoped for variation (yellow box).

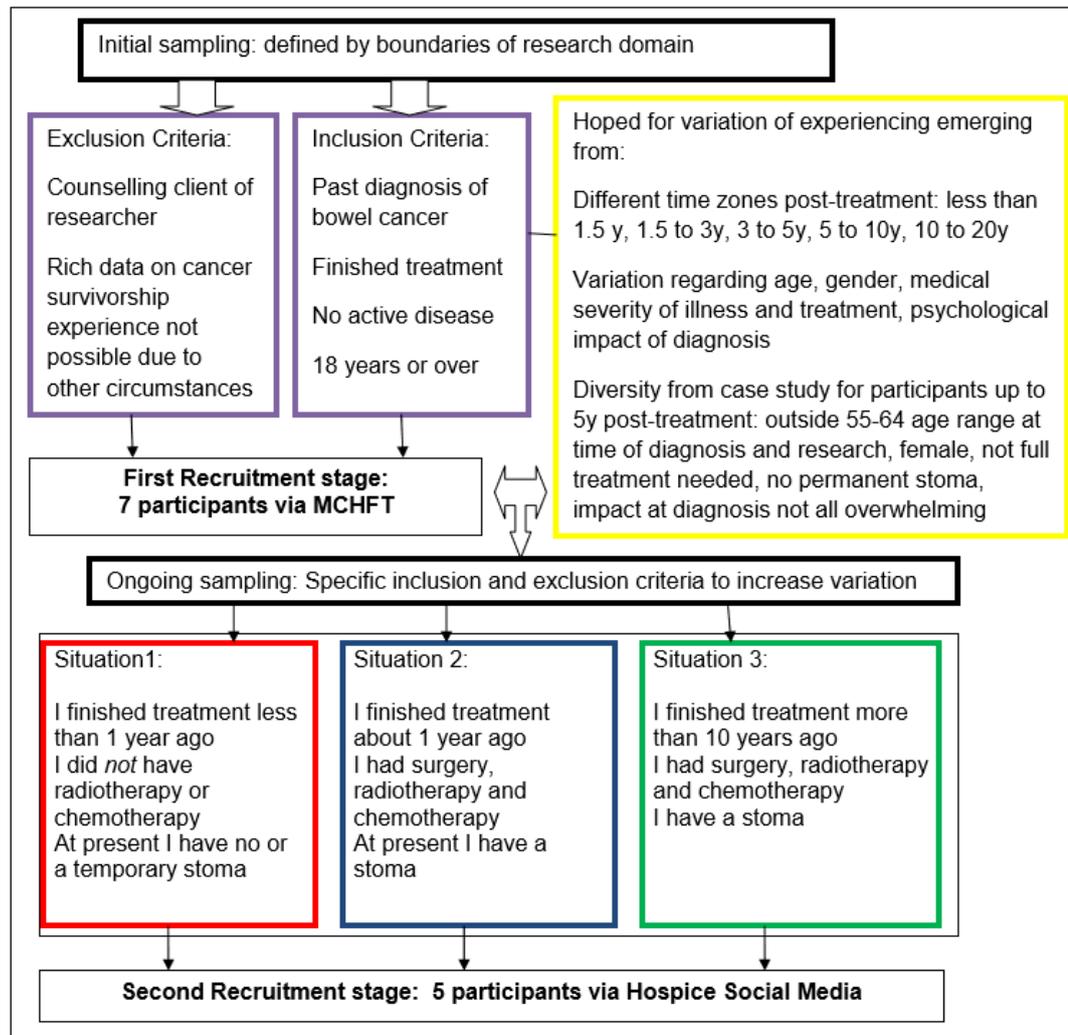


Figure 11: Summary of sampling and recruitment process

d/ All but one of the first group of participants were men. Contrary to my expectation the hospital support group, at least when I attended, was dominated by male cancer survivors. From conversations with those who expressed an interest to take part in the research I got the impression that the support group was seen as quick and reliable access to medical input if needed. Perhaps this reflects a rational, task orientated coping style that has

been associated more with men than women (Matud 2004). I also started to wonder whether men, more so than women, are inclined to participate in research. I decided to conduct the next recruitment stage using the hospice social media platform. I was hoping for more women to come forward but did not want to restrict my recruitment strategy in that way.

All the participants that came forward were white British. The experience and meaning attributed to illness, cancer and self are known to be strongly culturally influenced (Dein 2006). Creating a culturally varied sample would have needed a very focused recruitment approach. Given the small number of participants I anticipated that explicit cultural variation would no doubt enrich but also complicate data comparison, therefore I decided to leave this issue to coincidence.

With the new recruitment criteria thus defined, the recruitment process via the hospice media platform was started in January 2017.

#### **7.1.6 Second recruitment stage**

The hospice had given permission (app.D0) to recruit participants with a participant recruitment poster (appx.D3). This was posted on information boards, website and social media to inform potential research participants in the local community of my workplace. In co-operation with the hospice communication department, information about the research was circulated to hospice contacts via the hospice website (appx.D4), Facebook (appx.D5) and email (appx.D6). Recipients were encouraged to share the information. Some local newspapers took the initiative to refer to the hospice Facebook post. In total 12 people responded. As with the first group the assessment of the suitability of the participants was assessed through conversation and a Health and Care questionnaire (appx.10). Based on the experience with the first group I realised I could save time by sending and returning the questionnaire in the post or via email and by discussing the questionnaire and

the other assessment issues over the phone rather than face to face. Participants seemed comfortable with this and the face to face screening meetings with the first group had prepared me to conduct these conversations with the same care and scrutiny over the phone. It was established that five people did not match the criteria. With one participant there was a hint of depression but this did not seem to interfere with her ability to discuss her cancer survivorship experience in a reflective and explorative manner. From mid-February onwards the people who matched the purposive recruitment criteria were invited to start the research process. Unfortunately one person died before our first meeting and another person withdrew due to ill health.

At the end of March a cancer survivor who noticed the poster but did not fall within the criteria took the information to a peer support group for people with stomas and two more participants came forward. One person did not match the criteria. The second male person was close to 'situation 2' but including him would further add to the gender imbalance and I already met a female participant who corresponded to those criteria. When people were not included after they expressed their interest they were thanked for putting themselves forward. As they had been informed during the initial conversation (appx.9) that this might happen, they all expressed understanding and appreciation for researching the survivorship experience.

In conclusion the second recruitment round resulted in the recruitment of five more participants. More importantly the three sets of criteria I purposively recruited for were very closely matched.

### **7.1.7 Ending recruitment**

Having conducted the first stage of recruitment between November 2015 and February 2016 and the second stage during March and April 2017, the decision was made in July 2017 not to pursue further recruitment. I had by then generated the experiencings of 12 participants and felt that I had

reached a point of 'satisfaction'. By this I mean that I felt satisfied that, in combination with the case study data, I had generated enough diversity within the research participant group to be able to explore the data within the theoretical framework of this study, to extend and modify my pre-understandings, and to reflect in a meaningful way on the core concepts addressed in the cancer survivorship research literature. An overview of the participants whose metaphorical comprehendings will be explored in this study, is given in Table 7 which forms part of the introduction to the presentation of the findings (see Chapter 8).

### **7.1.8 Reflexive notes**

Note 1: Several participants expressed that they wished to participate because they wanted to help other survivors who were struggling more than they were. I had to keep in mind that their perception of themselves as coping well and able to help might, at least initially, lead to bias towards expressions of strength and control.

Note 2: Some of those who came forward were not free from cancer. This raised my awareness that participation into cancer survivorship research in itself may be an attempt to 'enact' survivorship. This might mean that survivors could be inclined to overstate that the physical cancer is gone.

Note 3: One participant who was two years into survivorship had a recurrence shortly after the research session. An early survivor died a week before the research session. A participant coming up to five years cancelled the research due to 'not being well'. These experiences tapped into my empathy with some survivors' beliefs that it brings bad luck to consider oneself cured.

Before moving to the methods of data inquiry, some procedural aspects, including the application for NHS ethical approval are addressed in the next chapter.

## **7.2 Procedures**

A number of ethical frameworks have guided this research. For details I refer to appx. D14.

### **7.2.1 Ethical considerations**

#### **7.2.1.1 General**

Guided by the frameworks listed in appx. D14 I considered how best to conduct this study in a way that was beneficial, did no harm, respected participants' autonomy, expertise and diversity. Details are also included in appx.D14. Before any recruitment took place a favourable review was received from a NHS research ethics committee, from the Research and Development Office at my local hospital, and from Bournemouth University (appx.D15).

#### **7.2.1.2 Anonymity and confidentiality**

All information about the participants has been handled and stored securely. Audio and photographic recordings of interview data have been deleted from the recording devices. Audio recordings were transcribed by an UK based transcription service with secure upload facility and registered with the Data Protection Act. Recordings and transcripts are saved on an external hard drive, anonymised with a separately saved coding system. Together with manual files containing demographic and background information all data is stored in locked cabinets at my home office.

The anonymity and confidentiality of participants, their circumstances and experiences is further protected by using pseudonyms in the thesis as will be the case in any written or verbal dissemination activities.

Although I have adhered to the ethical guidelines of the NHS and BU regarding the safeguarding of the confidentiality and anonymity of participants and the anonymisation of results, I have experienced this requirement as a dilemma. From my practice I have the impression that it is not uncommon for cancer survivors to want to voice their views and experiences in their own name. Most would consider research participation as a platform to do so. Research by Ho et al. (2016) confirms this as a strong feature in colorectal cancer patients. Silverman offers the thought that it is important to consider people's context rather than make assumptions about what research subjects expect or want (Silverman 2011). The question arising is whether people's right to have their autonomy respected includes that they can reject research anonymity. This is a delicate and complicated issue and further examination seems to be needed to shape changes in research practice (Giordano et al. 2007). In this study I have prioritised the value of anonymity for the following reasons: the aim of data generation is to build an understanding of a phenomenon through individuals but not of individuals. Secondly, people's wish to stand up as advocates, or to use research for therapeutic reasons is understandable and should be respected, but there are platforms especially designed for these purposes. Despite my decision, the thought of declining a potential participant's wish not to be anonymous, felt uncomfortable. It has increased my motivation to consider ways to involve ex-participants who wish to do so in research dissemination activities.

### **7.2.2 Risk assessment**

During the course of this research study I adhered to the Health and Safety policies at Bournemouth University and my workplace.

When the sessions took place within hospice premises, medical support was at hand. During sessions at participants' home or in other settings, the hospice's lone worker policy formed the guideline to keep both participants

and myself safe. Precaution was taken to reduce the risk of harm due to the research activity, e.g. use of comfortable chairs, no use of sharp creative materials, and the provision of water.

During the screening meetings I explored how likely it was that participants' vulnerabilities or sensitivities would turn the research sessions into a negative experience. How participants wished to be supported if they were to become emotionally distressed was contracted with them at the start of the sessions. For me as the researcher the option was available to process my own emotional responses to participants' explorations with my clinical and academic supervisors.

### **7.2.3 Patient and public involvement**

I am convinced of the value of involving service users and the public in defining research questions and certainly in the dissemination of results. However, I was also conscious of the fact that this is my first piece of research and that good and meaningful public and patient involvement is a skill in its own right. Therefore I chose to make a 'modest' start (INVOLVE 2012). I involved patients and health care practitioners in a final review of the participant information sheet and covering letter, informed consent form and information poster. I will offer the option to ex-participants to help defining how and to whom to disseminate the findings.

## **7.3 Methods of data generation**

At the start of the data generation process the task at hand was to plan the explorative sessions with participants in such a way that the data generated was relevant for the five research objectives, and that the method of generation expressed the methodological aspects of Enactive Hermeneutic Phenomenology (see Chapter 6). A Research Exploration Plan (REP) was composed and is included as Table 2 on the next two pages.

In this chapter I will start with an outline of the overall structure of the REP, followed by a more detailed presentation of the methods and techniques. Further detail on how the REP has been used flexibly as well as some reflexive notes, have been added in appendices D18 and D20.

### **7.3.1 Research Exploration Plan**

This explorative research plan was informed by considerations that emerged from my understanding of the research literature and from a set of personal 'pre-research experiences' (PRE) comprising of my general counselling practice, the on-the-job case study, regular facilitation of hospice cancer survivor support groups, and two research pilot sessions with a trusted colleague. With the majority of participants the sessions unfolded according to the REP.

A first point to make in this overview of the REP structure is that the explorations were conducted from a first person and third person perspective. These form the first and second part of the exploration (green font in REP in Table 2). With the first seven participants these two perspectives were taken in two separate research sessions. The other 5 participants were invited to one research session only, i.e. a session incorporating the two perspectives.

Table 2: Research Exploration Plan (REP)

SESSION STAGES	PART 1: EXPLORATION FROM FIRST PERSPECTIVE	As separate session – within single session
<p><b>Stage 1: Introduction</b> Meeting and creating safe, comfortable setting</p> <p><b>Tasks:</b> Ethically reflexive exploring of research space and relationship (1) Guiding participants towards expression of research topic (2) Taking receptive researcher stance (3)</p>	<p>(1) Venue: Checking out the impact of the venue (mainly hospice) on their state of mind</p> <ul style="list-style-type: none"> <li>(1) Arranging comfortable seating, offering drink, social talking</li> <li>(1) Introducing recorder and camera and contracting (signing consent form, confidentiality and boundaries, support in case of distress, info letter for GP)</li> <li>(1) Practicalities (toilet breaks, reimbursement transport cost)</li> <li>(1) Reminding they can end session at any time</li> <li>(2) Re-value: appreciation of focus on cancer survivorship</li> <li>(2) Re-assure: exploration of their needs in case of distress</li> </ul>	<ul style="list-style-type: none"> <li>(2) Guided expression: Transparency about the meaning of my input and communication style (use of expressive material, taking photos of work with expressive material, invitations to check felt sense, some prepared questions, expected duration and time keeping is my responsibility )</li> <li>(3) Responding to what they bring and not 'questioning' their responses</li> <li>(3) Encouraging participants to take an open, non-critical, explorative stance towards their own experience of cancer</li> </ul>
<p><b>Stage 2: Exploration</b> Task: Enable experientially based conceptualising</p> <p>Task: Eliciting metaphorical expressions (non-verbal)</p> <p>Task: Elicit intra- and interpersonal meanings flowing in response to the conceptualising</p> <p>Task: Eliciting metaphorical expressions (verbal)</p> <p>Task: Checking experiential base of conceptualising</p>	<p><b>of participants conceptualisation of</b></p> <p>Focusing (adaptation): Invitation to go inwardly and encouragement to let the general feeling (felt sense) of their present relationship to come to the fore.</p> <p>Sculpting with paper (adaptation): Invite an expression of their present sense of and relationship with cancer / clinicians through adjusting (or not) the size and shape of an A1 sheet of paper</p> <p>Check their non-verbal expression with their felt sense</p> <p>Sculpting metaphor verbally expressed: increase conscious awareness of their non-verbal expression by asking for a verbal description of the embedded image schema (shape, size, movement)</p> <p>Making the implicit explicit: Checking match with felt sense again but in a more directive manner by asking specifically "why this shape and size / position and not another?" (Socratic Questioning)</p> <p>Picking up and encouraging imaginative metaphorical expressions.</p> <p>Process exploration: At the end of the session, explore their process of deciding on a specific shape and position</p>	<p>2.1 Conceptualising of Cancer</p> <p>2.2 Conceptualising of self in relation to Ca</p> <p>2.3 Conceptualising of Clinicians</p> <p>2.4 Conceptualising of self in relation to Clin.</p>
<p><b>Stage 3: Ending</b> Researcher and participant satisfied with level of exploration</p>	<p>Short debriefing, checking ongoing consent, confirm practicalities of next session and/or dissemination, thanks</p>	<p>As separate session</p>

<b>SESSION STAGES</b>	<b>PART 2: EXPLORATION FROM THIRD PERSPECTIVE</b>	<b>As separate session</b>	<b>Within single session</b>
<b>Stage 4: Introduction second part</b>	Repeat (1) to (3)		
Meeting and creating safe space	<ul style="list-style-type: none"> <li>Arranging comfortable seating, offering drink, social talking</li> <li>Switching on recorder, settling transport cost</li> </ul>	<b>Stage 4.1</b>	n/a
Reflection on first session	<ul style="list-style-type: none"> <li>Have participants been unduly affected by the research / offer support?</li> <li>Has previous session functioned as a catalyst of reconceptualising?</li> <li>Explore first data that seemed insufficiently explored.</li> </ul>	<b>Stage 4.2</b>	n/a
Explain aim and method of this part of the exploration	<ul style="list-style-type: none"> <li>Experiencing of self and cancer (as first session) but with different materials.</li> <li>Introduce table with stones and shells.</li> </ul>	<b>Stage 4.3.</b>	<b>Stage 4</b>
<b>Stage 5: Exploration</b>	<b>Of present experiencing</b>	<b>self / Ca</b>	<b>self / Ca</b>
Task: Enable experientially based conceptualising	Focusing (adapted): Participants are encouraged to slow down and check their thinking against their felt sense. When needed this was repeated throughout the session.		
Task: Eliciting metaphorical expressions (non-verbal)	Explore the experience of self and cancer in the present through a sculpting exercise using stones and shells.		
Task: Eliciting intra- and interpersonal meanings flowing in response to the conceptualising	Making the implicit explicit: asking why this type of stone/shell (size, colour etc) and not another		
Task: Eliciting metaphorical expressions (verbal)	Picking up and encouraging imaginative metaphorical expressions.		
	<b>Of past and anticipated experiencing</b>	<b>self/Ca</b>	<b>self / Ca</b>
Task: Eliciting experiences at different times post-treatment	Explore past, future and process experience of self and cancer through sculpting with stones and shells	at diagnosis, treatment stages, future	before ca, after diagnosis
<b>Stage 6: Ending</b>	Short debriefing, thanks, enquire whether they want to be informed about the research results.		
<b>Stage 7: Research dissemination</b>	Participants who expressed an interest will be invited to attend an informative session about the research findings. There will be an option to join a 'patient and public involvement group' to discuss further dissemination avenues.		

The rationale for this change is given in point 1 of appendix D18. The sessions comprised of an introductory, explorative and ending stage (red font in REP).

During the first research session the topic of exploration (purple font) evolved around the participants' experiencing of cancer, their self in relation to cancer, the main cancer clinician and their self in relation to this clinician. In the second research session (or second session part) the explorations focused first on present and subsequently on past experiencing of self and cancer. With the first group of participants the past moments in time explored were diagnosis, different stages of treatment and the future. With the second group the past times explored were limited to pre-diagnosis and diagnosis. The exploration of the topics was a stepwise process in which a range of 'techniques' (black font) were used to fulfil the tasks (blue font).

The Research Exploration Plan (REP) was intended to (and proved to) be a help to stay focused on the research objectives whilst engaging in an empathic and participant focused manner (Willig 2001, p.22).

### **7.3.2 Methods and techniques**

To aid a more detailed discussion of the methods and techniques, I refer to Table 3 on the next page which presents core elements of the above REP. Column 3 lists the methods and techniques used for exploration. In column 1 the numbers refer to the tasks as they generally unfolded in the sessions and the colours refer to the methodological aspects that are involved and link the data generation methods and techniques to the master research Table 15 (unfolds at appx.C3). Column 2 refers to the overall research objectives.

Table 3: Data generation methods

1	2	3
<b>Tasks</b>	<b>Obj.</b>	<b>DATA GENERATION METHODS and TECHNIQUES</b>
		Meeting and creating safe space
1		Ethically reflexive exploration of research venue and relationship
2		Guiding participants towards expression of research topic
3		Taking a receptive researcher stance
		Exploration
4		Enabling experientially based conceptualising: Invite felt sense
		Eliciting and exploring non-verbal metaphorical expressions
5	Obj. 1/3	<ul style="list-style-type: none"> <li>• Sculpting present with paper and positioning in relation to body and room</li> </ul>
9	Obj. 1/3,5	<ul style="list-style-type: none"> <li>• Sculpting with stones and shells: present, past, future and process</li> </ul>
6 & 10	Obj. 1/3	<ul style="list-style-type: none"> <li>• Describing image schema of sculptures</li> </ul>
7&11	Obj. 2, 4	Eliciting linked intra- and interpersonal meanings / Socratic Questioning
8 & 12	Obj. 1	Eliciting and exploring verbal metaphorical expressions
13		Checking conceptualising was based in experiencing
		Ending
14		Ending with participants
15		Reflexive evaluation afterwards

### 7.3.2.1 Meeting and creating safe space (tasks 1 to 3)

The first three explorative tasks (*ethically reflexive exploration of research venue and research relationship, guiding participants towards expression of research topic, and taking a receptive researcher stance*), were addressed at the introductory stage of the research sessions. No special techniques were needed. The method of exploration was conversational. The conversation style was informative, transparent, supportive, accepting and encouraging.

A detailed description of this introductory stage and guiding reflections are presented in appendix D19.

The introduction formed the basis for the explorative stage (tasks 4 to 13 in Table 3 above). Overall the focus was on enabling participants' conceptualising to be experience and bodily based and on exploring their experience from angles informed by the research objectives. After ending the explorative sessions some reflexive notes were taken down and are now included in appendix D20.

The remaining part of this chapter consists of a detailed description of the methods and techniques that were used during the explorative stage

#### **7.3.2.2 'Focusing' on felt sense (task 4)**

During PRE I realised that reflections on experiencings that happened a while ago often sound well-rehearsed and rationalised. If I wanted participants to speak and think from their felt sense of cancer it meant that this needed to be "re-enacted" (Petitmengin 2006, p.238). To enable participants for their conceptualising to be experience based, and embodied, I took inspiration from Gendlin's 'Focusing' technique.

Focusing is a process that pays close attention to the 'felt sense'. This sense is felt in the body, yet includes all the meanings one is already living with. It is body and mind before they are split when experiencing is conceptualised (Gendlin 2003, p.165). Gendlin presents 'focusing' as a six-step therapeutic technique: it moves from (1) tuning inwardly and creating space for a general inner feeling, to (2) focusing on one problem and letting the felt sense of it form, to (3) getting a word, phrase or image that gets a handle on the felt sense and (4) repeated checking whether they are a good match. Then follows (5) an inner exploration of what is needed and (6) a receiving of how the body shifts the initial felt sense.

Although Gendlin's 'focusing' method has been used as a research method before, e.g. by Robbins (2006) in a study about the experience of 'joy', during my personal PRE with cancer survivors I found that people who had no previous experience with 'focusing', tended to resist the invitation to tune in with the initially undefined felt sense, and to let it 'form'. Similar resistance has been described by others introducing 'focusing' to patients (Olsen 1999). It has been suggested that after a physical illness such as cancer, people may disconnect from the diseased part of their body which may make it initially more difficult to psychologically tune in with a bodily felt sense (Grindler Katonah 1999). In 2011 I was searching for a way to translate my understanding of embodied cognition into an explorative exercise for cancer survivors who attended a support group. The approach that unfolded engaged people on a slightly more conscious level and was more readily accepted. In the research approach at hand I reduced and combined the first two steps of Gendlin's focusing into an invitation to go inwardly, and an encouragement to let the general feel of their present sense of cancer come to the fore. In other words I did not start with a specific question about their experiencings and, consequently, what Todres and Holloway (2004, p.59) call a 'near experience question' was in this situation, rather, 'a near experience focus'. I invited participants to focus on their present sense of cancer, paraphrasing the following message:

"I want to invite you to settle in this space – to quieten our selves – for now, we leave the hustle and bustle of life fade – and turn our attention to the focus of this research i.e. how you, today, 'feel' in relation to cancer ... with 'feel' I mean an overall, general feel of living after a cancer diagnosis and treatment - that what sometimes is described as living with or living beyond cancer ..."

Instead of inviting a word, phrase or image to get a handle on their felt sense, I introduced expressive materials which turned the 'Focusing' into a technique rooted in a therapeutic intervention called 'Sculpting'.

### ***7.3.2.3 'Sculpting' the present experiencing with the aid of a sheet of paper as a form of basic non-verbal metaphorical conceptualising (task 5)***

'Sculpting' in psychotherapy has its origins in Family Therapy and means to create a sculpture of a lived experience or interaction. In a therapeutic context clients are asked to portray members of their family and the essentials of family experience by placing them in terms of posture and spatial relation thus representing action and feeling (N. [sic] 2013). By changing the postures and positions until it feels right, 'sculpting' enables searching, checking with 'felt sense', and supports embodied conceptualising.

In PRE I had discovered that I could adapt the original 'family sculpting exercise' to explore how participants conceptualised their relationship with cancer and clinicians. In the first part of the exploration participants were asked to represent their experience of cancer and clinicians by shaping A1 sheets of paper before positioning these in the room and in relation to their own body. Presenting the sheet in its full size seemed to trigger a recognition process, a spontaneous comparison between the felt knowing and the look of the sheet of paper. Some participants swiftly adjusted the sheet to the felt knowing of cancer. For some participants this took more time but they managed with, encouragement, to trust the process. One could say that the sheet offered a 'partial handle' on their felt sense (Gendlin's step 3) which the participants completed by giving it a unique shape and size.

Using expressive materials rather than words or images (as proposed by Gendlin) to express a felt sense has several advantages. First I did not need to be concerned that people would not manage to express at least something of their experiencing. As van Manen (1997, p.101) points out all experiencing can be described in existential terms such as size and distance. Secondly, creative expressive materials makes it easier for participants to stay with the process and to slow down (Gauntlett 2007, p.31) which is necessary for their conceptualising to be based in their experiencing. Thirdly, although most of

our language and thinking is embedded in metaphorical concepts (see Chapter 4) this does not mean that everybody uses rich imaginative or metaphorical linguistic expressions. However, by first enabling participants to express their experience non-verbally, with expressive materials, the embodied layer of meaning making was made tangible from the start, i.e. the stage of data generation, rather than just at the stage of data inquiry. More importantly, there was also a gain on the following levels. In addition to instigating a dynamic between their felt sense and the non-verbal expressive handle on their felt sense, the shape and position they gave the sheet of paper captured the body schematic structure of their thinking and made it visible, e.g. Z positions 'cancer' behind himself and says that it is moving further backwards. It also seemed that the non-verbal metaphorical explorations subsequently triggered more elaborate linguistic metaphors, also with participants whose language was less imaginative.

As participants finished their creation, they were invited to check whether their creation was an accurate match with their inner sense of self and cancer. At times a slightly directive conversational approach was necessary to re-establish this focus. I took Petitmengin's (2006) advice to do this through paraphrasing, checking accuracy of understanding, on encouraging them to stay with their feelings if they were still blurred, and bringing them back to the issue if they diverted. Having focused on the implicit side of the conceptualising, the next step focused on the explicit side.

#### ***7.3.2.4 Describing the image schema of the sculpture as basic verbal metaphorical conceptualising (tasks 6 and 10)***

Participants were asked to give a verbal description of the shape, size and movement of their creation if relevant. This raised their conscious awareness of what they had expressed non-verbally. This prepared for the exploration of the first and third objective, i.e. how is the self vis-à-vis cancer structured and how not?

### **7.3.2.5 Socratic questioning to elicit implicit meanings carried forward by the metaphorical conceptualising (tasks 7 and 11)**

In order to explore objective 2, (i.e. which self does the self vis-à-vis cancer carry forward?) and 4 (i.e. which self does the transaction with consultants afford?), psychological and social meanings linked with the conceptualisings of self and cancer were explored using a Socratic questioning style. The goal of Socratic questioning is

“to make the client rediscover, with a series of questions, a piece of knowledge which he could otherwise know but is not presently conscious of” (Turkcapar et al. 2015, p.47).

Participants were asked why they chose this particular shape, size, movement and not another. From PRE I learned that precise and defensive responses confirmed that they were talking from the ‘implicit’ (4.2.2), but it also triggered people to verbally explicate meanings connected to their wider self as well as meanings experienced in the transactions with their consultant.

As the exploration of the non-verbal conceptualising and the underlying meanings progressed it was anticipated that verbal and idiosyncratic metaphorical expressions would spontaneously come to the fore. Why I was particularly interested in generating verbal metaphorical conceptualisations is explained in the next section.

### **7.3.2.6 Idiosyncratic metaphors as rich verbal metaphorical conceptualising (tasks 8 and 12)**

During PRE I became increasingly aware that creative idiosyncratic metaphors were specifically valuable as they gave further nuance to the basic spatial and kinaesthetic expressions elicited during the expressive exercise. For example a literal description such as ‘after surgery, I first had chemo and then radiotherapy and it was all finished when the stoma was reversed last week’ brings about an understanding of the treatment journey as an

experience with a sequence and ending, but a description of it being 'like a coast-to-coast walk' draws on extra aspects of journeying, e.g. by implying possible variations in effort (depending on landscapes, weather), the input of the self (walking) and the influence of external factors (others, tools).

When verbal metaphors emerged I actively engaged with them in the session. It was important to keep Lakoff and Johnson's warning in mind that metaphors only match part of an experience (4.2.1). I cautiously explored how and to what extent the metaphors resonated with their experience.

### ***7.3.2.7 Sculpting with stones and shells to elicit basic non-verbal conceptualising of present, past, future and process (task 9)***

The second research session returned to the use of expressive material. This time participants were asked to use a variety of mainly shells and stones, some pieces of wood and wool (see picture in appx.D17).

Both the choice of the sheet of paper and the shells and stones was based on PRE. I felt confident that these materials would be accepted by participants in contrast to more therapeutic material such as clay. Clay is, arguably, through its inherent plasticity and flexibility, the material that best engages people in thinking with their hands. It often proves to be very powerful in accessing hidden feelings and existential themes, and in triggering change (Souter-Anderson 2010). Yet several clients during PRE commented that it made them feel treated as a child or as a mental health patient. Although I trusted the research participants would engage with the stones and shells, I kept in mind that working with sensory materials might be experienced differently according to participants' gender, class, professional background etc. (Mason and Davies 2009). In the first session participants were asked to position the sheet of paper in relation to their body. An alternative would have been for participants to move as well (Lambooy 2014). Just as working with clay this would have created a more dynamic process. However, as my focus

was on participants' present comprehending I considered change seeking forms of expression less suitable. No doubt the materials I have used also have created limitations and many have 'directed' participants' expressions in ways that were less favourable. This awareness was a motivator to work with at least two types of material.

Participants were invited to choose a shell or stone that captured their sense of self at present and a second one that spoke of their present sense of cancer. They were encouraged to take their time and check the chosen object against their felt sense. In parallel to the first session, I asked them why they chose the specific objects, in order to elicit the implicit meanings that were carried forward with the conceptualising. Any literal and metaphorical verbal communication that was triggered by their non-verbal expression was encouraged and explored. The initial choosing and manipulating of the objects was similar to the shaping of the sheet of paper, and put participants in a first person perspective. But as they now also represented their self with an object, they shifted from a first to a third person perspective on their self. This perspective encouraged going back and forwards in time. Additional objects were then chosen to express their experience of self and cancer at the time of diagnosis, the different steps of treatment and an anticipation of potential future steps. Spontaneously the objects were laid out on the table, with varying distances, and following a certain path.

#### ***7.3.2.8 Checking that participants' conceptualising was based in experiencing (task 13)***

As mentioned above it was important that participants' conceptualising referred to and were intertwined with their cancer experiencings. The techniques were geared to trigger such a process. This was checked at several points during the sessions. First, participants' responses to the initial presentation of the expressive material were closely monitored. It was not

unusual for people to respond first to the material (e.g. 'I am not good at drawing', etc.). These I took to be signs of an initial struggle and it was important to nudge people further to trust the process and take their time so a real expression became available. Secondly, as people further engaged in shaping or positioning the materials I looked out for signs of incongruence, i.e. signs that they were exploring the material rather than their experiencings. At such points I asked them to check their work with their inner feeling again. Thirdly, if appropriate I asked them at the end of the session how it had been to first express some of their experiencings with the material. How did they know, for example, how to shape the sheet of paper that they were given? In their responses I was listening for what Gendlin calls the process of crossing of meanings and metaphors which eventually gets released in an expressive form (4.2.2.). Fourthly, it was not unusual for participants to comment on their experience of the research. Expressions of surprise about having shared their experiencings of cancer were not unusual, and were taken as confirmation that my intention to generate experience based conceptualising of self in relation to cancer had been achieved.

## 7.4 Methods of data inquiry

In view of to the five objectives (see Chapter 3) and the methodological aspects (see Chapter 6), the data inquiry process has unfolded as an 'enactive hermeneutic dance'. It included a multitude of steps which are presented in column 3 of Table 4 on the next page. In the left hand column and in the text below the data inquiry steps are numbered with a letter indicating the type of inquiry followed by a number. The colouring of the numbers links this Table with the master Table 15 (folds out from appx.C3) and refers to the methodological aspects that have guided this research. Column 4 explicates how the inquiry process entails an understanding of the whole by exploring the parts, and vice versa. The right hand column lists the documents that present the results of each inquiry step. The data recording stage that preceded the inquiry generated four types of data: recorded verbal data, photos, for some participants critical reflections at the end of the first session which then informed the next session, and a transcription of the verbal data generated during one or two sessions.

At the start of the data inquiry process I engaged in an 'embodied enquiry' (A) by tuning in experientially rather than analytically with each individual recording. This is described in more detail in section 7.4.1. After this connection with participants' individual data in their entirety, I felt ready to move on to a three-step analytical inquiry which resulted in an unravelling of 'parts' (B+C+D) that were relevant to address the objectives of this study. This time I approached the data in their transcribed form. The first step entailed an explicating of the conceptualised themes (B1), the dominant conceptual metaphors (B2), references to self-processes (B3) and to transactions with clinicians (B4). For the second analytical step I also drew on my pre-understandings of body schematic structures gathered during the on-the-job case study (C1). This step entailed pointing to, and expressing by means of a schematic drawing, the body schematic structure of the case-study and research metaphors and the meaning of these structures for the experience of self vis-à-vis cancer. These structures also shed light on the

Table 4: Data inquiry methods

1	2	3	4	5
		<b>DATA INQUIRY</b>	<b>Parts/Whole</b>	<b>Rich Presentation</b>
A		Embodied Enquiry	Individual data in their entirety	Metaphor: see PPT – slides EIQ (disk)
A1		Engaging with pre-conceptual felt sense		
A2		Attend to pre-understandings based on case-study		
A3		Reflexive awareness of personal meanings involved		
A4		Understanding expressed metaphorically		
A5		Listening to the 'more'		
A6		Listening with empathic openness		
B		Analytical Inquiry – Type 1: <b>pointing</b> to relevant data parts:	Parts within individual data	Summaries: in prose (appx.E0+F) + schematic 'Individual Files' (IF) (appx.E1)
B1		conceptualised themes, e.g. self, cancer...		
B2	Obj.1	dominant metaphors used to conceptualise themes		
B3	Obj.2	references to ongoing self-processes		
B4	Obj.4	references to transactions with clinicians		
C		Analytical Inquiry – Type 2: <b>pointing</b> to embodied dimensions of individual data:	Qualify parts within individual data	
C1		<i>Tool: original list of body schematic structure, part of <b>pre-understanding</b> built during case-study, is further developed during the inquiry</i>		
C2	Obj.1	the body schematic structure of dominant metaphors that sheds light on conceptualisation of cancer and self vis-à-vis cancer, and of understanding, time focus and place of authentic self		Individual + Group primary metaphor work tables (appxs.E3&E4.) + IF (incl. schematic drawing)
C3	Obj.3	Reflection on body schematic forms not used in metaphors		
C4	Obj.2	Reflection on wide self-processes		IF
C5	Obj.4	Reflection on type of transactions with clinicians		IF
D		Analytical Inquiry – Type 3: <b>pointing out</b> and clarifying the embodied dimensions of data based on comparison of data	Refine C + qualify place of individual data in overall survivorship process	
D1		Continuation C1		
D2	Obj.5	Ordering of metaphors based on combined consideration of time post-treatment and body-schematic developmental logic		Group primary metaphor work table (appx.E4)

participants' sense of understanding, their time focus and experience of authenticity (C2). This also implied bringing into awareness body schematic structures that were not used (C3). Notes were made about the type of self-processes (C4) and medical transactions (C5) that were mentioned.

A third type of analytical inquiry consisted of a comparison of all the previous explications. This allowed for further refining of the range of identifiable body-schematic nuances (D1) and for pointing out a sequence between the metaphorical comprehendings, based on a consideration of time post-treatment, and what would resonate with a natural body-schematic developmental process (D2).

In the subsequent sections a more detailed description is given of the embodied enquiry process, and of the different components of the analytical inquiry. References are made to the methodological aspects explored in Chapter 6, and to the documents that present the results of the different inquiry steps. Those documents are included either as appendices, or in the Power Point presentation (PPT) stored on the portable data-storage device attached to this thesis.

#### **7.4.1 Embodied Enquiry into individual data**

Within a few days of the first research session I attended to the participants' stories in their recorded format. A process of "Focusing" was used to engage in an 'embodied exploration'. In parallel with the way in which I guided the research participants, I aimed for the felt sense (of my experience of the participants' stories and their conceptualising) to form in myself (A1), I then let a first metaphorical conceptualising (A4) of the participants' story emerge from this. During the sessions, while not completely closing off spontaneous reflections or interpretation, I chose not to pursue these at the time. As Krycka (2011) points out, most research starts with distinctions and this leaves out wholeness. I did not want to be drawn into premature

conceptualising of the data. I wanted the conceptualising process to be a stepwise and slow process in order to engage as much as possible with the “whole” and the “more” of the storied experiences. By the ‘whole’ I mean the totality of the topics they addressed but I also mean that I aimed to hear, beyond the words, the “more”, the nuances and feelings that were conveyed through the participants’ voice, manner of speech, and other non-verbal communication (A5). It was with empathic openness (A6) that I engaged with the data. In that sense this formed the first step in a long hermeneutic process between the whole of their story and the parts. Participants talked not only about their present, but also about past experiencings of cancer and clinicians. However, guided by the core focus of this thesis, at the end of this embodied enquiry I focused on conceptualising metaphorically how I experienced their present experiencing and conceptualising of cancer and self. As I wrote down intermittent reflections while I was listening, and as I formulated the metaphor that emerged, I was aware that this first layer of understanding enabled and encouraged me to go further. As the metaphor emerged, a dialogue with pre-understandings based on the case study, or on other participant data, automatically unfolded. Hasty conclusions needed to be kept at bay. For example, when Dan and Simon (pseudonyms), like the case study participant (Edward, henceforth E), expressed having been intensely surprised with their doctor’s ‘all clear’ message, it was tempting to project the meaning this had for E onto both the research participants. As I will show in the findings there were however important differences. Other aspects of myself came into awareness and also played a role in this process of interpretation. For example, when hearing Mark’s (pseudonym) distress about his bereavement, as a bereavement counsellor I had to consciously negotiate with myself how to prioritise his experience of cancer. The main function of this embodied inquiry, and the generation of a metaphorical understanding, was to make a start with a gradual unfolding of a deeper understanding. The results of this inquiry are included in the EEQ-slides in the Power Point presentation. In Chapter 8 I refer to those when I discuss how they influenced the findings.

#### 7.4.2 Analytical inquiry into data parts

I summarized the first session (or single session with the second group of participants) shortly after the sessions were transcribed. Although the summaries led to an inevitable reduction of data, careful attention was given not to leave out parts that meaningfully contributed to the overall expression of the participant's experiencings (Willig 2001, p.16). In line with a hermeneutic approach I also tried to stay as close as possible to participants' 'lived experience' (B). On the one hand this was carried out by including participants' reflections and conceptualisings on the topics of the exploration, verbatim. On the other hand I also felt the need for "hermeneutic imagination". In a sense it is a totality of expression which conveys what people really mean. Therefore it was important to select those phrases that best reflected what the participants meant.

The summaries consisted of the *themes* that were directly linked to the objectives, i.e. comprehendings of cancer and self vis-à-vis cancer as experienced in the present (obj. 1), reflections on past and continuous self processes (obj. 2) and medical transactions (obj. 4). In addition conceptualisings related to the time of diagnosis and treatment, to other illnesses and views on the future were also included as research literature suggests their potential impact on the present experience. This data, I anticipated, might become relevant background when comparing my findings with other cancer survivorship research. Both verbal and non-verbal *metaphors* generated with the use of the creative tools were thus taken down.

I attended to the role of writing and language in exploring and understanding the data (6.1.3) and chose to write up the summaries as much as possible as coherent stories. Where appropriate issues were first described in individual terms and then relationally, and the verbal metaphors were given before the non-verbal metaphors. The narrative that brought the components of the text together was written from a third person perspective as this most genuinely reflected the position I took towards the data when I was writing these

summaries. It also reflects that at this stage I took a metaphorical 'bridling' position towards the data in terms of keeping pre-understandings at bay whilst fully aware that the way I ordered the data was informed by my theoretical framework and objectives (6.1.5). An example of the summaries can be found in appx.E0, while the rest of the summaries are included in appxs.F. The content of the summaries is presented schematically in 'Individual Files' (for an example, see appx.E1).

If a second session was organised within a day after the session I listened to the recording and took down notes to help the understanding of the transcription as some non-verbal communication and sculpting was not verbalised. Relevant themes and metaphors were added to the Individual Files. A brief interpretation of the objects (shells, stones, wood, wool) selected by the participants, as well as a comparison between the participants' choices, are included in appx.E2.

### **7.4.3 Analytical inquiry into embodied dimensions of data**

I did not come completely unprepared to this research task. The case study I conducted about 10 years ago generated a small list of body schematic structures which I believed underpinned different experiences of self vis-à-vis cancer (appx.A0). These findings had unfolded as I familiarised myself with the theoretical perspective of Lakoff and Johnson and their concept of 'primary metaphors'. At the start of this research, not only did I not wish to apply these pre-understandings uncritically, but previous familiarity with the aforementioned perspective was long gone. Bringing this back was an essential step in my inquiry. In the next section I will describe how this was achieved.

#### **7.4.3.1 Revision of the case study method of body schematic inquiry**

During the case study I brought into dialogue the metaphors offered by the participant (E) with Lakoff and Johnson's (1999) list of Primary Metaphors. The latter were derived from Grady's (1997) overview. This list had supported the distinction of five different 'enactions'. As part of this research I revisited the Primary metaphors which I had engaged with previously. However, I also wanted to step back from my pre-understandings as much as possible and start afresh. I set out to do this by widening the list of Primary Metaphors and by re-analysing the case study metaphors in parallel with the 'new' metaphors which were generated by the research participants. The list of Primary Metaphors was expanded with examples taken down by Grady (1997) and with examples included in Lakoff (1987) and Lakoff and Turner (1989). The Primary Metaphors and examples were brought together in an Excel document. For illustration, an extract of this Primary Metaphor resource document is included in appx.B1.

Initially the metaphors embedded in the individual data (see C2 in Table 4) were scrutinized for their body schematic structure and for the implied Primary Metaphors. This explorative work took the shape of an 'individual primary metaphor work document' (for an example, see appx.E3). The individual results were brought together in a 'group primary metaphor work document' (an extract for illustration can be found in appx.E4). This supported the next analytical inquiry phase which consisted in comparing data for body schematic similarities and differences (see D in Table 4).

#### **7.4.3.2 A developmental outlook on body schematic differences**

The case study inquiry had already resulted in a list of five body schematic structures which I called: presenting, positioning, moving, acting and directing. Finding that these 'enactions' could be ordered along a path of

increased complexity reminded me of the natural process of physical development and of Piaget's motor based cognitive development theory (in Schwebel and Raph, 1974). Although I kept in mind that Piaget's thinking was based in a different ontological perspective than is the case in this study (4.1.5), as indicated at the start of this thesis (1.3.5) I found that the case study findings led to a fifth research objective which, to repeat, aims to deepen the understanding of momentary comprehendings by putting them in a developmental framework. I explored some of the literature on child development albeit in a browsing manner since I wanted to raise my awareness for potential diversity in the literature rather than impose a defined theory of bodily development onto my metaphorical research data. This additional reading took place in the background, but it needs to be mentioned here as it was one source of information which influenced the identification and ordering (D2 in Table 4) of the enactions. Finally, one by one the research and case study participants' metaphorical conceptualisings were put in dialogue with a range of Primary metaphors and their body schematic form.

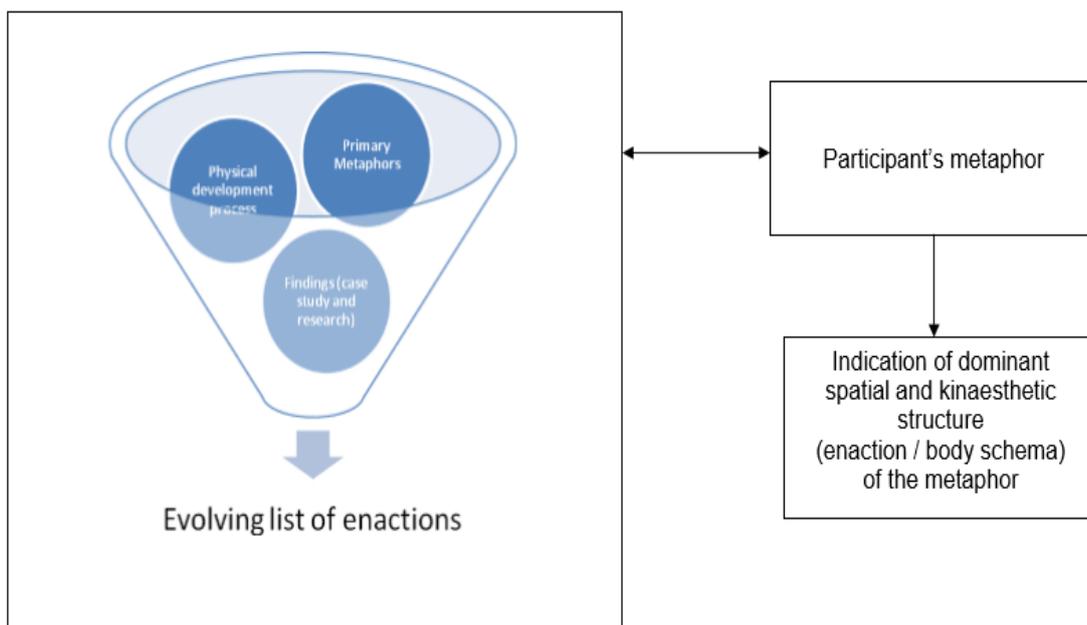


Figure 12: Evolving list of enactions

### ***7.4.3.3 The body schematic structure of self and other themes***

In this study I am not only interested in the “conceptually lived body” and in “conceptually lived space” but I also wish to look at other fundamental categories such as participants’ conceptualising of time, their sense of being able to understand, and their sense of authenticity.

According to Lakoff and Johnson (1991) time is metaphorically conceptualised as movement in space, the authenticity of self is expressed by a closeness (or distance) between the experienced self and the ‘true self’, and the ability to understand and think is conceptualised in terms of seeing and grasping. This means that from the spatial, sensory and kinaesthetic form that shapes the conceptualising of self in relation to cancer it was also possible to derive participants’ sense of time focus, authenticity and understanding.

### ***7.4.3.4 Psychological and transactional embodied dimensions of comprehending***

Whereas the analysis of the body schematic structures across the comprehending of different participants is grounded in, and takes account of human bodily communality, reflections on the nature of participants’ references to self (C4 in Table 4) as well as their medical transactions (C5 in Table 4) intend to grasp individual uniqueness and its relation to shared patterns of thinking. This inquiry, informed by Gendlin’s Process Model and Gibson’s ‘affordances’ concept, has been reflective rather than analytical and only came into full fruition once the body schematic work was completed.

#### **7.4.4 Updating the case study inquiry**

As shown in Table 11 in appx.A0, 5 out of the 8 metaphorical comprehendings offered by the case study participant have previously been analysed for their body schematic structure. The Table is arranged in a way as to draw attention to the increased (developmental) complexity of the structures. This resonates with objectives 1, 3 and 5 of this research. The analysis of the remaining 3 metaphors was made later, i.e. in parallel with the analysis of the research data generated by the 12 additional research participants.

At the time of generating the metaphorical comprehendings the case study participant spontaneously made references to his interaction with clinicians and past self which he deemed relevant in the present. These reflections fed into objectives 2 and 4 of this study.

#### **7.4.5 An ongoing process of inquiry**

The practice part of this thesis (see Chapter 10) evolves around an expression of the research findings in painted form. It soon became clear that at times the co-operation with the artist further developed the understandings from the earlier data inquiry. In the presentation of the findings (see Chapter 8) I explicitly mention when understandings come about this way. Not only did I want to thus give a transparent account of the hermeneutic process, but this also gives an insight in the type of understandings that emerge from different modes of inquiry. Taking forward the findings of the data inquiry has been a process of writing and rewriting, and has thus led to another lived experience of what could be called the fluidity of understanding. Therefore, the 'findings' in the next chapter are not static. On the contrary, the very presentation and discussion of the findings is in itself another stage of data inquiry that is bound to generate further interpretations and insights.

## 8. Findings and discussion

In this chapter I aim to present a nuanced and honest understanding of the experience of a relatively small group of survivors of bowel cancer. Such a study does not evolve around an attempt to, or a claim of wide generalisability, nor does it assume the opposite (Willig 2001). As the findings are compared with other studies, and disseminated to survivors and health care practitioners, it will hopefully transpire to what extent they also capture the experience of, for example, survivors with other types of cancer. Some parts of the findings may resonate more widely than others. To help further analysis of why that may be, this chapter starts with an overview of demographic and illness related features of the participants.

### 8.1 Participants

Following the sampling and recruitment strategies, data were generated from 12 research participants and their experiences considered in relation to the eight experiential sets of data gathered with the case study participant. This means that a total set of 20 cancer survivorship experiences form the basis of the findings presented in this chapter.

First the characteristics of the group of participants are described. This information is also presented in the overview Table 6 below. The following notations will support reading this table:

Notations to Table 6:

- In the top half of Table 6 : Information printed in italics refers to the case study participant. The different colouring of the information, refers to the type of treatment received as is further specified in this smaller Table 5:

Table 5: Overview participants' treatment packages

Number of participants & case study	surgery	chemo therapy	radio therapy	and temporary stoma	and permanent stoma	Total number of treatments + stoma (=s)
1p	1	1	1	0	1	3+1s
2p	1	1	1	0.5	0	3+0.5s
2p	1	1	1	0	0	3
1p+c	1	0/1	1/0	0	1	2+1s
3p	1	1	0	0	0	2
3p	1	0	0	0.5	0	1 or 1+0.5s

- In the lower half of Table 6:

Participants' gender is expressed with blue font for male and pink font for female participants. Some data is shaded in light grey which means that these participants specifically expressed that they did *not* feel overwhelmed at the time of diagnosis.

All participants had been diagnosed with bowel cancer and had not had a recurrence up to the time of their participation in the research. One participant had been diagnosed with a second cancer but this was now also inactive.

As indicated in the top half of Table 6, the mean time post-treatment of the research participants was 4 years 9 months and varied between 5 months and 19 years 6 months. When including the case study participant the mean time post-treatment dropped to 3 years 9 months. Sufficient research participants came forward who were at times post-treatment that allowed a comparison with the case study data: three participants were less than 1.5 years post-treatment (two metaphors in the case study fall in this category), four participants were between 1.5 and 3 years post-treatment (with four metaphors of the case study participant being expressed in this time frame) and one participant was between 3 and 5 years (and two case study metaphors belong in this time frame). Four longer term survivors were coming up to 7, 8, 12 and 20 years post-treatment.



Indicated in the lower half of Table 6 is that the mean age of the participants at the time of research was 68 and varied between 39 and 89 years. The mean age of the participants at the time of diagnosis was 62 years and varied between 37 and 82 years. When including the case study participant the mean age was 65 at time of research and 60 at time of diagnosis. Of the eight participants who were less than five years post-treatment only one participant was, like the case study participant, in the age range 55 – 64 at the time of diagnosis and at the time of research.

Recruiting female participants proved to be more difficult than anticipated. By purposefully recruiting two women during the second recruitment stage I managed to bring the total up to four. With 4 out of 12 research participants being female and 4 out of 20 sets of data being provided by women, there is an imbalance that will be taken into account in the discussion of the findings.

The case study participant had surgery, chemotherapy and a permanent stoma. Five out of the twelve participants had surgery, chemo and radiotherapy, of which one person had a temporary and one had a permanent stoma. The other seven participants had either surgery on its own or with either chemo or radiotherapy, and one of these seven has a permanent stoma. Of the eight participants who were within five years post-treatment, four had the same or less treatment, and four had more treatment (of which the person with a permanent stoma) than the case study participant.

Three of the eight participants in the up to five years time zone recalled that they did not feel overwhelmed at the time of diagnosis and in that sense were different from the case study participant. Two of the four longer term participants had not felt overwhelmed at time of diagnosis.

Any understandings of cancer survivorship that I present could not have formed without my research participants. Their input has been anonymised for ethical reasons although this is not necessarily their choice. Therefore at

the start of the presentation of the findings I want to repeat my thanks for their anonymous and generous contribution to this study.

The research participants' names have been exchanged with a pseudonym and their metaphors are abbreviated as follows: Ann-Hulk, Linda-Bat down, Rosy-Flow with, Karl-Blank canvas 1Y (1Y stands for 1 year), Mark-Open book, Simon-Forging forward, Noel-Chapter, Boris-Flown off, Jack-Ache, Tony-Done, Dan-Bad days and Wendy-Grounded. The case study participant will be referred to as E. His metaphors were gathered at eight different points in time and will be referred to as E1-Fog, E2-Terrorist, E3-Theatre play, E4-Unknowable, E5-Adopting, E6-Veteran, E7-Horror and E8-Healed.

Having discussed the characteristics of the participants as a group, in Table 7 below some of these characteristics are presented on an individual basis and are ordered according to the order that emerged from the exploration. Extracts from this overview table will be repeated to support the discussion of the findings in the next section.

Table 7: Characteristics of individual research and case study participants

Participants	Time post diagnosis	Time post treatment	Type of treatment	Permanent Stoma	Temporary stoma	Other ca	Age at diagnosis	Age at research
E1-Fog	7m	1m	S + C	Yes				
Ann-Hulk	6m	5m	S				55	56
E2-Terrorist	11m	5m	S + C	(yes)				
Linda-Bat down	1y11m	1y4m	S + C				37	39
Rosy-Flow with	2y2m	1y9m	S + C + R	Yes			66	68
Karl-Blank canvas 1Y	2y4m	1y5m/1y1m stoma reversal	S + C + R		yes		67	70
E3-Theatre play	2y4m	1y10m	S + C	(yes)				
E4-Unknowable	2y5m	1y11m	S + C	(yes)				
Mark-Open book	2y8m	1y10m	S + C				68	71
E5-Adopting	2y7m	2y1m	S + C	(yes)				
Simon-Forging ahead	2y10m	2y2m	S + C + R				70	73
E6-Veteran	2y8m	2y2m	S + C	(yes)				
Noel-Chapter	2y10m	2y3m/1y11m stoma reversal	S + C + R		yes		78	80
Boris-Flown off	3y10m	3y7m	S		yes		67	71
Tony-Done	7y7m	7y4m	S				82	89
E7-Horror	3y8m	3y2m	S + C	(yes)				
Dan-Bad days	12y3m	11y6m	S + C + R				45	58
Jack-Ache	6y8m	6y6m	S + R	Yes		yes	62	69
E8-Healed	4y7m	4y1m	S + C	(yes)				
Wendy-Grounded	20y3m	19y6m	S + C				47	68

## 8.2 Method of presentation

Following on from the data inquiry table (7.4) which comprised of steps A to D, Table 8 on the next page presents the structure of this findings chapter, which consists of two parts. In the first part the data and interpretations are presented in the form of nine clusters, called ‘enactions’, which consist of the metaphorical comprehendings of two or three participants (Table 8-E). In the second part the description refers to the survivorship process as a whole (Table 8-F).

Table 8: Presentation of findings method

		<b>PRESENTATION of generated findings</b>	<b>Parts/whole</b>	<b>Rich Presentation</b>
<b>E</b>		Holistic description of 9 clusters of data	Clusters of individual data	Expressions of structure and texture
E1	Obj.1	Presentation of clusters of individual data based on shared body schematic structure and internal nuances. Reference to the conceptualisings of self vis-à-vis cancer, of understanding, of time focus and of authentic self. The findings are based on hermeneutic revisiting of the Data Inquiry steps C and D (see 7.4) and further point out researcher understandings which emerged from embodied inquiry, schematic drawings and paintings.		
E2	Obj.5	Reflection of internal order based on developmental perspective		
E3	Obj.3	Reflection on what was not viable within the cluster		
<b>F</b>		Holistic description of survivorship process as a whole	Process as a whole	Rich description
F1	Obj.5	Reflection from a developmental outlook		
F2	Obj.1	A body schematic exploration of survivor liminality		
F3	Obj.2	Reflection on the role of the wider self in the emerging metaphors		
F4	Obj.4	Reflection on the role of consultant – survivor transaction		

In the first part I will address the objectives that evolve around the body schematic structure (enactions) of metaphors as this facilitates the clearest differentiation between the comprehendings of self and cancer. First the body schematic structures that are shared by the individual comprehendings in the cluster and any that are not shared will be unravelled (E1 - obj. 1). Secondly I will describe whether body schematic differences allow for an ordering of the individual comprehendings within the cluster according to a developmental body schematic logic (E2 - obj. 5). Thirdly the core meanings of the cluster are highlighted and awareness is raised for the body schematic

structures that did not seem viable at that time. This is repeated for each cluster and ends with a discussion about body schematic structures that have not been used at all (E3 – obj. 3).

In the second part I look at the totality of the comprehendings by taking a developmental outlook (F1 – Obj. 5). The body schematic structure of metaphors is further explored in relation to liminality (F2 – Obj. 1), a concept addressed in the literature review. The role of the wider self (F3 - obj.4) and the role of the transaction between survivor and consultants (F4 – obj. 2) in the emerging self vis-à-vis cancer are brought together in a single narrative which I call 'vignettes'. This is an attempt to present together what always happens together and only becomes split through theory and research. Five 'vignettes' are included throughout the different sections. They are listed at the end of the content table of this thesis.

### **8.3 Nine clusters of individual comprehendings**

The explication of the comprehendings of cancer and self vis-à-vis cancer by each of the participants centres around the body-schematic structure of their metaphors. As described in 7.4.2. participants' metaphors were included in the summaries of the transcripts (see appx.E0 and appxs.F). Occasionally additional metaphors came forward in the second session and those were included in the 'individual files' (see for example appx.E1).

The first step was to determine which metaphor best expressed participants' comprehending of self vis-à-vis-cancer. This process was guided by the following questions:

- 1/ which metaphor(s) captured their present experience?
- 2/ which evoked best their relationship with cancer in the present?
- 3/ which metaphor was most creative and/or clear?
- 4/ did the emerging metaphor resonate with the overall outlook in relation to cancer at the present and with the participant's stance in life as it speaks from

the complete summary (which also include reflections on the time of diagnosis and treatment)?

The metaphor that emerged from this process was considered to be the main metaphor and titles the discussed comprehending. By way of illustration, in appx. E0 this metaphor is highlighted in yellow. Other metaphors that further nuance or at times contradict the main metaphor are also deducted from the summaries and included in the discussion (see for example highlighted in pink in appx.E0).

A sense of the experience and meaning of the metaphors is evoked by using different sources.

First, a rather analytical exploration happens by pointing to the embedded Primary Metaphors (PM) (see for examples in appx.B0) and by explicating their meaning.

Secondly, where possible the metaphorical meaning is backed up with additional narrative provided by the participants about their experiencing (see for example highlighted in green in appx.E0). The narrative reflections are presented verbatim or are paraphrased. References may also be made to meanings that were expressed creatively with e.g. shells, stones or paper. The summaries of the research participants' sessions, from where the metaphors and narratives are taken, are included in appendices (see appxs.F). These include a photo of the creative expressions with stones and shells with notes added by the researcher afterwards to clarify what the shells and stones express. Including photos of the expressions in which the sheet of paper was used, was deemed irrelevant; here, rather than the end photo, the process itself was more important and this is not reflected in the photos. The photos functioned as a reminder for the researcher. The data sets where the case study participant's metaphors and narratives were deducted from are included in full in the appendices (see appxs.F)

Thirdly, the presentation is further refined with the researcher interpretations that emerged during the Embodied Enquiry process, the drawing of the body schematic structure, and the conversion of the findings into paintings. In the text it will be specified where these sources can be found on the Power Point presentation (see portable data-storage device). Several considerations led to the decision to present the paintings as a separate power point presentation rather than include them in the text: 1/ Although the paintings have at times deepened the understanding of the research findings, they are in the first place based on the research findings. Therefore, at this stage, they are secondary to the verbal exploration of the data. 2/ Visual material has the potential to overpower verbal data. The distance created by presenting them in another medium aims for a more balanced presentation. 3/ The paintings look more realistic on screen than on paper. 4/ The Power Point presentation allows for easy perusal if the reader wishes to do so.

This intertwined use of abstract, concrete and aesthetic language and expressions is intended to capture the findings in what was called, in the methodology chapter (6.1.3) 'a harmony of structure and texture'. An embodied sense of the participants' experiencings may be further helped if the reader consciously conjures up the imagery and the highlighted spatial and kinaesthetic characteristics of the metaphors.

As said above, the metaphorical comprehendings are presented in clusters and the name of the cluster refers to the enactive structure that unites the comprehendings in the cluster. Each section starts with a brief explanation of the terminology used to describe the enaction. The metaphors are outlined with a reminder of the time that passed since the participants were diagnosed and finished treatment. In the last part of the cluster discussion, the structure of the presented self vis-à-vis cancer is summarized but attention is also given to conceptualisings of 'understanding', 'time' and 'authenticity' when these come to the fore.

### 8.3.1 Enaction 1: Presenting and Positioning

In the early stage of cancer survivorship the self vis-à-vis cancer seems to be comprehended as an experience of: **'Presenting' and 'Positioning' of oneself** (P&P). 'Presenting' means that survivors express and create a sense of self-presence. Eight out of 13 participants described feeling threatened in the continuity of their existence at the time of diagnosis. This severe disruption of their usual sense of self was described as 'being beside myself', 'it felt like a conspiracy to end my life', 'my old self had gone', 'total confusion', 'written off by others'. Also those who were less shocked described an initial stage where they had to put their trust in their doctors to 'put me together again' or 'to sort me out'. 'Presenting' is a first step in coming back from this threat of self annihilation or unravelling. Positioning is to be understood as a demarcation of self in relation to something or someone else.

The delineation of a first self vis-à-vis cancer in this study is based on a metaphor used by the research participant, Ann, and two metaphors used by E (E1 and E2). All three sets of data were expressed in the first year post-diagnosis and in the first half year after completing their treatment. Their data have been titled: 'The hulk alongside' (Ann), 'Fog, the only place where I can be' (E1), and 'The terrorist has left the country' (E2). For ease of reading at times the terms Hulk, Fog and Terrorist will be used as shorthand.

The body schematic structure of the comprehendings of the research participant will first be explored and subsequently compared with the two metaphors presented by the case study participant.

The case study data and the research data summaries which include the metaphors, wider narratives and photos of shell and stones exercise referred to in the presentation and discussion of the findings are included respectively in appxs E0 (Ann), F0 (E1-fog) and F1 (E2-terrorist).

### **8.3.1.1 *The hulk alongside me (Ann)***

Ann compares cancer to the “Hulk”, a “monster” that is “alongside her”. Focusing on the image of the hulk first, its most prominent feature, apart from it being green, is it being big. Its **large size** is even emphasised as Ann visualises it alongside her. Based on the primary metaphor (PM) ‘Importance is Size’ this brings to the fore that central to Ann’s comprehending is that cancer is important. This resonates with her intense curiosity to figure out “what impact that (the cancer experience) is going to have on my life, how it will shape the rest of my life.” By considering a related PM ‘Functionality and viability is Erectness’, the image of the hulk as an erect figure, does not only conjure up cancer as an important but also as a potent presence. But Ann’s cancer-hulk is **not** visualised as **moving, acting or exerting its inherent force** and therefore does not communicate great fear that something bad is going to happen. If it did, it would draw on PMs such as ‘External events are large moving objects’ and ‘Self-propelled movements are movements that an agent carries out under the agent’s own force’. In conclusion, the experience of cancer by Ann is one of a potential force (the image of the hulk) that although in her immediate vicinity, is not active (no movement or action) and therefore a real presence but not a real threat. This was further qualified by Ann when she unexpectedly defined the hulk as a “thing”, taking out the capacity for self-propelled agency that defines ‘people’ or ‘person-like figures’. Accordingly she qualifies any fear she may feel as “fear you are able to overcome”.

The first draft of the painting of Ann’s data triggered a deeper understanding of what it might mean for Ann to be intrigued by rather than fearful of her cancer. It reminded me of Ann choosing an intricate shell to present herself “because it was intriguing”. This now evoked for me a memory of the Scallop Shell, symbol of the ‘Way of Saint James’, which in turn reawakened the sense of ‘pilgrimage’ I felt during the embodied enquiry into Ann’s recording (PP:Ann-EEQ-slide10). Adding the shell to the painting (PP:Ann-T-slide7) aims to capture that Ann’s experience is mainly one of being in a localised

space but there is also a tangible **aspiration for movement**. This embodied understanding is in tune with Ann expressing with a sense of urgency that she was “looking for a way forward” and that she has “got to get into gear”. Non-verbally her aspiration was expressed by moving the sheet of paper that represented cancer from her lap to her feet – as if symbolically trying to find her feet?

The use of the term **‘alongside’ (the hulk) to position** herself vis-à-vis cancer, further establishes Ann experiencing herself in the vicinity of cancer as an important issue but without being overwhelmed. ‘Alongside’ suggests a degree of alignment which is based in PMs like ‘Similarity is Alignment’, conjures up a sense that Ann experiences cancer more as a companion than an opponent. This resonates with her statement: “I *accept* cancer as part of me.” The PM ‘Self-control is Self and Subject being in the same place’ translates here as Ann comprehending her experience of control in terms of her core Self being in the same place as her cancer-part-self. In summary, the term ‘alongside’ expresses an experience of **‘being separate from cancer’**, but also communicates **‘alignment’** and **‘inhabiting the same space’**. This proximity does not mean that Ann is clear about cancer. She envisages her present feeling about cancer as a question mark that ‘touches on her heart’. I draw on the PM “Knowing is Feeling” to understand this image. Ann seems to experience her **knowing of cancer as touching on a bodily feeling** rather than grasping with rational clarity.

### ***8.3.1.2 Fog, the only place where I can be (E1)***

An experience of self as ‘emotionally and cognitively **not being clear**’ is central to E1’s ‘Fog’ metaphor. An image of ‘fog’ first of all conjures up the idea of ‘not seeing’ and in that sense refers in reverse to the PM **‘Knowing and Understanding is Seeing’**. Although this confused state of mind implicitly refers to the impact of his cancer diagnosis and treatment, in contrast to Ann, E1 does not explicate cancer as a delineated entity. I

assume this is a true reflection of his experience, but not without a critical awareness that the case study metaphors were not prompted by my research questions. By drawing on the PM 'Existence is Visibility', I would like to argue that E1, by omitting a defined cancer image, expresses that his **cancer experience does not exist separately** from his core self.

E1 also describes his present sense of self as 'uncertain' and 'abandoned'. This seems to be a response to his doctor and family deciding that no further treatment is needed without taking into account his viewpoint. E1 does not present cancer as separate from himself, but he **does set himself apart from his doctors and family** ("I live in a different world"). In the painting the figure puts his head above a dense layer of colours (PP-E1-T-slide3). This prompted an understanding of the 'Fog' metaphor as a freeing from what came before, i.e. the busyness of illness, treatment, being controlled by others. E1 **positions** himself in the fog as "the only place where (he) can be". With this phrase he draws on the PM 'Self-control is being in one's normal location' to establish a sense of **control. It is a minimal level** of control with the place being a 'foggy place'. In conclusion, although cancer is not explicated in E1's metaphor, he seems to seek a place to be where he can be true to the confusion that cancer emotionally and cognitively brings about. Self and cancer are in the same space, or perhaps it is more accurate to say that cancer is the space and that E1 lives 'within' the cancer-space as expressed in the conceptual drawing (PP:E1-Cb-slide5). The split that is inherent or created by Ann with the concept 'alongside', has not (yet) happened for E.

More even than for Ann, E1's expression of **movement is embryonic** and only expressed as an aspiration to engage with the foggy place he is in. Unexpectedly for me the artist fitted the figure in the painting with hands (PP-E1-T-slide3) and in doing so visualised that in the fog one resorts to feeling as a way to counter-act a lack of clarity. This helps to understand how E1 is not clear about but **touches on his emotions and thoughts**, an experience that Ann also revealed.

### **8.3.1.3 The terrorist has left the country (E2)**

Most prominent in this terrorist metaphor is the **distance** created between self and cancer. From the PM 'Important is Big' follows that 'Less important is Small' but based on the experience that things at a distance look smaller, it also means 'Less important is Distance'. Yet this needs to be nuanced in the terrorist metaphor. Self and cancer are not only at a distance, they are '**not on the same side**' (of the border). Based on the PM 'Agreement is being on the same side', this suggests an experience of loss of solidarity with cancer. This distinguishes it from the Hulk and Fog metaphor. Like Ann (hulk), E2 (terrorist) comprehends cancer as a potentially dangerous figure. Ann could envisage such a figure in her vicinity and thereby expressed a belief that it was not going to act. E2 contains the danger by envisaging cancer beyond a border and in doing so gives away his struggle to believe in its inactivity despite his doctor's reassurance that 'he should not worry about the shadow on his lung because the cancer was deemed inactive'. The comprehending of cancer as 'having left the country' refers to the PM 'Changes are Movements (into or out of bounded regions)'. The implication of the changed position of self vis-à-vis cancer seems to be a gain of space around the self. There is **no** indication though that this means the self is **moving about**. Together with the image of a terrorist just having left, it conjures up a feel of frozenness, something that, rather than in words, is better captured in paint: PP-E2-F-slide13 shows a white coldness between the red of self and the purple of a big reversed C(ancer).

E1-Fog and Ann-Hulk seemed engaged with an embodied and emotional understanding of cancer, while E2-Terrorist seeks a **rational understanding** ('keen for a medical view regarding the shadow on my lung'). The image of the terrorist is the handle E2 uses to think rationally of something abstract that is potentially dangerous but invisible like a shadow on a lung or an inactive cancer. Seeing (knowing) that what is unseen perhaps needs 'seeing' to be refined as 'watching out for, monitoring'.

**8.3.1.4 Ordering from a developmental perspective: Fog – Hulk – Terrorist**

In considering that an experience of being positioned in a space developmentally proceeds from ‘lacking awareness of what is around’ to ‘being aware of what is close’ to ‘being aware of what is outside’, then, taking into account these specifications, the metaphors can be ordered as 1.fog – 2.hulk – 3.terrorist.

	Time post diagnosis (TpD)	Time post treatment (TpT)
E1-Fog	7m	1m
Ann-Hulk	6m	5m
E2-Terrorist	11m	5m

This extract taken from Table 7 shows how the suggested order broadly corresponds with TpT be it that the Hulk and Terrorist metaphor both emerged at 5 months. It also broadly corresponds with TpD although the Fog and Hulk metaphor occurred at a similar time of 7/6 months.

This invited the question: Is Ann’s specific experience of being ‘alongside’ the Hulk closer to the experience expressed in the ‘Fog’ or to the experience expressed in the ‘Terrorist’? As the experience of treatment was still relatively recent, I considered whether the type of treatment and severity of diagnosis (as is suggested in literature) might shed light on this.

Ann only needed surgery which suggests that the diagnosis was less severe. Although the diagnosis floored her (“a black hole”), the surgery happened quickly and no chemotherapy was needed. The hulk alongside may express just that: the scary cancer was taken out of her body and there was no doubt about it. E on the contrary needed chemotherapy which might explain why his initial experience post treatment was dominated by ‘not knowing’ (Fog) and that creating a sense of clarity demanded a more elaborate differentiation by having the cancer not only conceptualised outside his own body but also at a distance and across a boundary (Terrorist).

One may wonder whether Ann or a survivor in her situation will need to move into an experience akin to the Terrorist at all. This draws attention to another difference between Ann and E: Ann expressed an urge for movement. Movement is the body schematic structure of the comprehendings of self and cancer presented in the next clusters. In that sense the 'Terrorist' experience may not be between her and the next type of comprehending. On the other hand Ann not being able to move could mean that despite the different treatment experience she needs to conceptualise more space between her and cancer before the urge for movement can come to fruition.

These comparisons instigated the thought that a body schematic sequence may not mean that an individual cancer survivor takes all the steps. It is useful to imagine the body schematic structures as 'stepping stones' (Figure 13) which are laid out in a specific order but individuals may step on specific stones while skipping others. With the above example I suggest that the nature of the cancer diagnosis and treatment may influence which of the stones they step on. A range of other factors will influence the way Ann and E comprehend their experience. For example, Ann and E are of different gender. No doubt this experience also is gendered, yet as neither of them framed their experience in those terms I do not wish to speculate.

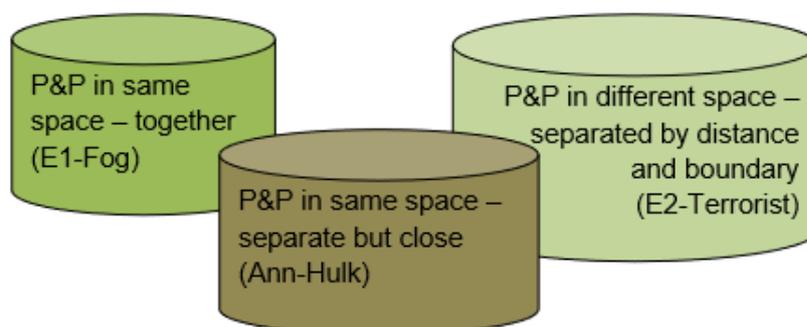


Figure 13: Variations in Presenting and Positioning

### **8.3.1.5 *What lies outside Presenting and Positioning?***

The metaphors of the Fog, Hulk and Terrorist all focus on the space survivors inhabit and the way this space is shared with cancer. The presence of cancer is in all three metaphors enveloped in a negotiated tension expressed through invisibility, bigness or uncertain distance. Comprehending oneself with such precariousness of being vis-à-vis cancer is what seems viable at this stage of survivorship.

Embedded in the comprehendings was an interest in 'understanding cancer'. The type of understanding that is expressed draws on the PMs 'Knowing is Feeling or Sensing' rather than 'Knowing is Seeing or Grasping'. This suggests a lack of clarity and rational understanding. It feels more important though to note how the participants positively appreciate their embodied, felt knowing of cancer.

In bodily development 'presenting and positioning' would be preceded by 'not presenting or positioning', and would be followed by some form of 'movement'. It seems that for the study participants it was not viable to structure their experience of self and cancer at this stage of survivorship according to either of these schemas. Some metaphors used to describe the time of diagnosis might shed light on the experience of being at risk of not being present (see above) but further exploration of those experiences is outside the remit of this thesis. Initial physical movement might be expected to show in an engagement of hands and feet. Two of the metaphors in this cluster imply 'trying to find feet' (Hulk) and 'feeling one's way' (Fog). This minimal or frustrated ability changes in the next metaphors as the experience of self is presented by referring to an ability to push and balance. This body schematic structure is explored under the label 'handling and rising'.

### 8.3.2 Enaction 2: Handling and Rising

For the second cluster of cancer survivors the comprehending of self vis-à-vis cancer comes across as an experience of: 'Handling' and 'Rising' (H&R). 'Handling' was chosen to capture a comprehending based in experiences of 'manipulating' cancer. The term 'rising' was chosen as it refers to the physical ability to stand up, to be upright, to be on your feet and therefore, potentially, move around, but also for its connotation with 'resistance' as expressed in the term 'uprising'.

The delineation of this second self vis-à-vis cancer is based on the metaphors used by research participants Linda and Rosy and will be explored in that order. None of the case study metaphors fall in this category. Both participants were around the second anniversary of their diagnosis and finished their treatment about one and a half year prior, with Rosy a few months ahead of Linda. Their data have been titled: 'I can bat it down a bit and don't let it stop me' (Linda) and 'When it comes to the surface, I go with the flow' (Rosy). The terms 'Bat down' and 'Flow with' will be used as shorthand.

The research data summaries that include the metaphors, wider narratives and photos of shell and stones exercise referred to in the presentation and discussion of the findings are respectively included in appxs F2 (Linda) and F3 (Rosy).

#### **8.3.2.1 *I can bat it down a bit and don't let it stop me (Linda)***

When Linda first creatively expressed her relationship vis-à-vis cancer with the use of a sheet of paper, she crushed it into a ball, saying "I want to break it... because of my feelings of fear... I am hating it and the effect it's had". In terms of the PM 'Causation is **Forced Movement**', it expresses her wish to impact on cancer, to hurt it back. With her metaphor Linda acts **against** and

rises up against cancer. This is followed though by expressing that one does not have control over cancer as an illness: “it’s mapped out”, “it’s out of my hands”, “if it is down for you it is”. A distinction is made between cancer as a physical illness and the psychological impact that the thought of cancer can exert. Linda concludes “I want control over how I deal with it, so it’s a case of keeping it together really.” The embedded PM ‘Self control is having the Self together’ brings to the fore that **self control**, rather than controlling cancer, is the focus and challenge for this participant at this stage of survivorship.

What kind of a challenge it is emerges from a string of metaphors: Linda **positions** (fear of) cancer somewhat lower than her head, expressing this further with “I am a little bit on top of it”, “It is not overshadowing me”. Based on the PM ‘Being in control is being above’ this expresses a sense of control. That this positioning and controlling of (fear of) cancer is **her doing**, speaks from: “I can bat it down a bit” and even “I can close the door on it if I need to”. The slightly forceful nature of her acting, gives away that she **deliberately** brings herself to **act** on her fear (see PM: ‘Causing the Self to Act is the Forced movement of an Object’).

Using the sheet of paper, Linda positioned ‘it’ on her lap (not on the floor) and says “I **carry it** with me”, but it is not on her shoulders because “it is not really a burden”. The resistance to acknowledge it as a burden is further expressed by “It doesn’t weigh heavy on my heart but it is always there”. This implies that it is not a weight that stops her or as Linda puts it “I **don’t let it stop me getting on** with life”. Nevertheless (fear of) cancer is experienced as a force capable of “knocking me of my feet (but not quite at the moment)”. In other words it could undo the rising and undermine her functioning and acting. This is in line with the PMs ‘Functionality is Erectness’, ‘Suspension of action is the Stopping of movement’ and ‘Causes are Forces’. This intrinsic power of (fear of) cancer that Linda manages to control has been painted in vivid rather than shadowy colours (PP:Linda-T-slide16).

The control over space and movement Linda negotiates in day time, is often lost in the evening when “my space is closing in” and “cogs going feeling”. The latter referring to PMs ‘Mind is Machine’ and ‘Ideas are entities with an independent existence’, and suggesting a loss of mental or self control. Also when blood tests or scans are coming up, cancer “is overtaking a little bit”.

The ‘bat down’ metaphor expresses **a delicate control**, which goes hand in hand with Linda saying “I am cautious”, “not complacent”, “not foolish”, “not tempting fate”, “not quite out of the woods but it is good”. Her engagement with future is limited; she only looks at the next event and concludes “**I live life in chunks** really”.

The image that emerges from the body schematic structure of the ‘bat down’ metaphor feels quite laborious. Based on my initial embodied enquiry (PP:Linda-EEQ-slide19) I feel this needs to be nuanced. I titled my own felt sense of Linda’s story: “With a tiger kitten in the sun”. This not only captures the emotional labour of living with a tiger kitten but also a genuine joy that was expressed.

### ***8.3.2.2 When it comes to the surface, I go with the flow (Rosy).***

Rosy expresses less anger than Linda as she does not crush the sheet but folds it a few times, but like Linda she emphasises that she has no real control over cancer but says “what I can control, I try to”. This means she sets herself the task not to lose (self, mental) control over it (cancer, fear of cancer): “I do not allow it to take over because that is compromising the future” and concludes “it is there but it is also **contained**”.

In contrast to the ‘bat down’ metaphor, this ‘flow with’ metaphor does not express any exertion of force against cancer in order to contain it. Rosy portrays a more open relating with (fear of) cancer which she expresses by folding the sheet of paper roughly (instead of her usual precise way): “I am

bold and I'm wanting to still keep an open mind about the things that arise", "not setting things in stone", all right to "step out of my comfort zone". For Rosy, when cancer pushes through the surface, she borrows its force by using it as a 'flow'. She **uses its force and works with it**. Not only to avoid it becoming an impediment to getting on with life but almost as an advantage as it encourages her to practice gracefulness, a life approach she values highly. This came to the fore as the overriding sentiment during the Embodied Enquiry (PP:Rosy-EEQ-slide24).

Despite cancer not being an impediment Rosy does not deny that cancer interferes with her as it is **not completely still**: "it is there... loosely but ... it impinges on my blank sheet (= life without fear)", "(like the sheet of paper) it keeps lifting up, you see, now and again", "it is like a spiky shell, it raises its head now and then (e.g. scans)". Both Linda and Rosy position cancer (represented by sheet of paper) and experience cancer as 'close' (see PM 'Emotional intimacy is Proximity), but when Rosy puts it on the nearby table, rather than in her lap (as Linda did), Rosy expresses a less intense relationship with cancer (see PM 'Interrelatedness is Physical interconnection').

Rosy specifies that cancer is **close and 'down there'**, in contrast to it being high up and out of sight. The PM 'Looking is Paying attention' seems at work here. Rosy's way of controlling cancer is more conceptualised as monitoring it, not forgetting it.

Rosy has a permanent stoma. It does not hold the same threat as cancer "I saw it as a means to an end to getting rid of the tumour", "I didn't think of it as anything but a consequence of that fact that I was diagnosed with cancer." Nevertheless there is also a similarity between the way cancer and stoma is perceived: it is there, it takes "a role of its own", it is a "nuisance" at times but "not an enemy", it needs attention but "does not get me down". Although "it governs her days and weeks", it "impinges" on all she does. Rosy's coping with the stoma varies between pushing it away as if it has nothing to do with

her and facing it and dealing with it, “coming to grips with it”. In the painting the stoma is presented as something big that she carries but presented in a way that expresses Rosy’s gracious manner (PP:Rosy-T-slide21).

**8.3.2.3 Ordering from a developmental perspective: Bat down – Flow with**

Where Linda, with metaphors like “bat it down”, ‘break it’, “crush it” primarily draws on the specific physical experience of manipulation, Rosy’s metaphorical expressions “go with the flow” in response to a cancer that now and then “comes to the surface” and her statement, “grateful that you’re still standing”, draws on the gross motor skills. Developmentally the ability to manipulate precedes the ability to stand up and could suggest that it is logical that conceptualisings of new experiences will first draw on manipulating and then on keeping upright and balanced.

	Time post Diagnosis	Time post Treatment
Linda- Bat down	1y11m	1y4m
Rosy- Flow with	2y2m	1y9m

That Rosy draws on a more advanced bodily experience than Linda could possibly be explained by the fact that more time has passed since diagnosis and since finishing treatment (see extract taken from Table 7). The impact of passing the second anniversary of

diagnosis was also considered based on the ‘stones and shells exercise’. Where the other participants, including Rosy, chose a big stone or shell to reflect their present self, Linda together with Ann, chose a smaller stone. As they were the only participants who had not passed the second anniversary this could suggest that the recovery of their sense of self was less advanced (see appx.E2).

Apart from the subtle body schematic difference between Linda and Rosy's metaphors, the difference in emotionality also demands attention.

Both participants felt very overwhelmed at diagnosis. Although Linda only needed surgery and chemo whereas Rosy also needed radiotherapy and a permanent stoma, Linda was, at 37 years of age with two young children, potentially left with a greater sense of unfairness than Rosy who was 66 years with grown up children and grandchildren. The higher degree of anger expressed by Linda might have been more intense from the start. Although Linda expresses this with imagery of 'crushing', it could equally be expressed as 'kicking'.

Rosy expresses a temperate relationship with cancer. One could wonder whether this has been enabled by a conflation between cancer and having a permanent stoma, which means that on a daily basis Rosy has to live and practice acceptance of something that is unpredictable and not chosen. But again, although Rosy expresses her temperate relationship with cancer as managing to keep gracefully upright while cancer lifts up the surface, this could also have been expressed as a skilful '(manual) juggling'. In other words without wanting to exclude that the nature of the emotion felt at the time may influence the body schematic structure that participants draw on to express their overall experience, each body schematic ability can be honed in different ways and allow the expression of different emotions. In other words it is not their differing emotionality that explains the difference in bodily ability embedded in their metaphors (hand versus feet).

Based on the comparisons of the metaphors in Enaction 1 the suggestion was made that survivors may not step on every stepping stone. The comparisons of the metaphors in Enaction 2 bring to the fore that the body schematic stepping stones, in the first place refer to a physical *ability* (e.g. manipulating, standing up right) but, secondly, are executed in different ways depending on the *emotionality* of the experience at that time. Plutchik's 'wheel of emotions' (see appx.E5) has been used to give a brief indication of

the emotions expressed by participants. It is outside the remit of this thesis to pursue this in any further depth. Linda's forceful handling imagery has been labelled as 'aggressiveness' while Rosy herself labels her temperate approach as being guided by 'love'. This difference is expressed with different tones of colour; in this case I have chosen the warmer tone for Rosy's and the cooler tone for Linda's approach (Figure 14).

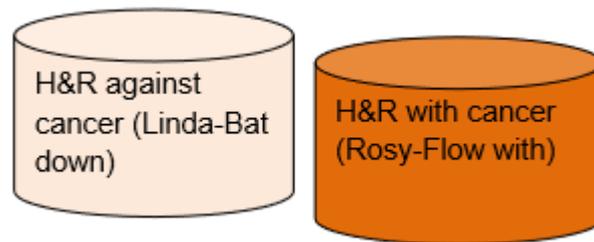


Figure 14: Variations in Handling and Rising

#### **8.3.2.4 What lies beyond Handling and Rising?**

Implied in the handling and rising metaphors is a changed positioning in relation to cancer. Both metaphors suggest a sense of being on top of cancer, albeit with effort and only just. As in the metaphors of Enaction 1, embedded in the achieved conceptualisings is a sense of precariousness. The handling and rising in relation to cancer brings about that cancer is conceptualised as in their space, in an invasive but controlled and contained way.

The understanding of cancer is not explicitly addressed by the participants. One can only surmise that the more tactile connection gives away a process of learning to know it in a tangible, grasping manner.

In both metaphors cancer is presented as an impediment but one that does not or is not allowed to stop the participants getting on with life. Although it did not seem viable at this stage of survivorship to conceptualise the experience of self vis-à-vis cancer by actively drawing on imagery of 'moving

forward', the reference to life at least conjures up some feel for movement. Movement is expressed as focused on the present and near future. Linda expressed this explicitly with "not looking beyond the next event" and "living in chunks". In PM terms 'Time is conceptualised as Motion', motion in space, and between events happening in locations. It is through moving or observing movement that one experiences the passage of time (Lakoff 1999, p.137-169). One can anticipate that comprehendings structured in terms of 'movement' will go hand in hand with conceptualisings of the experience of time. This is the enaction described in the next section: 'Moving in Space'.

### **8.3.3 Enaction 3: Moving in Space**

I have defined 'Moving in Space' (MiS) as the third enacted experience of cancer during survivorship. Two comprehendings were rooted in this physical experience of 'moving in space'. The addition 'in space' is important. First it differentiates from the on the spot movement of hands and feet which was at the core of the previous enaction. In other words it is more a 'moving about'. Secondly although the term space expresses a level of free movement, it simultaneously conveys a limitation as a space has boundaries.

This enaction underpins the metaphors used by research participant Karl and by E, the case study participant. Both are 2 years and 4 months past diagnosis. Karl's treatment ended just over a year ago with the reversal of his stoma, while E finished 1 year and 10 months ago. Their metaphors have been titled: 'A blank canvas in the year ahead' (Karl) and 'No guest appearances of cancer in the theatre play' (E3). 'Blank canvas 1Y' and 'Theatre play' will be used as shorthand. Both reflections are triggered by recent medical assessments that there is no noticeable cancer activity. Karl looks ahead, while E looks back.

Karl's research data summary is included in appx.F4 while appx.F5 presents the case study data E-Theatre play.

### **8.3.3.1 A blank canvas in the year ahead (Karl)**

Only a week before the research sessions Karl had a scan which confirmed he was cancer free and his next appointment was set in a year's time. In response Karl put the sheet of paper, unfolded, on the floor and indicates that this represents his life in the coming year. By leaving the sheet unfolded, the emphasis is on 'size'. PMs such as 'Quantity / Importance / Desire / Need is Size' all seem applicable to Karl's experience. In other words the experience he portrays suggests a sense of **having a considerable amount of space**. As he chooses a polished stone in the shape of a heart to represent his self in this coming time, it feels right to argue that life ahead is seen as really important, needed and desired.

Cancer, previously a pressure within his everyday life space, is now envisaged outside this space. His life ahead is like the sheet, a 'blank canvas' or as he puts it "not full of pressures" and "for the first time in three years... life is under my control, whereas (cancer) controlled me". In other words **cancer is not moving (for now) and not invading his space**. Subsequently he **does not have to act or respond to it** on a daily basis in order to control it as was the case for Linda and Rosy. Drawing on the PM "Morally good is Clean" one could imagine that by conceptualising a year free of cancer as 'blank' also gives away that he experiences this new state as a morally deserved change.

Karl represented a year in terms of space (unfolded sheet). Metaphorically 'time' can be conceptualised in a range of ways but the PM 'Times are Locations in space' is prominent. Karl draws on it again when he puts the sheet of paper (representing life in the coming year) close to his feet and says "I have a fresh start", "it is here and now". The feeling he expresses is one of **just stepping into a cancer free space** and out of a long stretch of relentless problems as expressed in the painting (PP:Karl-T-slide30). Time experience is also rooted in the experience of events (Lakoff 1999, p.139). The 'blank canvas 1Y' metaphor space stretches between two medical events

and moving from his recent to the next medical appointment, conjures up the image of a path and direction. Karl though is just at the start and is not particularly focused on the next event or on the direction of his movement. His **focus is on the present** and his reasoning about the nature of cancer underpins this (see below).

Karl does not add any other events within this space or between the two medical events. This implies a **fluidity of motion** and subsequently a fluid experience of change is suggested (see PM 'Continuous change of state is Continuous motion'). On the other hand living and **moving is** not represented with active images of moving but rather with **passive** expressions like "it is likely to happen", "will last until the end of year".

Like previous participants Karl refers to the unpredictability of cancer when he reflects on the chances of longevity: "it is all ifs and buts" and it can go from "cure to no cure" anytime as it is "a blunt instrument that does not care for you". Yet, unlike other participants, he dares to make a concrete **personal interpretation** of the medical information regarding the behaviour of cancer in the **nearby future**: "I don't think cancer can come back and kill me within a year if there's nothing there now". In other words experience of time brings about an experience of probability, which in turn supports a sense of understanding and, certainly for Karl, an ability for the self to speak about cancer in his own name, albeit that he builds on the information received from the clinicians.

### ***8.3.3.2 No guest appearance of cancer in the theatre play (E3)***

Looking back at the past year, E3 metaphorically comprehends his medical visits as performances of a theatre play, with the consultant as the protagonist and scriptwriter, cancer in a role of potentially making guest appearances, other patients and helpers getting on and off the stage and himself as an amateur actor. Similar to Karl using the 'blank canvas 1Y' metaphor, with the

'theatre play' metaphor, E3 uses space and movement in that space as the core bodily schema to comprehend the present experience of self and cancer. E3 presents cancer as having a role in the play as a figure that could make "surprise guest appearances", but so far has not done so. In other words the **space belongs both to cancer and self but cancer does not show up** in that space at the moment. The performance repeatedly ends with the consultant saying "come back in a month". Even if in reality the visits were less frequent, E3's experience of not being with cancer or cancer being inactive is shorter and less secure than Karl's (who is convinced it will not return within a year).

Although cancer in the theatre metaphor does not come onto the stage and therefore there is no visual or physical contact, it has a role which suggests it is personalised or at least alive and **could invade the space** of the participant any time. E3 saying: "the unspoken but known secret of the play is called 'cancer'" brings home that the 'theatre play' is all about cancer and its control. That E3 was attempting to conceptualise an active engagement with the realisation that living, also after almost two years, was experienced as ultimately depended on the way cancer behaved, became more tangible when the painter presented cancer as a small figure in the corner but one that opens the curtains to the play and therefore opens up the space to be (PP:E4-T-slide26). This imagery gained additional meaning when another participant (Linda) – also drawing on the PM 'Life is a Play' - referred to dying with the expression "you think it's 'curtains'".

E3 describes himself as an amateur actor "who stumbles over his lines". This could be read as an expression of **struggling to express and/or move himself** smoothly and confidently.

E3 frames the consultation as a 'script' and says "the consultant guides me around my mistakes to arrive at the right line – in my case up till now: "come back in a month" – at the right time. With this he implies that there will be a next showing." Not only does E3 express an experience of lacking

confidence, he also describes a sense of path and direction, but known by the consultant and not by E3 as the patient. This resonates with the PM ‘Progress is a travel schedule; A schedule is reaching prearranged destinations at pre-arranged times’. It seems that the theatre metaphor incorporates an experience of progress that is less present in the blank canvas metaphor. This follows from a difference in the way motion occurs. Rather than the continuous motion of Karl, E3 script-like motion is more akin to the PM ‘Process is Motion through a linear sequence of locations’. Add to this that E3 ‘stumbles’ and ‘is guided around mistakes’ and the theatre metaphor seems to express process and **progress but in an uneasy form and not autonomously**. With reference to the PM ‘Purposeful Action is Self-Propelled Motion to a Destination’ E3 is moved to a destination but is not yet experiencing an ability to drive it himself.

In contrast to Karl, E3 does **not express an opinion** about the behaviour of cancer, on the contrary in describing cancer in the play as “at this moment we do not quite know ‘its’ role apart from the reputation it has of giving surprise guest appearance’, the impossibility of making an evaluation is expressed.

**8.3.3.3 Ordering from a developmental perspective: Theatre play – Blank canvas 1Y**

Although the ‘theatre play’ and ‘blank canvas 1Y’ metaphor were expressed

	Time post diagnosis	Time post treatment
Karl-Blank canvas 1Y	2y4m	1y5m/1y1m stoma reversal
E3-Theatre play	2y4m	1y10m

at the same time post-diagnosis (extract taken from Table 7) beyond the shared conceptualising of ‘cancer not being present in the space of the self at the moment’, they also capture differences.

Although E3 has finished treatment a while before Karl, the bodily functioning embedded in the 'theatre play' (E3) seems less accomplished than the bodily functioning in the 'blank canvas 1Y' (Karl). At the core of the 'theatre play' is E3's inability to move independently and needing guidance from his consultant. This is not expressed by Karl. Based on the bodily logic that one first moves about with help before self-propelled movement becomes possible, the 'theatre play' captures an experience of self and cancer that precedes the experience expressed in the 'blank canvas' metaphor. Also Karl's ability to decide that the absence of cancer is a fact for the coming year, speaks of the emergence of a self, an 'I' that has (re)gained the ability to rely on its own opinion, that is not present in the 'theatre play' metaphor.

Nevertheless, there is an element of confusion. Karl's strength is expressed in relation to the year ahead. He does not look beyond that, nor does he look backwards. This feeling of 'The Time is Now' strongly emerged during the embodied enquiry (PP:Karl-EEQ-slide33). This limitation is not present in E3's reflections. By comprehending the experience of repeated messages of 'no cancer' E3 only reveals an experience of time passage. By comprehending an experience of the previous year there is also an integration of past, present and near future. This might suggest that E3 expresses a more in depth process than Karl which could mean that Karl is at risk of falling back later on. A range of factors may influence this difference, e.g. one might argue that the frequency of consultations, for better or worse, impacts on patients' engagement with the uncertainty of cancer's absence. Or living with a stoma (E3) may make it more difficult to ignore cancer. This comparison opens up the idea that comprehendings may differ in their degree of body schematic coherence. Those with less coherence will be represented as more shallow stepping stones (see Figure 15 below).

Emotionally Karl expresses joy about the year ahead, but his attitude to cancer, which he describes as a "blunt instrument", is one of contempt. Excluding it radically outside his space is partially an expression of that. By giving 'absent cancer' a role in the theatre play, E3's feelings are perhaps

best captured as 'submission', hovering between acceptance and apprehension (see appx.E5).

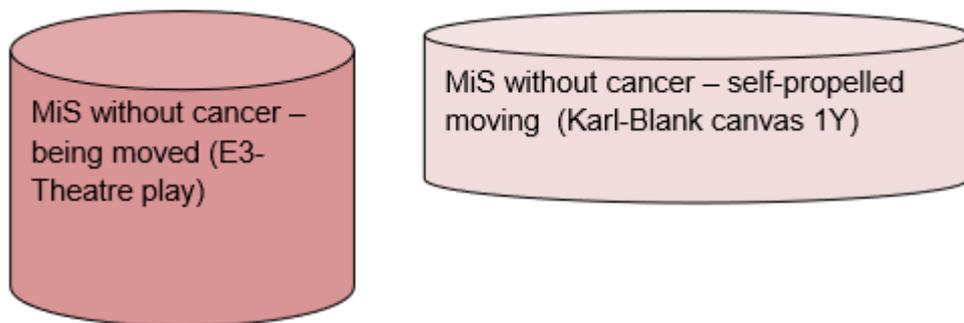


Figure 15: Variations in Moving in Space

#### **8.3.3.4 What lies beyond Moving in Space?**

Comprehending self in a cancer free space shows to be difficult for both participants. Where Karl manages by limiting his view to one year, E3 engages even more with the precariousness by giving cancer a role that entails making surprise guest appearances. Their movements are either a struggle (E3) or implied happenings that are just about to start (Karl). In order for survivors to experience their self and cancer in terms of moving confidently on a path, with a sense of direction and chosen destination, a self is needed that experiences an ability to choose and act autonomously and has a more integrated and less episodic experience of time. The 'I' that on a narrow time basis is expressed by Karl and the self that looks back and forward, as expressed by E3, have emerged more fully and combined in the metaphors that are described in the next section.

*So far the metaphors and wider narratives of the study participants have implied a time focus that was mainly on the present and/or the near future. This is about to change in the following metaphors.*

#### **8.3.4 Enaction 4: Expressing a Viewpoint on the Future**

'Expressing a Viewpoint on the Future' (EVF) is the caption for the fourth enaction of self and cancer during survivorship. At the centre of the participants' comprehendings seems to reside an expression of a personal opinion on cancer and their future life. A more detailed exploration revealed that at least five aspects of self jointly come into fruition as part of this. The participants emphasise the importance of talking about (1) cancer. This confidence to express their opinion is based in a sense of 'understanding' (2) cancer. The personal character of their understanding triggers a repositioning in the relationship with their consultant (3) who so far was the main source of understanding cancer. This in turn seems to generate a reflection on their authenticity (4). Expressing an opinion about the state of cancer in the present has implications for what they believe will happen next; in other words the future (5) comes into view.

'Viewpoint' has of course also a literal, kinaesthetic and spatial meaning that refers to a position in space from where one can see. Where the first enaction referred to 'positioning', this enaction entails a 're-positioning' of self in relation to self, consultants, cancer and what lies ahead.

This enaction structures metaphors of the research participant Mark and of the case study participant. Both are coming up to two years post treatment but Mark has been diagnosed 3 months before E. Their metaphors are titled:

‘Cancer is an open book for me’ (Mark) and ‘I embrace the unknowable aspect of cancer’ (E4). ‘Open book’ and ‘Unknowable’ will be used as shorthand. E4 expressed the ‘Unknowable’ metaphor only one month after and as a development from the ‘Theatre play’ metaphor.

Karl, who was discussed in the previous section, also expressed a future viewpoint on cancer, but this only referred to the next year. The present comprehensions of Mark and E4 go beyond an episodic time concept and instead imply a belief in longevity. Also, in Karl’s Blank canvas 1Y and E3’s Theatre play metaphor, the conceptualisation of being alive depended on envisaging a space without cancer, which as will become clear below is not the case for the next metaphors.

Mark’s research data are summarized in appx.F6 and the case study data that incorporate the ‘unknowable’ metaphor are presented in appx.F7.

#### **8.3.4.1 *Cancer is an open book for me (Mark)***

The expression “cancer is an open book” draws on the PMs ‘Thinking is Linguistic activity’ and on ‘Knowing is Seeing’. As the book is ‘open’ this metaphor emphasises that cancer holds no secrets. Moreover Mark qualifies the way he has come to understand cancer as “I have looked at the whole thing and then folded it up” suggesting the objectivity of his **understanding** (PM ‘Understanding is Seeing from an Objective perspective’).

But part of the process of understanding for Mark **is talking** about it: sharing with others means “getting more than one mind on the job” and “getting the monkey off your back”. Both metaphors convey talking as **purposeful**. The latter incorporates the PM ‘Freedom of action is the lack of impediment to movement’ and brings the aim of ‘freeing oneself’ to the fore.

In the creative exploration with a sheet of paper, the tightly folding of the sheet triggered the following metaphors: cancer “is in my back pocket – with an elastic band around it”, “it is getting to the stage where it is down the end of the garden” and “it is like the memory on a computer”. This is the first participant who does not conceptualise cancer either alongside or in front of him. In contrast to the previous metaphors, cancer is not so much conceptualised as absent in the present life-space but as present **in the background**, a term used by Mark himself: “It is in the background, but never disappears”. Based on the implied PM ‘Important is Central’, cancer is in that sense presented as less important but it is still conceptualised as in his personal space (pocket, garden, computer), albeit contained. This containment means that **Mark does not need to respond or exert force** onto it (as was the case in Enaction 2); cancer is objectified and is believed to stay in the background. This refers both to the medical aspect and the thinking of cancer, as Mark describes being reminded (by other people or scans) of cancer as unusual: “hitting the wrong button on the computer” while normally it is “at the back of my mind”.

The sense of having developed an understanding of cancer, colours the way Mark sees his present **relationship with his consultant**: “because I know so much about the background to things (cancer) I could almost talk on a level playing field with him (consultant)”. This positioning in a peer position further shows in Mark explaining that he “does not stand on ceremony” and recalls walking up to the consultant in the corridor saying “ ‘consultation went well yesterday’, shaking hands and walking off again”. With reference to the PM ‘Causal relatedness is Physical impact’, the handshake symbolises that Mark sees the relationship as one where he does not just receive but **acts and influences**.

The present containment of cancer opens the possibility to see a **future**. Without saying it explicitly, it speaks from the statement: “I am now 90% happy that nothing is coming back”. The PM ‘Reasoning is Adding’ is used here to express that he is quite convinced that he has a future without cancer.

In the shell exercise it is noticeable that the self is positioned well away from the edge of the paper. The space ahead could suggest that Mark expects to live for a long time. He backs up his belief by referring to a range of facts varying from the limited number of infected lymph nodes, to survivorship of a relative with a similar diagnosis, and to his exercise regime. And extra cautiously, he delegates the care for the 10 % to his consultant: “he and his team will spot anything that is likely to transpire. He has the GPS that shows the pathways. I am leaving that up to him.” All this gives the impression that at this stage the reasoning and talking is used to substantiate a belief in a long future. This I realised with more depth when the figures (Mark and consultant) were painted with their heads just above a friendly yellow barrier as if looking over a fence and their bright minds shining light onto the future (PP:Mark-T-slide39).

When Mark says “The way I deal with cancer is very much an expression of how I am” and details this with reference to his personality, life and work experience, he communicates that his way with cancer is an expression of his **authentic** self. He points out that even at the time of diagnosis when ‘cancer was a closed book’, it was “never on top” of him and did not interfere with his ability to respond in his typical way.

#### ***8.3.4.2 I embrace the unknowable aspect of cancer (E4)***

**Authenticity** is also a major theme for E4 at this stage. Where for Mark this meant a continuation of his normal self, E4 points out how cancer has freed up the option (desire, wish, learning to) for his future self to be more trusting, satisfied and less critical than his previous self. Building on the theatre play metaphor where the consultant wrote the script, E4 states “I am ready to re-write my script”. In the paintings a silver blob represents this new self (see PP:E4-F-slide36). This felt sense of growth seems both real in the present and an inspiring goal (see PP:E4-T-slide35).

By expanding on the theatre play metaphor E4 further explains his reclaiming of control: “I relive my last consultation and decide to turn my play metaphor into an Augusto Boal Forum Theatre play in which actors or audience “stop” the play and intervene with the script where they feel oppressed. The person who stops the play takes the place of the original actor (consultant) who stays on stage but to the side. I feel it is only right for me to be the star, the protagonist.” As for Mark, a sense of **purposeful action** is expressed, geared mainly in taking an independent position in **relation to the consultant**.

This imagined physical repositioning in relation to the consultant includes a re-evaluation of the possibility and need of **understanding** cancer as E4 boldly puts: “They (consultants) do not know at a *fundamental* level what is going on or what will happen. And neither do I. ... Instead of being haunted by its uncertainty I find myself elaborating on it. ... I know now there are no *definite* truths about my cancer ... I embrace the unknowable aspect of cancer. ... I like the confusion, the chaos, it somehow gives me freedom”. In other words, the ‘unknowable’ metaphor conceptualises a letting go of the possibility and importance of knowing cancer. As the metaphor is still one of scripts and theatre, cancer is still conceptualised in a ‘role’ rather than objectified.

This thirst for freedom E4 also expresses as a “desire to **speak freely** about cancer and the effects it has upon me, particularly emotionally” (including the experience of living with a stoma).

While Mark built a belief on medical facts which suggested possible survival, E4 had to deal with medical facts that suggested the opposite (short prognosis, shadows on liver and lungs), yet do not fit with his present experience of feeling and looking well. E4 resorts to discarding that anything said about cancer by medical people is ‘fundamental’ or ‘definite’ in order to conceptualise his subjective belief in a **future** and long term survival. This enables E4 to say “I think I will never die of cancer, just old age ... I believe that I am a survivor.”

### 8.3.4.3 Ordering from a developmental perspective: *Unknowable / Open book*

Both Mark and E4 position cancer in the background with no need to take action towards it. They both step forward and take initiative in relation to their consultant. They share an emphasis on freedom and independence and have both formulated an opinion on cancer. They both envisage a long term future. Although they both express some form **of connection with** cancer at the moment, Mark’s conceptualising of it being an object on the edge of his personal space suggests this may in time either not be the case or of very little consequence. E4 on the other hand, by seeing cancer as unknowable and, unspoken, visualised in a role, implies that the relationship will be ongoing. Whether E4 objectifying cancer is a developmental move that

	Time post diagnosis	Time post treatment
E4- Unknowable	2y5m	1y11m
Mark-Open book	2y8m	1y10m

is still to come or not, will transpire in later metaphors. As said above this difference between Mark and E4 is more likely to be because of different medical information than because of the slight difference in time post diagnosis compared to Mark (see extract taken from Table 7).

As the difference has to do with what is conjured up for the future, this led to the consideration that cancer survivors may not only skip some stepping stones (see Enaction 1), or shape them with different emotional energy (see Enaction 2) or depth (see Enaction 3), but that especially when they reach the point of expressing a personal viewpoint on cancer, they may walk different paths. It is this interpretation of the difference between Mark and E4 that has been expressed below (Figure 16). Emotionally for both there is no negativity expressed; they both express their views with optimism.

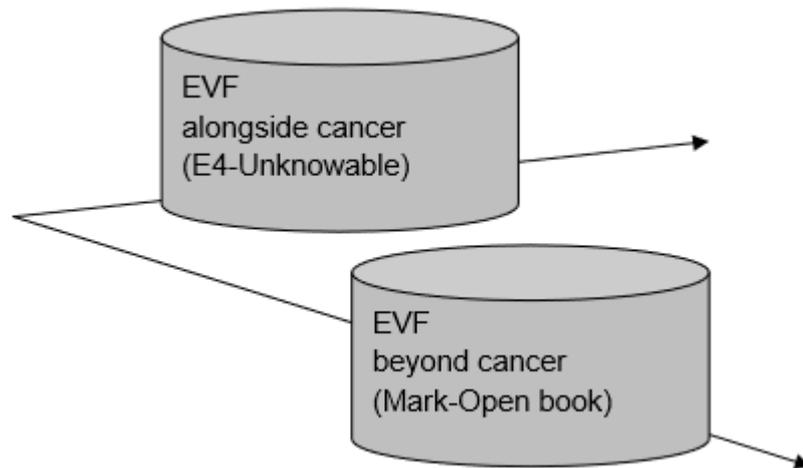


Figure 16: Variations in Expressing Viewpoint on Future

#### **8.3.4.4 What lies beyond Expressing a Viewpoint on the Future?**

The 'metaphors 'Unknowable' and 'Open book' show that it has become viable to move and talk with purpose. The purpose is freedom from cancer as a burden, from an unequal relationship with their clinician and from any impediments to be authentic. This makes it possible to envisage cancer within their personal space without feeling threatened, and to think about future and longevity. The precariousness of the achievement of these metaphorical comprehendings is in the fact that the path ahead is talked about but not walked yet. It is this enaction that structures the next metaphors.

#### **8.3.5 Enaction 5: Moving Forward**

The fifth enaction of self and cancer has been defined as 'moving forward' (MF). The term 'forward' captures the sense of direction, which is whatever direction life takes. This makes the movement purposeful, a sense that was instigated in the previous enaction.

The metaphors of the research participant, Simon and the fifth metaphor of the case study participant, E5 are structured according to this enaction. They finished their treatment just over two years previously.

Simon's metaphor 'Forging ahead while cancer drifts into the background' will be referred to as 'Forging ahead'. E5's metaphor 'Adopting cancer and accept good and bad times to come' will be shortened as 'Adopting'.

The summary of Simon's data can be found in appx.F8, while the case study data are presented in appx.F9.

#### ***8.3.5.1 Forging ahead while cancer drifts into the distance behind me (Simon)***

With the term 'forging' the forward movement could not be stressed more. It is a term that usually also implies a moving forward that is gradual or steady and is driving and active. Moving forward encompasses the idea that **Simon has started on a path and is making progress** (see PMs 'Making progress is Forward movement' and 'Starting out a purposeful action is Starting out on a path').

This is put in contrast to the movement of cancer which Simon metaphorically describes as "drifting in the distance behind me". Based on the PM 'Undoing progress is Backward movement', this conveys not only that **cancer is** comprehended as having taken a back position (e.g. Mark sees it as an object at the back of his personal space) but is **moving further backwards**. With 'Manner of action is Manner of movement' (PM): the drifting movement of cancer in this metaphor suggest that Simon experiences it as a natural process that cancer is less and less prominent in his life. It is a process that he has no control over but nevertheless he aims "to help" it.

Simon uses a parallel metaphor that covers the totality of his experience with cancer: “at diagnosis cancer is like cordial at the bottom of the glass, which is then dispersed more and more as water is added.” He likens the ‘drifting’ to the ‘dispersing of the cordial’, again choosing ‘fluidity’ to describe the force with which cancer moves back.

The backwards drifting cancer is specified further: “it is not bunched up behind me ... it is like a tall wall, it is everything behind me, the whole world wide”. This may express that despite cancer becoming less threatening it is still important (PM: Importance is Size). It may also suggest that in the past cancer covered his whole life.

About the cancer behind him Simon says “I can still see it in the corner of my eye” and “I can get to it when I need it.” But “Cancer had a place in my life and I am trying to keep it there”. He likens it to a tall bookcase where things you don’t need much are filed on the top shelf (because “he does not want to forget”). In other words the positioning of Cancer is similar to that in Enaction 4. This spontaneously emerged in the paintings: as there is a small gap between the figure (self) and the book (cancer) in PP:Mark-T-slide39, there is an **emerging gap between the drifting bookcase (cancer) and the self** in PP:Simon-T-slide48.

**Life ahead is not restricted.** Simon refers to his parents dying in old age and is setting out to mirror their lifestyle. If cancer were to “crop up again” he “would face it then”. Although not excluding that cancer could recur, Simon does not entertain a sense of it continuously being there.

### **8.3.5.2 Adopting cancer and accepting good and bad times to come (E5)**

The Adopting metaphor is spoken by E5 a month after the theatre metaphors and in its fuller version goes as follows: “I feel exhausted by ‘hosting’ this cancer that could make ‘guest appearances’... I decide to adopt the cancer. It is a matter of accepting that it is mine, for now and probably forever. Like with a child I accept that I will have good and bad times with it but that is how it is.”

Similar to the ‘forging ahead’ metaphor, **progressive and purposeful moving forward** is at the core of this metaphor be it indirectly suggested by conjuring up the image of raising a child.

Although for E5 the ‘Adopting’ metaphor is a stepping away from the ‘theatre’ metaphors, cancer is still presented as a person and the relationship between self and cancer is still ongoing. E5 continues to envisage a relationship with cancer as part of his present and future self. E5 in this metaphor takes **‘ownership’ of his cancer**. In the painting cancer is carried while moving forward (PP:E5-T-slide44). As pointed out in Enaction 4, Mark conjured up a Future with no tangible relationship with cancer and so does Simon saying he does not want to forget but does what he can to help cancer drift into the background. One could say that for them cancer is still in their ‘possession’ but not ‘owned’.

E5’s ‘ownership’ seems to go hand in hand with a further reduction of the threatening nature of cancer. It is now conceptualised as a child, which is visible and touchable and positioned lower than an adult, three characteristics that speak of E5 experiencing a level of control over cancer (see PMs ‘Seeing and Grasping is Understanding’ and ‘Being in control is Being above’).

Any problems in the **future**, are just like for Simon, approached with acceptance and plan to **deal with it as and when it comes**.

### 8.3.5.3 Ordering from a developmental perspective: Adopting / Forging ahead

Although in different ways, in the ‘Forging ahead’ and in the ‘Adopting’ metaphor, cancer is presented as less controlling, either through distance (Simon) or size (E5). As in Enaction 4, there is a view on the Future, but now the journey towards that future is also conceptualised: both metaphors centre around ‘moving forward’. In the ‘Forging ahead’ metaphor cancer moves backwards, while in the ‘Adopting’ metaphor, cancer moves with or alongside the self.

	Time post diagnosis	Time post treatment
E5-Adopting	2y7m	2y1m
Simon-Forging ahead	2y10m	2y2m

Although Simon is slightly ahead of E5 in terms of time post diagnosis and treatment (see extract taken from Table 7), as argued in Enaction 4 the body schematic difference of these comprehendings does not fit a

developmental sequence, but rather opens up different paths. By increasing the distance between self and cancer Simon is following the path that was nascent in Mark’s ‘Open book’ metaphor, while E5 takes cancer with him and continues on the path he took with the ‘Unknowable’ metaphor (Figure 17). The tone taken by Simon and E5 is again best described as a neutral optimism (appx.E5).

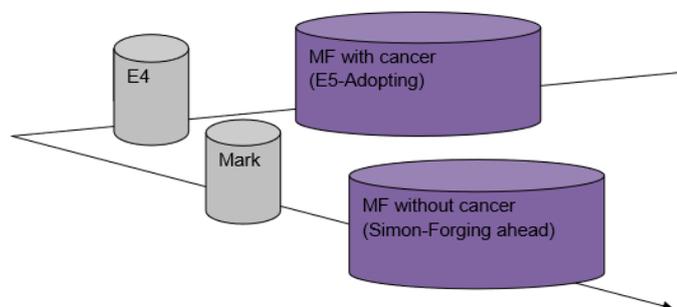


Figure 17: Variations in Moving Forward

#### **8.3.5.4 *What lies beyond Moving forward?***

The metaphors 'Forging ahead' and 'Adopting' show that at this point it is viable to comprehend the experience of self and cancer in terms of a path that one is walking on. The imagery used for it, 'adopting' (raising a child) and 'forging ahead' (while cancer disperses), suggest an inevitable transition at some point in the future. A child becomes adult, eventually the cordial is nearly completely diluted. In other words the present metaphors open up the query 'Does living with cancer 'alongside' or 'in the back' at some point become something else?' and if so 'how is this conceptualised'? This is the topic of the next enaction.

#### **8.3.6 Enaction 6: Surpassing and Assessing**

The term 'surpassing' is used to convey the idea that participants move *beyond* a point rather than *towards* a point where cancer is considered to be gone and unlikely to return. This is in contrast to the word 'arriving' which much more encompasses the idea of reaching a destination at a specific time. The awareness of being in a position where cancer is felt or said to be absent, seems to trigger an 'assessment' of the past, present and future.

This sixth enaction, 'Surpassing and Assessing' (S&A), will be illustrated with reference to the metaphors of the research participant Noel and the case study participant E6. They have finished treatment at similar times and are coming up to the third anniversary of their diagnosis. These times are also close to the times that the 'Adopting' and 'Forging ahead' metaphors were spoken, yet they bring to the fore another experience of self vis-à-vis cancer.

Noel's metaphor 'A chapter in my life' will be shortened as 'Chapter', while 'Veteran' will refer to E6's metaphor 'A war veteran in a wheelchair and no medals'.

Noel's research data are summarized in appx.F10 and the background of E's Veteran metaphor is included in appx.F11.

### **8.3.6.1 A chapter in my life (Noel)**

In addition to the metaphor cancer was “a chapter in my life” Noel describes it as “a past era” and “a phase”. Each of these expressions draw on ‘time’ and emphasise that cancer is not in the present anymore but in the past. The time gap creates a boundary around the experience with cancer and expresses that Noel is now in a different state (PM States are Locations). The present self and cancer are **positioned** in **separate times/spaces**. In the explorative exercise, Noel put the sheet of paper, representing ‘cancer’ on the floor at a distance from himself, rather than putting it outside the room. This gave the impression that cancer was conceptualised as only in the ‘**near past**’.

Noel also states that cancer is now static, it does not move. This suggests that, more than in the previously discussed metaphors, cancer is experienced as **not only gone but also as not returning**. Yet further exploration reveals that he is not experiencing it in such absolute terms. He takes back a spontaneous comment that “it is in the bin”, adding that it is an expression that seemed more fitting for his wife whose cancer was diagnosed ten rather than three years ago.

Noel explains that he has been “thinking less and less about cancer”. This presents his arrival in a zone without cancer as **a gradual** process. This does not exclude that it continues to come back into his awareness and causes some concern at times of scans or other reminders.

He concludes that he “has had a lucky escape from cancer” but add that this is due to him taking medical advice in time and pushing his doctors to act quickly. Although Noel is very appreciative of his doctors’ care, by

comprehending his own role as an autonomous actor in being now without cancer he makes it at least **partially his achievement**. Also the term 'escape' conveys the idea of some force (PM Causes are Forces) which means that despite cancer's control, his own actions are perceived as having played a role in it now being gone. This 'victorious' place is expressed in the painting with a figure that stands free with arms in the air (PP:Noel-T-slide57).

Noel put the sheet of paper representing cancer on the floor explaining that he "has put it down and does not have to hold it anymore". This suggests that the freedom to be oneself (enaction 4), is here extended to a **freedom to move and act unrelated to cancer**.

During the embodied enquiry, the feeling that prevailed was an acknowledgement that the whole experience had ended well but nevertheless had caused a greater **vulnerability** which demanded care (PP:Noel-EEQ-slide60). Noel expresses a desire to talk about his experience and contrasts it with the fact that nobody asks anymore. He likes the "vividness" of his memories and **enjoys "opening up"** to peer survivors. Where talking about cancer in enaction 5 was in service of the participants' own understanding of cancer, it now seems to serve an emotional need for the experience with cancer to be expressed and seen.

Noel has no worries about what he needs to do in the **future**: "I am where I'd like to be for my age." He does not exclude that cancer may return but based on his age evaluates this as of little consequence.

### **8.3.6.2 A war veteran in a wheelchair and no medals (E6)**

In contrast to Noel, the experience of having surpassed cancer did not come gradually for E. With the previous metaphors (Theatre play, Adopting) the relationship between E and cancer was comprehended as continuous. Yet during a doctor's visit E was told "cancer is not going to come back. There is

no need to see yourself as a patient. We have done well.” E captured his experience of this message as “I feel like a sad war veteran, in a wheelchair and with no medals”.

In this metaphor the term ‘veteran’ is used to express a comprehending of being **positioned** in a place **separate from cancer**. But rather than an escape (Noel), E6 calls it “being pushed out” (by the clinician). Moreover he feels pushed out from “the place where he was “winning, a hero, a good battler, a victor”. Keeping in mind that E, with the ‘Adopting’ metaphor (enaction 5), comprehended the relationship with cancer as part of self, the separation from cancer also brings about a **separation from his self**.

Although this new state came about **abruptly**, the intense feeling that underpins the ‘veteran’ metaphor suggests that E fully engaged with the message that he is no longer a patient. Yet at the same time he asks himself “Should I keep up my fighting skills in case it returns?” In other words: is this absolute?

As in Noel’s narrative, E6’s metaphor and surrounding narrative points out that being in this new place, comes with reflections on ‘achievements’, ‘freedom’, ‘vulnerability’ and ‘being listened to’. Where these were ‘positive’ experiences for Noel, they present as losses for E6.

First, E6 resists the “we’ have done well”, spoken by the doctor, as this **ignores his own achievement** in finding a way to live with it. Drawing on the battle metaphor, E6 expresses the need for a clearer acknowledgment of his part in the journey with cancer by referring to “medals”. In contrast, the consultant is experienced as the protagonist again (Theatre play). Although free from cancer, with the ‘wheelchair’ metaphor E6, expresses that he **lost his ability to move freely**. In terms of E’s earlier ‘Theatre play’ metaphor one could say the consultant is writing the script again but this time this is not experienced as a help but as a **breach of the autonomy** which E had established with the ‘Unknowable’ metaphor.

E6’s metaphor conveys his present **vulnerability** but he has not let go of the future. In the painting this is expressed as a ‘being thrown onto a rock from where to get up again’ (PP:E6-T-slide53). E6 assesses his ability to function with questions like “Can I put my cancer experience to use? Am I seen as too weak to be useful in a non-patient world?” Like Noel, he expresses a wish to speak about his experience: “**Who will listen** to my scars?”

### 8.3.6.3 Ordering from a developmental perspective: Veteran / Chapter

Both the ‘Veteran’ and ‘Chapter’ metaphor conceptualise a recent experience of cancer as being that unlikely to return that it gives rise to a ‘self beyond cancer’. This is expressed by imagining self and cancer in separate places and/or times.

In this change Noel’s sense of self as active, autonomous, expressive and confident about the future, continuous. Consequently his emotional state seems one of optimism. For E6 this change has led to the experience of a ‘self beyond cancer’ that is incapacitated and unsure about the future. Hovering between sadness and surprise, his feelings could be labelled as disapproval (see appx.E5).

Although Noel is a few months ahead of E6 in terms of time post diagnosis and treatment (see extract taken from Table 7), it is more likely that this

	Time post diagnosis	Time post treatment
E6-Veteran	2y8m	2y2m
Noel-Chapter	2y10m	2y3m/1y11m Stoma reversal

difference is due to the fact that E had comprehended the ongoing relationship with cancer as part of his competent self, while Noel probably comprehended his self as gradually moving away from cancer,

Just as Simon did (Forging forward). The split between these two paths started with enactment 4 and seems to continue (Figure 18).

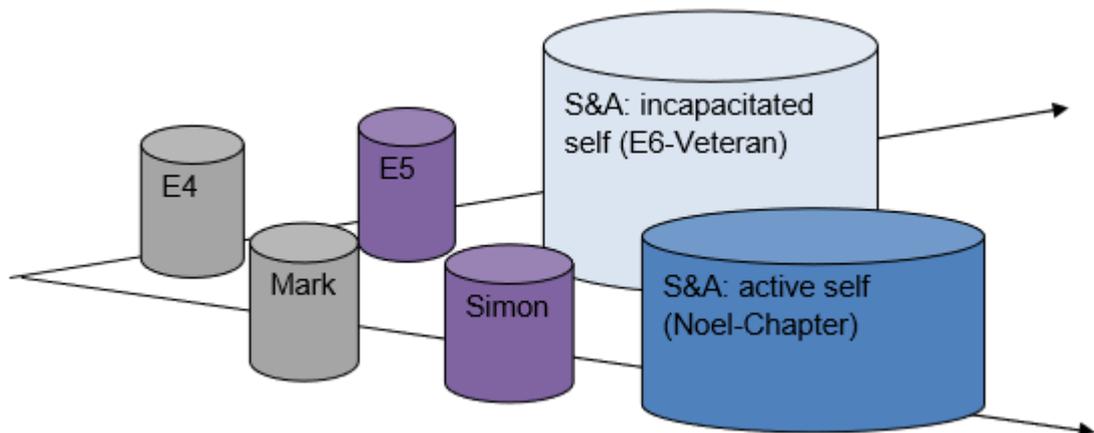


Figure 18: Variations in Surpassing & Assessing

#### **8.3.6.4 What lies beyond Surpassing and Assessing?**

Although E6 and Noel express their ongoing thinking about cancer, including the potential for it to recur, their metaphors mainly create a handle on the relatively recent view that they are no longer a cancer patient.

The remaining participants in this study are all more than three years post treatment and have developed a clearer sense that the cancer they had is in the past. This is incorporated in their comprehendings. Being free of cancer of course comes with different levels of certainty, depending on a range of factors. In the following sections participants have been clustered according to whether they comprehend cancer as 'absolutely gone and leaving little impact', 'gone but reliving it from time to time' or 'gone but incorporated in their outlook on life'. The corresponding self enactments have respectively been labelled as 'ending', 'registering' and 'holding'.

*The metaphors structured according to the last three enactions focus on a longer-term future. In that sense they are different from the earlier metaphors which focused on the present and near future.*

*The last metaphor also incorporated the near past. The next metaphors convey a time perspective that encompasses present, future and past.*

### **8.3.7 Enaction 7: Ending**

In this section the comprehendings of participants who consider cancer to be gone forever will be explored. To express what this entails for the experience of self in relation to cancer the term 'ending' (E) has been chosen. This term captures that it is about closure of a previous process of engaging with potentially present cancer.

This seventh enaction structures the metaphorical comprehendings of two research participants, Boris and Tony. How their comprehending of 'ending' varies will be explored below. They are respectively in their fourth and eighth year post cancer treatment. Boris called cancer 'A big aeroplane that has flown off forever' and Tony says 'It is gone and successfully done'. The shorthand used for these metaphors is 'Flown off' and 'Done'.

The summaries of Boris's and Tony's research data are included in appxs. F12 and F13.

### 8.3.7.1 A big aeroplane that has flown off forever (Boris)

In the 'Flown off' metaphor the ending with cancer is comprehended in spatial terms, i.e. cancer and self are not in the same space, and this is qualified as permanent by adding 'forever'. Boris uses some additional metaphors that are in sync with and further refine the spatial comprehending of the 'Flown off' metaphor. By **positioning** cancer "out of the room" he repeats that it is **no longer in his space**. He goes on describing it as "in the bin" which also communicates that this new or none position of cancer is **permanent**. By comparing it to "the little knot that is gone in a piece of wood" he communicates a sense of cancer being **nowhere**.

More than the 'flown off' metaphor, the last metaphor conveys a comprehending of how cancer can end permanently. By choosing the image of a knot in wood that has fallen out, cancer seems to be comprehended as organic material that has come to be shut off from its food supply and through this becomes inanimate and **disconnected** from its surrounding body of wood.

Where the 'big aeroplane' in the 'Flown off' metaphor suggests a change that has **happened outside his actions** (PM 'External events are Large moving objects'), Boris also talks about "having escaped cancer" and having "crunched it up". Especially the latter expression gives away that his sense of disengagement is to be qualified as negative and emotionally driven. His statement that he will "**never be at peace** with cancer" confirms this.

His emotional stance is further revealed in the exercise with the sheet of paper, where Boris likens cancer to "a piece of paper that is as big as this with nothing on it because the **fear it all had is gone**". This was the felt sense that emerged from the 'embodied enquiry' which I captured with the metaphor 'cancer turned out to be a blank bullet' (PP:Boris-EEQ-slide65). It also showed in the exercise with stones where it did not matter whether the cancer stone was put close to the present self stone or not.

Like all the other participants that will be discussed later, Boris reflects on the impact of **cancer reminders**. Treatment of side-effects or scans “do not bring cancer back into the room” and once done he is “back off again”. In other words the experience is one of practical inconvenience rather than emotional. Boris experiences other people reminding him of cancer as annoying as it causes “awareness of cancer to circle around me”. Something he deals with by “shutting off from others’ negativity”.

The impact of having gone through the experience on his stance in life and experience of self echoes the experience of Noel. At the core is an experience of **vulnerability**: “I do think you realise with cancer, I never felt before, how vulnerable you are”. He considers himself “**lucky**”. Boris expresses a strong **appreciation for the medical** people. He symbolically suggests his consultant’s greatness by saying he should have his “picture on the wall with a crown”. He engages in activities to **help other patients**. This ability to empathise he feels means that **cancer has made him a better person**.

#### **8.3.7.2 Gone and successfully done (Tony)**

The fuller metaphor was “it is a phase of my life that is gone and successfully done” what even more emphasises that **cancer is in the past** and subsequently cancer and self are, like in the ‘Flown off’ metaphor, in separate spaces.

Tony also conceptualises the ending of cancer as I have “wrapped it up”. Together with “successfully done” this draws attention to the fact that in this case the process of ending is a **result of successful action**. This may suggest a more mechanical outlook in which treatment is comprehended **as a process of deactivating cancer**.

The metaphor 'Done' conveys a calm and measured stance. The depth of this stance emerges even more when Tony expresses that he is “**at peace with cancer**”. It is now a topic of conversation he is willing to engage with if it helps people. This relaxed attitude to cancer shows when the sheet of paper is calmly folded and put in his lap. In contrast to Boris, Tony had never felt fear of his cancer.

In line with the lack of fear, Tony does not speak of an increased sense of vulnerability. He **never felt out of control** because from the start he “delegated” what needed to be done to a medical team that he completely trusted. From the start Tony approached the cancer experience with an academic and technical interest. This was also expressed in the moderate stone he chose to present cancer in contrast to other participants (see appx.E2). When the painter suggested expressing this with writing on a blackboard (PP:Tony-C-slide69) it deepened an understanding of the depth of difference with previous participants. His experience of cancer is not lived anymore but is fully understood. This parallels the metaphor of a ‘cancer portfolio’ that emerged during the embodied enquiry (PP:Tony-EEQ-slide70).

### ***8.3.7.3 Ordering from a developmental perspective: Flown off / Done***

The ‘Flown off’ and ‘Done’ metaphor respectively conceptualise the ending of the relationship between self and cancer as a disconnecting and as a deactivating, conveying a different perception of the nature of cancer activity. Tony’s perception is more abstract and rational and shows no emotion while Boris’ view and behaviour is more emotionally, specifically aggressively (see appx.E5), driven. Considering that Boris has not reached five years post-treatment while Tony is in his eighth year (see extract taken from Table 7), one could imagine that Boris will develop a more abstract stance over time. Although, neither needed chemo or radiotherapy, but Boris, unlike Tony,

	Time post diagnosis	Time post treatment
Boris-Flown off	3y10m	3y7m
Tony-Done	7y7m	7y4m

lived with a temporary stoma and experienced more fear at the time of diagnosis. Age may also play a role with Tony being 89 years of age and Boris twenty years younger. These

factors could permanently influence the difference in how living without cancer is comprehended. This has been expressed below (Figure 19) by representing the emotional tone of their comprehending as intense (Boris) versus more neutral (Tony).

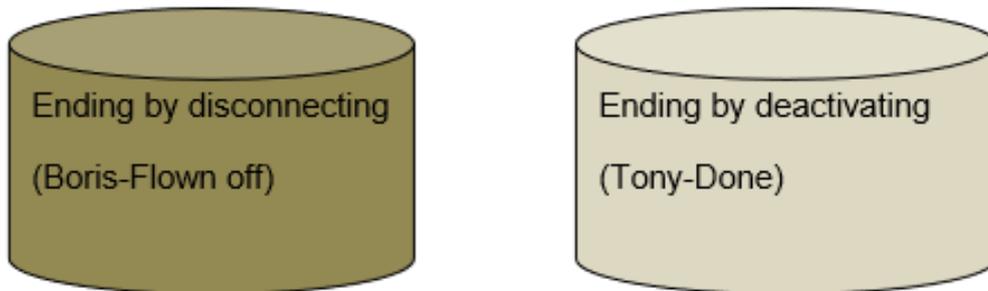


Figure 19: Variations in Ending

#### **8.3.7.4 Is there an alternative for Ending?**

In the metaphorical comprehendings of Boris and Tony there is no consideration of any re-visiting or re-living of a potential recurring of cancer. This is different for the participants whose comprehendings will be explored in the next session.

### 8.3.8 Enaction 8: Registering

The term 'registering' has been chosen to describe how participants in this cluster comprehend their awareness of potential cancer in their life and how they comprehend the way they react when this happens. Although in general they consider the way they have known cancer to be gone, the experience of side-effects, other people's experiences, unknown bodily reactions, in contrast to the participants who were explored in enaction 7, alarm them, to different degrees, of a potential recurring of cancer.

This eighth enaction structures the metaphorical comprehending of two research participants, Dan and Jack, and the seventh metaphor provided by the research participant E.

E7 comprehended a possible return of cancer just over three years post treatment with the metaphor: 'Like in a horror movie something in the basement tries to drag me down but I kick and fight and run towards the light'. Jack was almost six years post treatment when he likened the awareness of potential cancer after treatment to 'Like when a broken leg is fixed, it leaves an ache which is in my awareness 25 % of the time' and Dan, about twelve years post treatment, spoke of reminders of cancer as 'Occasionally, 5 % of the time, the bad days come back from the past'. Jack's metaphor will be discussed first and is shortened as 'Ache', Dan's second and referred to as 'Bad days' and E7's last and called 'Horror'.

Jack's and Dan's research data are summarised in appxs. F14 and F15. The case study data in relation to the Horror metaphor are included in appx.F16.

### **8.3.8.1 Like when a broken leg is fixed, it leaves an ache which is in my awareness 25 % of the time (Jack)**

Jack feels that his bowel cancer has been dealt with and expresses this with the metaphor: “hearing the diagnosis was like the table cracking... but now the table is smooth again... the French polishers have been in”. This now unseen cancer he **positions** “in a drawer... pushed away.” In other words, it is **contained** and **controlled by force**. Yet the picture is more nuanced. Thinking of the PMs ‘Accessible to awareness is Out’ and ‘Remembering is Retrieval’ it comes to the fore that what is in a drawer can always be taken out and brought to awareness again, or as Jack says himself “... it is **not to be forgotten**.”

When **cancer that is still present** in his life is conceptualised with the ‘ache’ metaphor, a broader picture emerges. Saying that it is there 25 % of the time is based in the PM ‘Quantity is Size’. The tone in which Jack speaks about this, conveys that 25 % for him means that its presence is **limited** and therefore implies that it is not that important (PM ‘Importance is Size’). Another metaphor, “it is a bit like with an annoying boss, but without being able to change jobs”, expresses that it is **always in the background** and confirms the ‘ache’ metaphor. The exploration with the sheet of paper revealed that its presence is also experienced as **variable**: “usually like a small corner of the sheet but when e.g. stoma is playing up it unfolds to half a page”. In **future**, Jack does not **express an expectation of cancer becoming less** in his awareness. He wonders whether he “is liable to get cancer” as close relatives died from cancer and he was diagnosed with a second cancer three years ago.

Jack describes his response as “I **put up with it**” and “get on with life”. In other words it may affect but does not stop his **movement**, as is also implied in the metaphor “the broken leg is fixed”.

Jack expresses very little emotion. Although he feels “victimized”, and in that sense expresses **vulnerability**, he accepts it as “one of them things that happened”. This rather submissive stance in the presence of a constant and forever ache or annoyance, resulted in a painting with rather subdued colouring which presents cancer more as an atmosphere than an event (PP:Jack-T-slide81). This approach to life also surfaced in my embodied enquiry and left an impression of a life focused on ‘essentials’ (PP:Jack-EEQ-slide84). Jack is adamant that “**cancer has not changed him**”, which suggests that his essentialist approach was part of his personality before his experience with cancer.

### ***8.3.8.2 Occasionally, 5 % of the time, the bad days come back from the past (Dan)***

Complementary to the 5% metaphor, Dan says: “95 % of the time cancer doesn’t register anymore”. This is repeated when cancer in relation to his life is positioned on the edge of the sheet of paper. As the PM ‘Importance is Central’ suggests, it is life without cancer that is now important.

The limited **presence of cancer** is conceptualised with the “5% of the time” and ‘the edge of the sheet’ but also by choosing a small stone to represent cancer. The presence of cancer was further qualified with reference to the “ragged edge” of the sheet, expressing both its ‘**badness**’ and the variety (“**not uniform**”) of the shape its takes. Dan refers to the impact of scans or other people dying. In the same vein the cancer stone was small but “not perfect”. To express how cancer comes into awareness, it is likened to “a disease that comes back in a mild fashion once you’ve had it”. As Dan puts it “it comes **from the past**”. This implies that cancer is not constantly there but comes and goes. This also speaks from the use of the term “occasionally” in the title metaphor. This sense emerged during the embodied enquiry which made me wonder whether it was like ‘a roaring plane flying over’ (PP:Dan-EQQ-slide79). The mildness expressed in the returning disease metaphor, is

also expressed with reference to a noise metaphor: Dan's overall metaphor for the intrusiveness of cancer is "an intrusive sound that can't be turned off... which makes that you can't hear or see other things". At this stage when cancer presents, the noise returns but "it has **quieted down**". Despite these metaphors Dan also emphasises that when it is there "it **can be very, very vivid** ... it is not just a memory, it's alive". This sense of realness, Dan manages nowadays because "things kick in to make you **cope with it**". Dan seems to live from two places, one without and one with cancer. This understanding unfolded during the painting and resulted in adding a smaller cancer self that pops up and deals with cancer when needed (PP:Dan-T-slide76). Dan has never been one to look into **the future** and cancer has not changed that.

By being explicit about the badness of cancer Dan does not shy away from expressing a sense of **vulnerability** in the present. At the time of diagnosis another illness was noticed and could be treated. Dan considers this as a '**silver lining**' of cancer. He is very **appreciative of the medical** care he received and feels cancer has made him **a better person**. He marked his 10 years post-diagnosis with a charity event.

### ***8.3.8.3 Like in a horror movie something in the basement tries to drag me down but I kick and fight and run towards the light (E7)***

In contrast to E's previous conceptualisings which were based in an imagined goodwill between cancer and self (Theatre play, Adopting, Veteran), in the above metaphor cancer is conceptualised as a horrific experience. The return of a comprehending that speaks of cancer as a threat, emerged from a surprise message that a peer survivor, diagnosed about the same time as himself, was re-diagnosed. The metaphor was introduced with "it is as if I have been living in the brightness of a well-lit room, a comfortable home" because "I looked at five years as a place of safety but now wonder whether the chances of recurrence increase coming nearer to five years". That this

has dawned on him is expressed with “Do I hear something in the basement”. The deep challenge of his previous view on the one hand shows in the **vividness** of the metaphor, on the other hand by framing it as a movie it is made **less real**.

The imagery of ‘being dragged down’ into a ‘dark basement’ is also reflected in E7’s comment that “he felt thrown back to the time I was preparing for death”. The images speak of progress undone, loss of control, harm and not knowing. This first response is followed though with a purposeful and forceful action (“kick and fight”) aiming to return to understanding and safety (“to the lights”).

The image of the basement also reveals that potential cancer was comprehended as in a contained separate place but within one’s personal environment, or, as E7 puts it, “panic yet resting in something I suspected was there all the time”.

#### **8.3.8.4 Ordering from a developmental perspective: Horror – Bad days / Ache**

Both E7 and Dan describe thoughts of cancer potentially recurring as abrupt events that trigger panic. E7 describes it as a sudden first experience, while Dan already knows the phenomenon and posits it rather as an intermittent experience. That Dan’s panic is more controlled is likely due to him living

	Time post diagnosis	Time post treatment
E7-Horror	3y8m	3y2m
Jack-Ache	6y8m	6y6m
Dan-Bad days	12y3m	11y6

with it eight years longer than E7 (extract taken from Table 7). This time difference may also explain why for E7 it takes him back to the past while Dan experiences it as the past coming into the present.

Jack's experience differs from E7 and Dan, as it is "always in the background" (and coming into full awareness for 25 % of the time) and triggers annoyance rather than panic (see appx.E5). These differences are not unimportant. As Jack, in contrast to E7, has moved beyond the five year time post-diagnosis, it seems more relevant to explore in more depth the difference with Dan. Referring to their own metaphors: is it meaningful that Jack captures his awareness of cancer as being there for 25 % of the time versus Dan for 5 %? I suggest it is; more specifically, I believe it refers to their different medical situation which could be described as Dan is 'living beyond cancer' while Jack, inhabits a place between 'living beyond cancer' and 'living with cancer' (see Figure 41 in appx.G3). In vignette B (see appx.G0) a more detailed comparison is made based on an exploration of the dynamics between their self and the affordances of their medical context.

What joins the comprehendings is that their registering of cancer seems to be expressed with sound metaphors: hearing something in the basement (E7), hearing a table cracking (Jack), hearing an intrusive sound (Dan).

As expressed below (Figure 20), their differences have partially to do with time elapsed since diagnosis but the difference between Dan and Jack also has some essence. Depending on how E's medical situation develops he may be more likely to evolve in the direction of Jack or Dan, or yet another variation may develop.

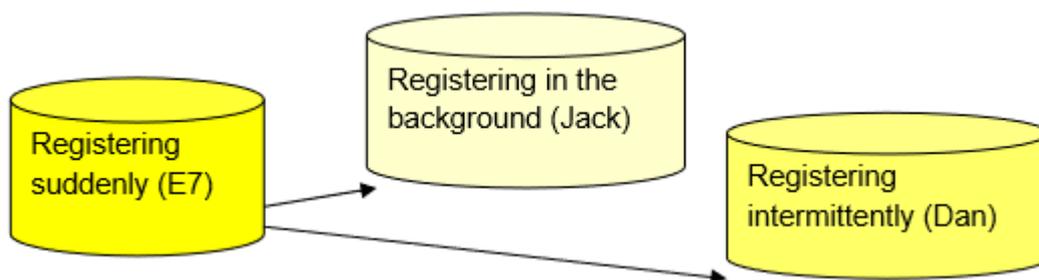


Figure 20: Variations in Registering

### **8.3.8.5 *What lies beyond Registering?***

In the Registering cluster of metaphors the co-existence of cancer-free being and coping with potential cancer return, has been comprehended as an experience of being in two places. This begs the question whether it is possible to comprehend being engaged and not engaged with cancer from the same place. What this entails shows in the metaphorical comprehendings explored in the next session.

### **8.3.9 Enaction 9: Holding**

In this last section two metaphorical comprehendings that locate cancer within the self will be explored. The term 'holding' (H) was chosen as it expresses a stance that is not afraid of touching on cancer, as well an ability to stay with it.

This ninth enaction structures the metaphorical comprehending of the research participant Wendy who is twenty years post-treatment and the eighth metaphor of the case study participant E8 at four years.

The metaphorical expressions used by Wendy to comprehend cancer are brought together as, 'Cancer is tucked away, safe in the deep dark recesses of my mind but grounds me in the reality that we are not eternal'. E8 presents his relationship to cancer as 'Holding a sculpture of me as a healed being in a womb-like structure with dormant cancer invisibly arranged inside or around my body and connected to others as they connect to me.'

These metaphorical comprehendings will be shortened as 'Grounded' (Wendy) and 'Healed' (E8).

A summary of Wendy's research data is enclosed in appx.F17 and the case study data on the 'Healed' metaphor are in appx.F18.

**8.3.9.1 Cancer is tucked away, safe in the deep dark recesses of my mind but grounds me in the reality that we are not eternal  
(Wendy)**

Considering the PM 'Accessible to awareness is Up', 'in the deep recesses of my mind' expresses the opposite and communicates that nowadays cancer is **not often in Wendy's awareness**. This is also expressed with the sheet of paper that "cannot be folded small enough" to represent the little time she spends thinking of cancer. This is linked with a sense of cancer being "tucked away, safe" which implies cancer is conceptualised as **not moving and not threatening**.

Yet the recesses are also "dark". With reference to PMs like 'Knowing is Seeing' and 'Bad is Dark' I suggest that an element of uncertainty is nevertheless embedded in the metaphor. This resonates with Wendy pointing out that "it **never goes away completely**", a statement that she repeats with verve at the very end of the research session.

Wendy projects her experience of cancer onto a little notebook with addresses of peer cancer patients from the time of treatment. Wondering whether she will take it with her when she moves house, she says "I'll probably give it a very serious look and I'll probably move it with me... You have to have realistic expectations, that's maybe why I keep that, to ground me, to bring me back to reality." Wendy expands on this existential reflection with "it's a **reminder that we're not eternal**... we are not here for infinity but life is infinite." It is in this spiritual awareness of mortality that the shell she chooses to represent herself is big and spiral shaped.

Rather than cancer being something that needs to be dealt with, it rather seems to define her identity and outlook on life. The PM 'Degree to which an attribute defines an entity is Depth' invites the interpretation that the use of the expression "deep recesses of her mind" gives away that what is there, i.e. the memory of cancer, **defines her being**. This resonates with Wendy's

reflection that it is hard to let go of something that represents the experience of cancer, because “that’s such a personal thing”.

On a more practical note, the impact of the occasional physical reminder, e.g. a tummy upset, is described as “you think, oh, is it starting again, but nothing that worries me seriously.” They are experienced as “warning signs not to take life for granted” but do not impact on her sense of **future**. Wendy’s viewpoint is that “**cancer is inherent within us**”.

### ***8.3.9.2 Holding a sculpture of me as healed in a womb-like structure with dormant cancer invisibly arranged inside or around my body and connected to others as they connect to me (E8)***

Where the existential dimension of the ‘Grounded’ metaphor evolved around ‘mortality’, E8’s ‘Healed’ metaphor focuses on ‘holism’. This metaphor comes in three layers: it is a sculpture, it has a form and it expresses meaning.

Comprehending the experience of self and cancer as a ‘sculpture’ communicates that **self and cancer are considered as together**, as one. This is a first expression of a sense of restored wholeness. E8 also points out that the sculpture is small enough to be held. The multiple selves PM ‘Subject as parent of the Self as child’ seems to be at work here especially as the imagined sculpture is womb-like (see PP:E8-T-slide86). This is in line with E’s earlier metaphor ‘Adopting’, in which living with the thought of cancer was likened to having a child. A sculpture is an object and this is the first time that cancer and cancer-self are ‘objectified’ by E. The PMs ‘Understanding is Seeing’, ‘Understanding is Grasping’ and ‘Thinking is Object manipulation’ are all applicable and suggests that this metaphor expresses perhaps not only an ongoing aim to understand cancer but also the realisation of a **comprehensive and deep understanding**.

In imagining the form of the sculpture E8 describes the self as being surrounded by a gold rugged changeable lining that represents cancer. Despite cancer being 'objectified' as a sculpture, by presenting it as 'rugged' and 'changeable', E8 expresses that cancer is experienced as having the **potential to recur**. Presenting it in 'gold' may express a sense of preciousness. Cancer is not recognizable as cancer by other people who look at the sculpture while he "knows it without looking". This goes back to a previously expressed **understanding of cancer that is personal and sensed**. In the sculpture other people are linked with E and with each other by being part of one lymphatic system. This does not only communicate a sense of support but it also positions the **possibility of cancer in everybody's life** (based on the thought that traces of cancer may live in the lymphatic system).

Representing self and cancer as a sculpture of birth, suggests that E8 is expressing and experiencing change or hope for change of self and continuation of life. This speaks of a sense of **future**.

### ***8.3.9.3 Developmental order: Healed - Grounded***

E8 and Wendy's metaphors express an engagement with the thought of cancer without fear. Moreover the acknowledgment of it being such a personal experience leaves an impression of a sense of 'awe' (see appx.E5).

Both comprehendings express a philosophical outlook. The intimate connection between self and cancer is not comprehended within illness but is used as an existential touchstone for wholeness and mortality. They think of cancer as a dormant presence within their self and within every person. This thought creates a connection with anybody who has not been diagnosed with cancer. Cancer becomes part of the human condition rather than an illness, a signifier for the vulnerability of life and mortality which is also what makes life valuable.

In a metaphorical way they also position cancer inside their self. Wendy positions it in her mind and engages with cancer mindfully, while E8's imagery is bodily (Figure 21). This conjures up the feel that E8's experiencing is more

	Time post-diagnosis	Time post-treatment
E8-Healed	4y7m	4y1m
Wendy-Grounded	20y3m	19y6m

tangible than Wendy's. This makes sense when taking into account the difference in time post-diagnosis (see extract taken from Table 7). The contrast between cancer being positioned in the 'recesses' of Wendy's mind while it forms the lining of E8's embryonic self, sheds further light on the difference in

experience between two very different stages of survivorship despite their shared philosophical approach. As the longest surviving participant (20 years), in the shell and stones exercise, Wendy presented cancer as less harmful than anybody else (see appx.E2).

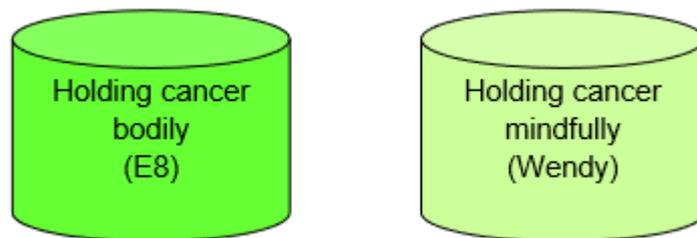


Figure 21: Variations in Holding

#### 8.3.9.4 What lies beyond 'holding'?

The body schematic closeness between self and cancer expressed in the 'holding' metaphors is closer than in any other metaphors. In the next section I explore these comprehendings of self vis-à-vis cancer in more detail and why this is relevant. I explore whether any closer relationship is imaginable and if so, viable as a conceptualising of survivorship.

### 8.3.10 Boundaries of viable comprehendings of self in cancer survivorship

As will be further discussed in 8.4.3 some survivors in this study comprehend their self in terms of closeness, and others in terms of distance vis-à-vis cancer. The most *distant* stance was expressed in the comprehendings of Boris and Tony. The degree of distance was definite and defined as an enaction of 'ending'. The most *close* stance has been expressed in the Healed and Grounded metaphor with images of cancer being inside self. Yet in these metaphors two slightly different images of closeness are presented.

First, in body schematic terms cancer is positioned inside the body (E8) or inside the mind (Wendy), but within that space cancer is presented as an entity. Cancer is spatially located: as a lining around the body-self (E8) and as something in the deep recesses of the mind (Wendy). Although both, E8 and Wendy, present a reflective rather than an 'action' self vis-à-vis cancer, by locating cancer in a specific place it leaves open the option to act upon it (through movement or force) if needed. The first question I entertain below is: although none of the metaphors of the participants in this study show a self that intertwines with cancer, could this be a viable way of comprehending self in cancer survivorship? In other words, where the 'ending' metaphors conjured up a feeling that no further distance could be imagined, the body schematic structure of the 'holding' metaphors does trigger the question whether even more spatial and kinaesthetic closeness is imaginable.

The second image of closeness between self and cancer in the Healed and Grounded metaphor comes from E8 and Wendy explicitly expressing a viewpoint that cancer is a dormant presence, not only in their body but in every person. One could argue that this image expresses a higher degree of closeness than the above, yet it somehow also is of a different order, i.e. it seems to make the idea of a kinaesthetic action-self superfluous. The second question I will explore below is: what makes this image viable for a cancer survivor?

As pointed out in the theoretical discussion of the third research objective (4.2.3), my motivation to explore these two questions is because I believe that understanding the boundaries of how an experience can be comprehended is easily overlooked but can deepen the understanding of that experience.

As a start of the exploration of the first question, it may be useful to look back at how closeness between self and cancer has been comprehended. Cancer was imagined in the vicinity of self but as time since diagnosis increased, the presentation of the type of connection changed from physical (Fog, Hulk) to action (Flow with, Theatre play) to cognitive (Unknowable) to relational (Adopting) and in the Healed and Grounded metaphor becomes philosophical and internalised.

As pointed out above E8 and Wendy express the psychological internalisation of cancer with a body schematically positioning of cancer inside their self, yet the two also remain distinguishable. This would be different if expressions were used like 'swallowing, absorbing or digesting' cancer. In other contexts metaphors with such body schematic structures are used to express states of mind, e.g. "it took me ages to digest or absorb that I was never going to walk again". States of mind such as searching for acceptance, understanding or coming to terms, are all prominent issues in living after cancer, yet none of the research participants, even those who take ownership of cancer, express this in terms of e.g. "having absorbed or digested cancer". Such imagery, e.g. swallowing cancer would entail a deliberate action of putting into the body and of bodily receiving something that is life threatening. It would also conjure up an image of cancer as broken down in the body and ceasing to be something separate from the self. Such an action also leaves a person defenceless against the effects. The responses of a digestive system do not match the autonomy and control expressed in the body schematic structure of the metaphors explored in this study.

Most participants expressed strong awareness that they have no control over the physical recurrence of cancer but that their focus is on controlling the way

they think about cancer, in other words on imagining a self and strengthening a sense of self that feels in control. Conceptualising a self that deliberately acts in a way that scatters cancer throughout the body and outside their control, as described in the above thought experiment, goes against this need for self-control. From this I think it is reasonable to conclude that a metaphorical comprehending that is structured according to such a body schematic structure is not viable for the cancer surviving self.

Looking at the way cancer patients with active disease comprehend their self vis-à-vis cancer, complements this conclusion. Borrowing some examples from Semino et al.'s (2017, p.62) research, cancer patients who live with active disease, or who feel unsure about the stability of their remission, do envisage (the risk of) cancer inside their body as a scattered spatial experience, e.g. as 'attacking from the inside' and 'invading the body' or 'living with a time bomb'. However these patients do not comprehend their self as active in this process. The force exerted by cancer is overriding their force. These metaphors are expressions of helplessness, in contrast to expressions of surviving which evolve far more around degrees of agency and control (over cancer).

The second question, what makes it viable for cancer survivors (at least in this study) to actively entertain the idea of cancer being inherent to their and every person's body?

Comprehending is structured in spatial and kinaesthetic terms. The less fear cancer induces the less participants needed to imagine their self as physically (bodily force) acting against or towards cancer. Certainly E8 and Wendy do not feel any need to express their relationship with cancer in such a way. Yet, they do not press the idea that cancer will not return either (in contrast to Tony and Boris). On the contrary, it is part of their philosophical outlook that this cannot be excluded and needs to be kept in mind. Entertaining this existential outlook may mean that some source of control needs to be envisaged. By seeing cancer as inherent to the body, E8 and Wendy

spatially locate cancer, not only physically but also psychologically, in the bio-chemical dimension of self. Yet, there is a second element embedded in their metaphorical thinking that is not spoken, i.e. that it is also inherent to the body to be able to fight rogue cells, to fight for survival. In other words it seems as if the need to comprehend safety and control is constructed in terms of bio-chemical functioning rather than body schematic functioning. It should perhaps not come as a surprise that a self ultimately envisages survivorship by drawing on the bio-chemical immune system as it is the most basic mechanism that protects life and self. Or as Applewhite (1991, p.160) puts it:

“The immune system is the biological source for a claim to selfness. It is the physiological vessel of identity.”

Perhaps cancer survivors come to a point where they yearn to think safety from cancer in a way that does not demand an imagery of self that is acting, moving or monitoring. In other words, I believe that for cancer survivors, the viability of imagining cancer as inherent to the body lies in it being a comprehending of cancer as being controlled while it allows the self to be more relaxed.

The fighting and battle metaphor is very prominent with cancer and has been criticized for not always being helpful. This is often the case when cancer becomes a terminal illness. It may be important to keep in mind that cancer survivors in their choice of metaphors may vary between aggressive and non-aggressive metaphors but either way their choice serves a purpose and based on the above reflections, I suggest that it is very likely that the fight for survival and control of cancer will be structurally possible within any chosen metaphorical comprehending. These choices emerge from non-conscious and conscious processes. Therefore, as also Semino et al. (2015) point out, health care practitioners should be cautious in their evaluation of the usefulness of survivors' metaphors, and focus on jointly exploring their meaning (see also 8.5.3).

In conclusion, the body schematic structures that were pointed out as not-viable within a specific cluster turned out to be temporarily not viable but became viable at later stages. From the last exploration, I conclude that as long as people engage with the thought that cancer might return, some form of protective activity against cancer will be embedded in the metaphorical comprehending of self vis-à-vis cancer, and imagery that suggests uncontrollable, scattered cancer will be avoided.

Moreover, I would like to point out that even when survivors cope with cancer by taking an engaging and open stance, the underlying non-conscious biological drive for survival is watching and metaphorical structures and imagery that suggest uncontrollable cancer will be evaded. In chapter 2 it was discussed how conceptualising and self are enabled and shaped by the multiple dimensions of human embodiment and how all these layers mutually influence each other. This above exploration may be an illustration of how the bio-chemical drive for survival can influence which neurological body-schematic structures are used, or better, cannot be used, in comprehending a situation.

## **8.4 Discerning the overall process**

### **8.4.1 Metaphorical outlook**

The above descriptions focused on the research and case study participants' momentary experiencings. But, in this thesis the framework is one of process and change. This originated from the initial exploration of the first five metaphors in the case study. At the time I suggested the following metaphorical comprehending of the process of survivorship up to two years post-treatment (see appx.A0):

Surviving cancer is like **long-distance running on a track**.

Runners first take their position in the starting block (*E positioned body-self in relation to cancer and clinicians in Fog and Terrorist metaphor*), then run blindly within their lane (*E moves guided by the clinician's script in Theatre play metaphor*), then assess their own and others' performances and potential and try to take first position (*E acts away from script in Unknowable metaphor*) and then acknowledge that they need to take control over this vivid, small runner who seems to stay in their trail (*E accepts that cancer is staying and is better owned and directed in Adopting metaphor*).

The exploration of the body schematic structure of all the case study metaphors in combination with twelve metaphors from research participants still generated a spontaneous understanding of the process in terms of a path. But, by exploring experiences of different people and over a longer time post-treatment, the metaphorical understanding of the overall survivorship process spontaneously altered from 'running on a track' to '**walking on a path with stepping stones and forks**' (see Figures in previous section).

In the second phase of my explorations my attention needed to move from the parts to the whole and this brought a new image to the fore. Below, as part of section 8.4.2.2 the above findings are presented in the shape of a **tree** (Figure 23). Exploring a totality of data creates a need for a presentation that practically and metaphorically generates a sense of overview. A single 'object' serves that purpose better than an image of a path with steps and forks. The tree metaphor also resonates with the research objective to understand the participants' comprehendings from a developmental perspective.

## **8.4.2 Developmental outlook**

### ***8.4.2.1 From presenting to holding***

I want to reiterate that taking a developmental outlook is an interpretive lens that was chosen (objective 5) based on a theoretical appreciation of teleological and accumulative embodied dynamics and therefore feels logical and real to me, but proving or arguing that it is, is not the aim of this thesis. The aim of using this lens was to understand the emerging subjective variations as enabled and shaped by sub-personal processes.

The chart below (Figure 22) shows how time post-treatment relates to the body schematic structure of the metaphors for the participants in this study. Note that up to about six months post-treatment Presenting & Positioning was the dominant enaction. The comprehendings of participants who are in the second half of the second year post-treatment might be structured as Handling & Rising, Moving in Space or Express Viewpoint on Future. The comprehendings of participants who had gone beyond the second anniversary of finishing treatment were structured as Moving Forward and Surpassing & Assessing. From three year onwards (in the chart '7' stands for minimum '7') it would be one of the three longer-term enactions: ending, registering or holding. I want to suggest that survivors in the first year, and certainly in the first half year post-treatment, are unlikely to comprehend their self vis-à-vis cancer in terms of action or movement. Although the time passed does not really differentiate between Handling & Rising, Moving in Space, Expressing Viewpoint on Future and Surpassing & Assessing, I feel it is justified to consider a difference between survivors coming up to the second anniversary and those who have passed it. I make this judgement as I consider the Expressing Viewpoint on Future to be a turning point that makes a difference, which I discuss in more detail below. It is, based on the data, not possible to determine whether any of the longer term stances sets in before three years.

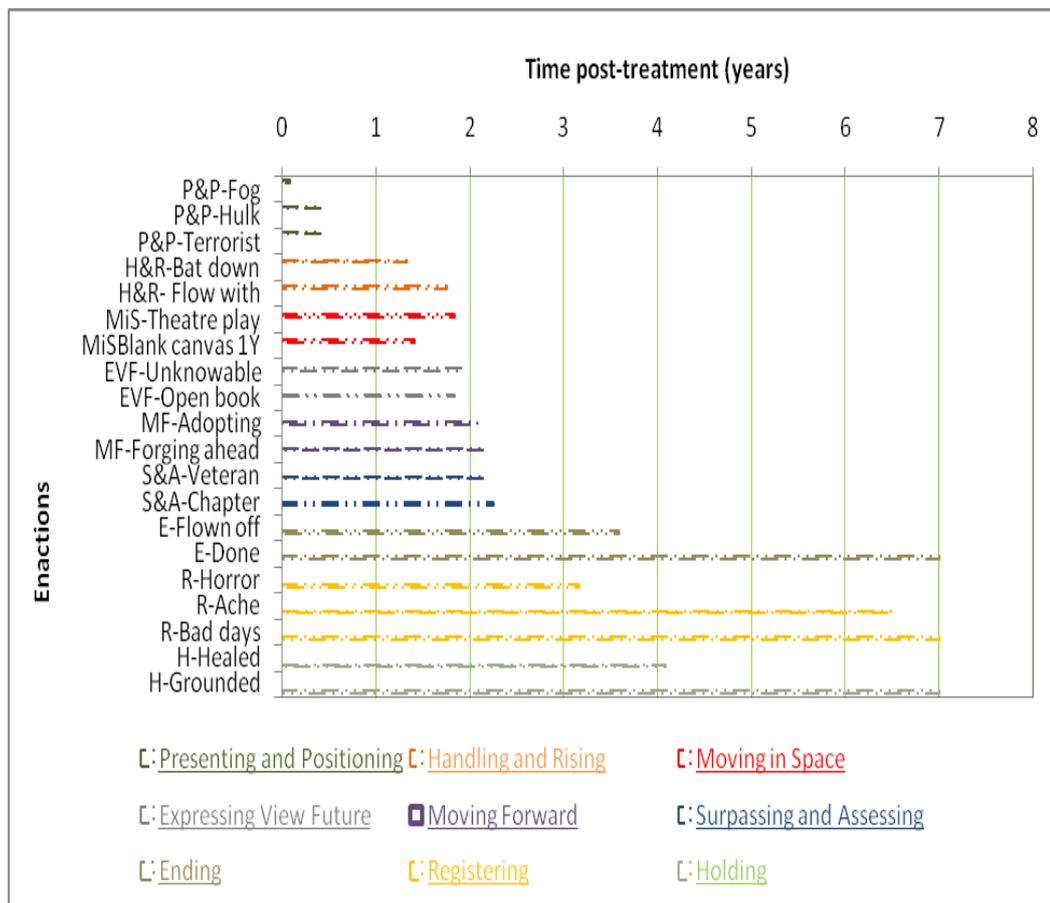


Figure 22: Body schematic structure of metaphors at different times post-treatment

In appx.G1 I split Figure 22 and reflect on the specific contributions of the case study participant versus the research participants.

Reading through the different enactions as ordered in the previous section no doubt resonates with what one knows as a bodily logic based in the way a child gradually develops their awareness and use of space and their motor skills. This stepwise increasing sophistication of the body schematic structures, I found, became more tangible after translating the description into a Tai Chi – like movement exercise. A description of these movements is

included in appx.G2. They may inform an exercise during workshops with health care practitioners or cancer survivors. This touches on the role of motion in cognition and will be revisited in the practice part.

Ordering the enactions of different participants according to a bodily logic does not generate answers to questions like: do all survivors steadily walk the path or climb the tree, or do they go backwards at times, do they enter at the same point and go the full distance? Although the case study sheds some light on this, to explore the process of self enaction in such detail another research approach would be needed.

#### **8.4.2.2 *From self to 'I' and beyond***

In this study the focus is on survivors who have no active disease and whose experience is often described as 'living beyond cancer' (1.1.1). Exploring the totality of enactions, resulted in the delineation of four cancer survivor selves that nuance the experience of 'living beyond cancer'. I call these cancer survivor selves: 'minimal cancer self', 'autobiographic cancer self', 'beyond cancer patient self' and 'beyond cancer self' (see Figure 23 on the next page and Figure 41 in appx.G3).

The enaction 'Expressing Viewpoint on Future' I considered above as reflecting one of the most prominent changes in self. It structures the metaphors 'Unknowable' and 'Open book' in which E4 and Mark envisaged cancer as needing less action on their side to create safety. This differed from the earlier enactions where the relationship with cancer was merely comprehended in actionable terms, e.g. kept in place through spatial boundaries (e.g. Terrorist), physical controlling (Bat down, Flow with) or imagining a cancer free zone (Theatre play, Blank canvas 1Y). Embedded in these action structures is a focus on the present, a sense of not or limited knowing of future cancer movements, a reflection on the effort it takes to

function autonomously consistently. In contrast, Mark and E4, at that point were focused on expressing their self as autonomous, capable of developing

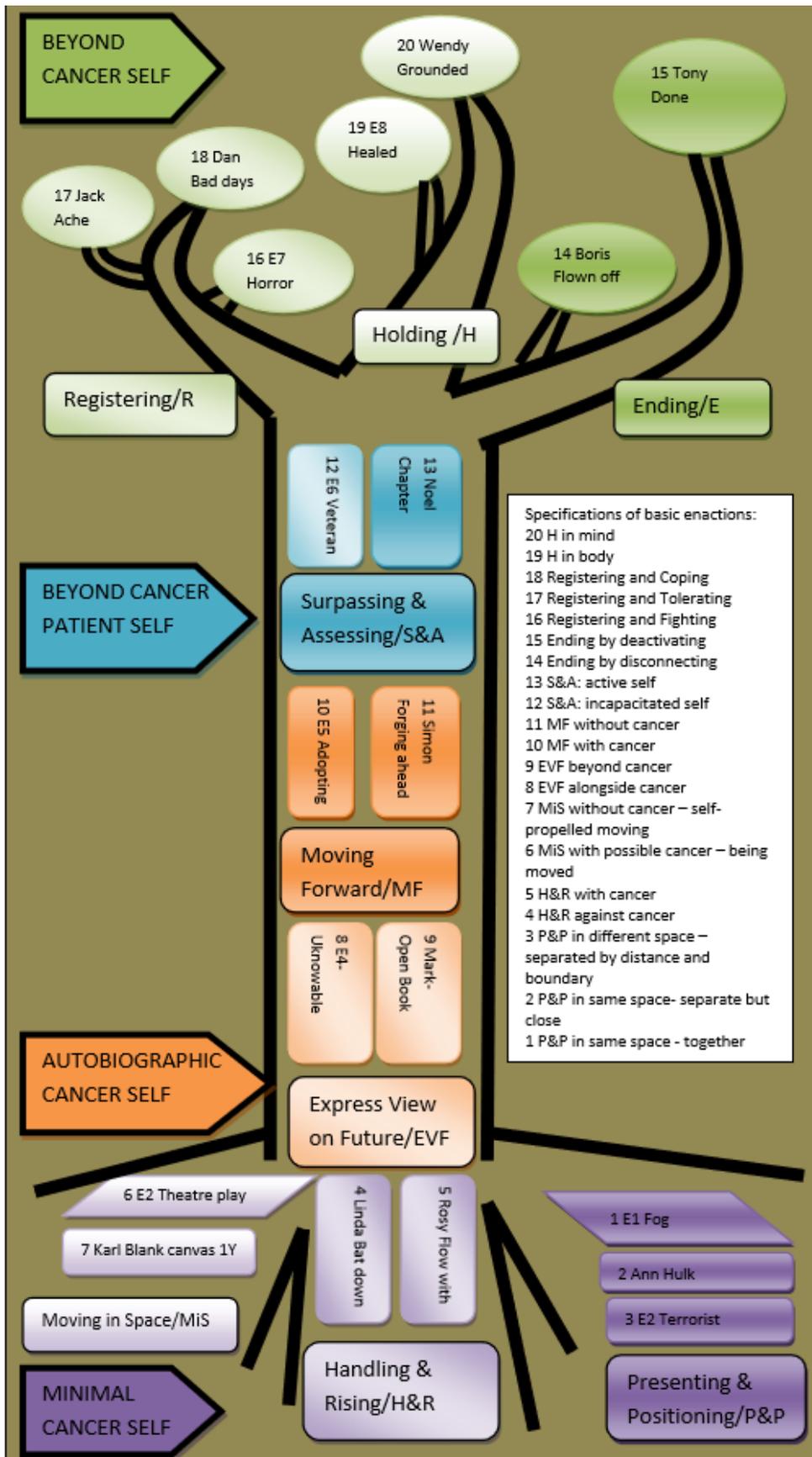


Figure 23: Overview nine enactions and four types of self

and keen to express a personal opinion about their cancer experience, future orientated and concerned with acting according to who they were or wanted to be. In other words their self vis-à-vis cancer presents as a fully fledged self, a self that resonates with how Gallagher and Damasio (see Chapter 2) describe the '*autobiographical or narrative self*', i.e. a self that says 'I', expresses a personal identity and sense of continuity and functions through conceptualising and talking.

The self vis-à-vis cancer comprehended with the earlier, action-orientated enactions resonates with the descriptions of the '*minimal self*', i.e. as basic, immediate and devoid of temporal extension. With this analysis I wish to highlight how these cancer survivors used their wider narrative, autonomous self to comprehend a self vis-à-vis cancer that for most, in response to the shock of diagnosis, starts off as a minimal self that gradually works its way up from the unified quality (see Johnson in Chapter 2) of the initial experiences, and drawing on bodily schemas of action, draws lines of control until free enough for the reflective self to surface, to say "I" and take the lead.

The comprehendings of self vis-à-vis cancer that have been described as enactions of 'surpassing and assessing' (Noel-Chapter and E6-Veteran) form a third turning point. A certain gap with what came before is expressed. I call this the establishment of the '*beyond cancer patient self*', which as later enactions illustrated, is not the same as a self that no longer relates to cancer. The message of being beyond patient-hood is likely to be instigated or confirmed by a medical consultant.

It is the comprehendings of Boris and Tony that were assessed in the previous section as a severing of the connection with cancer, not only physically but also mentally. At this fourth turning point one can speak of a '*beyond cancer self*'. In this study other long-term survivors have not taken that step. In the discussion of liminality below this will be further discussed in comparison with the 'holding' metaphors of Wendy and E8.

### **8.4.2.3 Variations**

So far I have discerned a development from a minimal to an autobiographical to a 'beyond cancer patienthood' and potentially to a 'beyond cancer' self vis-à-vis cancer, by ordering the metaphors according to a sub-personal body schematic logic. This does not take away that on top of these sub-personal dynamic, variations that were shared by several participants, or were entirely personal, were also noted. After briefly listing possible causes of variations, deducted from participants' circumstances, I will reflect on the variations that emerged.

The factors that were noted as possible explanations for individual differences in the clusters I hereby summarize as follows: impact of being of different age groups with their related issues (being young with young dependants, being elderly with co-morbidities), the impact of cancer-related issues (outspoken differences in severity of diagnosis, having a stoma or not, being at different times post-treatment and the potential role of symbolic meanings attached to 5 or 10 years) and differences in personality and/or spirituality. Only one cluster included a female and male participant. The different comprehendings there did not give the impression that they were gender related. During the second sampling it was decided to specifically recruit a survivor who only needed surgery but had been diagnosed less than a year ago (Ann). It was interesting to note that her comprehending was structured according to the basic 'presenting and positioning' schema. Although I recognize from other research (see literature review) that all these factors impact on cancer survivors' experience and thinking, these factors are not the focus of this study.

From listening to participants' other narratives a range of variations came to the fore. With a brief discussion of five of them I clarify the boundaries of this study and justify the focus on liminality in the next section.

To start I would like to point out that participants vary in their experience of change. Three types of change were noted. First, most survivors report a higher level of empathy or altruism instigated by their own experience of vulnerability and the support they have received. Secondly, some people reflect on changes in their psycho-spiritual being, e.g. living with a greater sense of purpose (Ann), more trusting (E), more independent (Linda). This has been widely researched under the label of Posttraumatic growth. Linda's experience has been explored from this angle in vignette C (see appx.G4). Thirdly, in this study many participants (e.g. Karl, Mark, Simon, Noel, Boris, Jack, Tony) emphasise that they have not changed despite the event. They have coped with cancer the way they cope with other things in life. This experience best resorts under the label of 'resilience' and has gained some attention in cancer survivorship research. Survivorship explored through the lens of PTG tends to frame this continuation of self as assimilation over accommodation and is discussed as contrary to growth. I wonder whether the focus that comes with a continuation of self in a new challenging context is appropriately acknowledged. Although this is not the focus of this study I wish to draw attention to this phenomenon with vignette D (see appx.G5) in which I describe Mark's resilient self as emerging from a wider self seeking expression in a transaction with his consultant. Participants' reflections on change and sameness will be further explored to gain a view on how the wider self is carried forward by the way the self vis-à-vis cancer is comprehended (see 8.4.4.1).

Another type of variation lies in the feelings interlinked with the comprehendings. It was not the aim of this study to explore the body schematic structure of, or dynamics involved in the occurring of specific feelings. In the theoretical framework (4.2.1) I briefly refer to work by Kovecses (2000) whose main point is that emotion is metaphorically captured by imagery of force. An example of this emerged in this study with Linda who is angry and 'bats down' the cancer. At other times emotion influenced the comprehending in a more unobtrusive manner, e.g. Karl's conceptualising of the coming year as a space without cancer, does not directly convey that

positioning cancer outside his space is partly driven by a strong contempt for it. In order to give a more comprehensive reflection of the participants' comprehending of self I chose to add a brief indication of their overall feeling by referring to Plutchik's 'wheel of emotions' (see appx.E5). I would suggest that, even when the emotion is tangible in the structure, it is still the 'image' on top of the structure that really captures the feeling (e.g. Linda's handling is structured 'against cancer', but it is in the combination with the figurative element of the metaphor, 'bat down', that an aggressiveness really becomes tangible). For an adequate understanding of the emotional state of mind based on participants' metaphorical comprehending I would recommend exploring both the body schematic structure and the imagery.

The variation which, as will be explored further, runs through the whole data set, is the difference between taking an engaging versus a disengaging stance towards cancer. Body-schematically this is mainly constituted by position (e.g. are self and cancer in the same space?), direction (towards or away from) and action (e.g. is the engagement active or passive?).

As shown in the tree figure above (Figure 23), although the *basic* body schematic structures allowed for the clustering of two or three comprehendings, sometimes the internal variations, which have been added as *specifications* to the basic structure (see box on the side of the tree), can be more important than the differences between the clusters. This is especially the case with the difference between connecting or disconnecting from cancer as is illustrated by E5's 'Adopting' and Simon's 'Forging ahead' metaphors. These share the basic enaction: 'moving forward', but E5 envisages this 'alongside cancer', whereas Simon sees a growing gap between him and cancer. This conveys a difference of experience that could be seen as more crucial than the difference between Simon and Noel. Noel's 'Chapter' metaphor is structured as having 'surpassed' cancer, which makes his metaphor and present experience different from Simon's but merely because more time has passed. Therefore, for an understanding of the

comprehendings it is essential to engage with both the basic structure and the specification.

One of the frameworks used to shed light on cancer survivorship (see literature review), is liminality. It is often described as 'living in-between two places'. As mentioned above any concept, e.g. 'growth' or 'resilience', could be explored in terms of positioning in space, direction, movement etc. Yet, the concept of liminality, defined as 'in-between' is in itself strongly structured by the image of 'space'. In cancer survivorship liminality can be experienced in different ways, e.g. feeling between gender or between young and old. It is also experienced as living in-between health and cancer; or, between 'being disconnected from cancer' and 'ongoingly connected with cancer', and in that sense it ties in closely with the focus of this study on self vis-à-vis cancer.

From the literature review two questions regarding cancer survivorship liminality seemed open for further exploration: 1/ Is liminality either a stage or a continuous experience for cancer survivors and 2/ What are the characteristics of existential liminality for cancer survivors? In the next section the body schematic structure of participants' metaphors will be explored with those questions in mind. In other words I will explore how the participants in this study have, or have not, enacted an experience of liminality.

### **8.4.3 Enaction of liminality**

The exploration of liminality will be carried out in two steps. The first exploration focuses on space and movement, while the second focuses on the type of engagement with cancer.

### 8.4.3.1 *Is cancer still there?*

In this thesis I explore the experience of survivors whose cancer has been treated successfully and where there are medical grounds to expect them to have returned to a place without cancer. Three out of the twelve research participants expressed that not only physically but also psychologically, cancer was “not there” anymore. These were survivors whose comprehending in the previous section was evaluated as ‘surpassing and assessing’ (Noel-Chapter) and ‘ending’ (Boris-Flown off and Tony-Done). They expressed the absence of cancer as:

“...something’s there and something’s gone, as far as I’m concerned” (Noel, 2y10m).

“The cancer’s gone, yeah” (Boris, 3y7m).

“I’ve wrapped it up, I really don’t think about it” (Tony, 7y4m).

Yet, nine research participants and the case study participant expressed that, although they are physically not ill with cancer, “cancer is still there”. Although this is a mental rather than a physical experience of cancer, it may suggest that participants still live as in a place with cancer. Some implied this within their metaphor, others expanded on it beyond the metaphor. The reasons why cancer was present or not, varied, but were often linked to side-effects of cancer (e.g. stoma, changed toilet habits), ongoing clinical monitoring, other people or societal procedures reminding them, and of course concerns about recurrence. Some examples of how participants at different stages post-diagnosis expressed that cancer was still there:

“It doesn’t weigh heavy on my heart ... but it’s always there” (Linda, 1y11m).

“...they still don’t really know what is going to happen. So it’s always there” (Karl, 2y4m).

“It’s really not there ... it’s not a big part of my... but it’s there” (Dan, 12y3m).

“That part of my life is done ... But it doesn’t, it never goes away completely” (Wendy, 20y3m).

This type of experience of being in one position but also being in the opposite position has been labelled as being in a place of liminality. As indicated in the literature review, a number of researchers have framed the experience of cancer survivorship as an experience of liminality. It is described as being *on the threshold* from one place to another. In this case participants’ mental experience of “cancer is (always) there” may suggest that they have not fully crossed over to the physically declared place without cancer. A threshold experience *exceeds the experience of either of the two positions* rather than being the sum of the two, in this case the experiencing of ‘cancer being there (psychologically)’ and the experiencing of ‘cancer not being there (physically)’ (Meyers 2008). When below the conceptualisings of cancer presence are explored this could be seen as a conceptualising of the experiencing of ‘cancer being there’ only. It is important to keep in mind that cancer survivors simultaneously know that they are medically considered not to have cancer which even if not explicated, is part of their cancer comprehending.

With its emphasis on being in-between two places, liminality is a concept that centres around the body schematic structure of space, and movement in space (Kupers 2011). In the previous section the clustering was carried out based on the varying basic structures that differentiated the metaphors but as the spatial expression of the relationship between self and cancer is the most basic schema (Presenting and Positioning) it is embedded in all

metaphors. It seemed worthwhile to explore the totality of the metaphors in terms of the *spatial* positioning of self and cancer.

The data exploration above revealed different time foci at early, middle and late survivorship. By taking not only spatial but also time structure into account, I suggest that the experience of ‘cancer is still there’ (or not) refers to different experiencings. These nuances are detailed in Table 9 (second column).

Table 9: Cancer positioned in space and time

<b>Body schema and metaphors</b>	<b>Positioning cancer in space and time</b>	
Presenting and Positioning: Fog, Hulk, Terrorist	<i>No cancer, but cancer is always here ('there' in the here).</i>	A
Handling and Rising: Flow with, Bat down		
Moving in space: Theatre play, Blank Canvas 1Y	<i>No cancer, but it is always 'there' (just outside the here).</i>	B
Express Viewpoint on Future: Unknowable, Open book		
Moving Forward: Adopting, Forging ahead	<i>No cancer, but is 'there' for a time to come.</i>	C
Surpassing and Assessing: Chapter, Veteran	<i>No cancer and it is not here anymore.</i>	D
Ending: Flown off, Done	<i>No cancer, it is not here anymore and will never be.</i>	E
Registering: Ache, Horror, Bad days	<i>No cancer, but it is and will always 'sometimes' be 'there'.</i>	F
Holding: Healed, Grounded	<i>No cancer, but it is and will always be both 'here' and 'there'.</i>	G

Cancer seems to be imagined as ‘here’ or ‘there’, the latter being further specified as ‘for a time to come’ or ‘forever’. Absence of cancer seems to be experienced as ‘not here’, which some further define as a permanent state. Based on this more nuanced description, I distinguish four ways in which presence or absence of cancer is comprehended by the participants in this

study. I define them with the term ‘survivor liminality’ further qualified as ‘negated’, ‘early’, ‘late’ and ‘existential’.

### 1/ Negated survivor liminality

When survivors have – even if only briefly at the time of diagnosis – experienced a sense of liminality, but at some point communicate that cancer is not impacting on their state of mind or even barely comes into their awareness, I call this negated liminality. This coincides with the body schematic cluster called ‘ending’ and is one form of ‘living beyond cancer’ (see Figure 41 in appx.G3).

Ending: Flown off, Done	<i>No cancer, it is not here anymore and will never be.</i>	<i>E</i>
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Tony and Boris were adamant that cancer was gone for them. This is an experience that I found not easy to accept. First, in the literature review it was highlighted that although liminality was originally seen as a temporary middle stage of a tripartite ‘rite of passage’, several studies suggests that cancer survivors experience life-long liminality (e.g. Little et al. 1998, Wake 2016). This resonates with biological literature on the human bias towards fear, as addressed in Chapter 1. Some authors argue that this does not deny that with time there is also a re-anchoring in normality (Crouch and McKenzie 2006), or emphasise the existential character of late liminality (e.g. Pascal 2010, Assing Hvidt, 2016). Secondly, I became aware that my professional counselling experience biased me towards hearing Tony’s and Boris’s view as rationalisations of emotions that were difficult to bear or express, as has also been suggested by McKenzie and Crouch (2004). Yet, I set aside those preconceptions after repeatedly engaging with the data and especially after considering their viewpoint within the wider dynamic of their self and transactions with the medical environment. This is illustrated in vignette E (see appx.G6).

In this study the majority of survivors, however, express a form of sustained liminality, but it is important to acknowledge that some have moved beyond the liminal stage. This finding supports findings in Scott's (2014) research.

## 2/ Early survivors liminality

When survivors metaphorically express an experiencing of cancer in the present, or near future, as positioned within or in relation to their own living space (examples A, B and C below), their sense of liminality has a strong experiential basis. After deliberation I also included the comprehendings of Noel-Chapter and E-Veteran (example D) in this category. E's comprehending was based on his oncologist's statement not to consider himself as a patient anymore. In that moment E incorporated this in his understanding, yet also wondered whether this really meant cancer would not return. In other words his sense of liminality had not ceased. Noel was adamant that cancer had gone (see 8.4.3.1), but on the other hand expressed a desire to recall the experience of cancer and in doing so showed a need to entertain a sense of liminality in this more relaxed form. Based on the examples, I consider this early version of liminality to be experienced at least till one is medically speaking no longer considered to be a cancer patient.

Presenting and Positioning: Fog, Hulk, Terrorist	<i>No cancer, but cancer is always here ('there' in the here).</i>	A
Handling and Rising: Flow with, Bat down		
Moving in space: Theatre play, Blank Canvas 1Y	<i>No cancer, but it is always 'there' (just outside the here).</i>	B
Express Viewpoint on Future: Unknowable, Open book		
Moving Forward: Adopting, Forging ahead	<i>No cancer, but is 'there' for a time to come.</i>	C

and

Surpassing and Assessing: Chapter, Veteran	<i>No cancer and it is not here anymore.</i>	D
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### 3/ Late survivor liminality

This category is based on the experience of Jack, Dan and E (Horror) and coincides with the body schematic cluster called 'registering'.

Registering: Ache, Horror, Bad days	<i>No cancer, but it is and will always 'sometimes' be 'there'.</i>	<i>F</i>
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They acknowledge that the awareness of cancer is less prominent in their life - expressed for example as "there 25 % of the time" (Jack) or , "5%" (Dan) or 'unexpectedly triggered by an event' (E). This brings about that their metaphors also conjure up a self that is away from cancer (at times). That this duality is now put into words, brings about that the sense of liminality is also more conceptualised and comes with a greater degree of control than the earlier experienced liminality. This sense of control is expressed less when this late liminality is specified as 'sustained' (Little et al. 1998) or 'pervasive' (Bruce et al. 2014). In vignette B (see appx.F0) the difference between cancer being in awareness for 25 % or for 5 % of the time was explored and attributed to the fact that Jack, although without active cancer since three years, had been diagnosed with two separate cancers and overall was more at risk of a recurrence. In this sense Jack was different from the other participants. His specific circumstances position him in-between living beyond and living with cancer (see Figure 41 in appx.G3).

### 4/ Existential survivor liminality

Holding: Healed, Grounded	<i>No cancer, but it is and will always be both 'here' and 'there'.</i>	<i>G</i>
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In the previous section the exploration of the metaphors Grounded (Wendy) and Healed (E8) were clustered under the heading 'holding'. Their metaphors revealed their engagement with wholeness and mortality. In other words their sense of liminality experienced through cancer, is held on the wider platform

of general existential liminality. In their metaphors paradoxical positions such as 'in' and 'out', 'here' and 'there', 'objective' and 'subjective', were transcended. Some researchers consider 'existential liminality' as a form of 'sustained liminality' (e.g. Pascal 2010, Little et al. 1998, Scott 2014). Their descriptions seem to focus on an ongoing fear for cancer recurrence. Others perceive expressions of integration and acceptance of cancer as expressions of an existential outlook and as a post-liminal state of being (Sleight 2016, Hvidt 2015, Wake 2017).

I decided to call the experiencings described by E8 and Wendy 'existential *survivor* liminality'. Both position cancer metaphorically within their self in a way that creates a connection with others: Wendy by implying that cancer is part of human biology, E by using the lymphatic system as a metaphor for the connection between him and others. These thoughts and imagery I hear as an expression of the liminality of life in general, but in a way that, I suggest, is specific to their previous experience of cancer, i.e. 'everybody else is mortal like me'. An engagement with the liminality of Life, when one has not met 'death' on a personal level, I believe, is rather expressed as "I am mortal like everybody else". Little and Sayers (2004) differentiate 'death salience' (i.e. an awareness of personal death) from 'mortality salience' (i.e. an awareness of a shared fate of humankind). It seems the two conflate in those cancer survivors who take an existential perspective on life.

Despite the specificity of their experience of existential liminality, when cancer is framed as part of humanity, survivors may not just be shrugging off their illness state (as suggested in 8.3.9). They also could be expressing and enacting a sense of 'normal' health. Some participants came to this conclusion based on an assessment of the probability of recurrence (see those clustered as 'Ending'), but those clustered as 'Holding' establish this via a philosophical route. What previously may have been seen as impossible and as 'beyond', now seems to reveal itself as a reality, as a felt knowing. What previously felt as 'beyond' is perhaps better called a "beyond within" (Rochelle 2008). In Gendlin's terminology this knowing may have been

'implied' for a while but is now 'occurring'. When cancer survivors refer to cancer as part of the human bio-chemical state, this may not be so much a stating of an understanding of human biology as a metaphorical vehicle for the 'occurring' and 'enacting' of an inner sense of health. In their case this does not come with a rejection of cancer, therefore this 'existential cancer awareness' has been presented in Figure 41 (see appx.G3) with a link to those who ongoingly 'register' cancer.

So far liminality has been explored as a concept structured *by time and space*. In the next section it is explored as a *relational* concept, which moves the focus from cancer to self vis-à-vis cancer. This is introduced by positioning the concept of liminality within the theoretical framework that underpins this study.

#### **8.4.3.2 An interrogative self vis-à-vis cancer**

Meyers (2008, p.78) argues that Merleau-Ponty's concept of embodied non-dualism and the 'in between' helps us to understand what it is that makes it possible "to think the liminal". As discussed in Chapter 4, Merleau-Ponty posits a sensory consciousness that is prior and more fundamental than intellectual consciousness. Intellectual consciousness may be geared towards scrutinizing and studying objects, to establishing what they are and what they are not, or as Merleau-Ponty (1968, cited in Meyers 2008, p.101) metaphorically describes "to hold them with forceps, or to immobilize them under the objective of a microscope". Such an approach which below I will refer to as a 'dominating stance' does not let the things reveal their ultimate and primary being. The latter is more likely to happen through sensory consciousness, which is a pre-reflective dimension that takes place through the body and its ability to 'look'. Within such a sensory approach perception is understood as an 'interrogative thought" (Meyers 2008, p.101). It "lets the perceived world be rather than posits it". With such a stance one inhabits a place 'on the threshold of', or 'in-between', mind and world. In this place a

part of the self pre-reflectively 'knows', is saturated and synchronised with objects in the world and "the things form and undo themselves in a sort of gliding, beneath the yes and the no" (Merleau-Ponty 1968, cited in Meyers 2008, p.101). It "calls attention to the irreducibly liminal status of the perceived world" (Meyers 2008, p.102).

I set out to distinguish participants' metaphorical comprehendings that expressed an 'interrogating' from those that expressed a 'dominating' stance towards cancer. This was done by taking both the basic structure and specifications of their metaphors into account (Figure 24 below). This resulted not in two but in four groupings:

**1/ Active interrogative:** envisages a close and positively engaged relationship with cancer, in the specifications expressed with prepositions such as 'with', 'alongside', 'in'. This was expressed by Rosy (Flow with), Wendy (Grounded) and by E with the metaphors Unknowable, Adopting and Healed (see red texts and boxes in Figure 24).

**2/ Passive interrogative:** envisages a being in the vicinity of cancer in a rather factual manner. Ann (Hulk), Jack (Ache) and E with Fog and Theatre play expressed this stance. These metaphors focus on space and suggest subdued movement (see pink texts and boxes in Figure 24).

**3/ Active dominant:** envisages a distancing engagement with cancer, specified by words such as 'away' or 'against'. Linda (Bat down), Simon (Forging ahead), E (Horror) and Dan (Bad days) revealed this type of comprehending of their self vis-à-vis cancer (see blue texts and boxes in Figure 24).

**4/ Passive dominant:** rather than expressing a movement away from or against, the distance or gap is established in metaphors used by E (Terrorist), Karl (Blank canvas 1Y), Mark (Open book), Noel (Chapter), E (Veteran), Boris (Flown off) and Tony (Done) (see green texts and boxes in Figure 24).

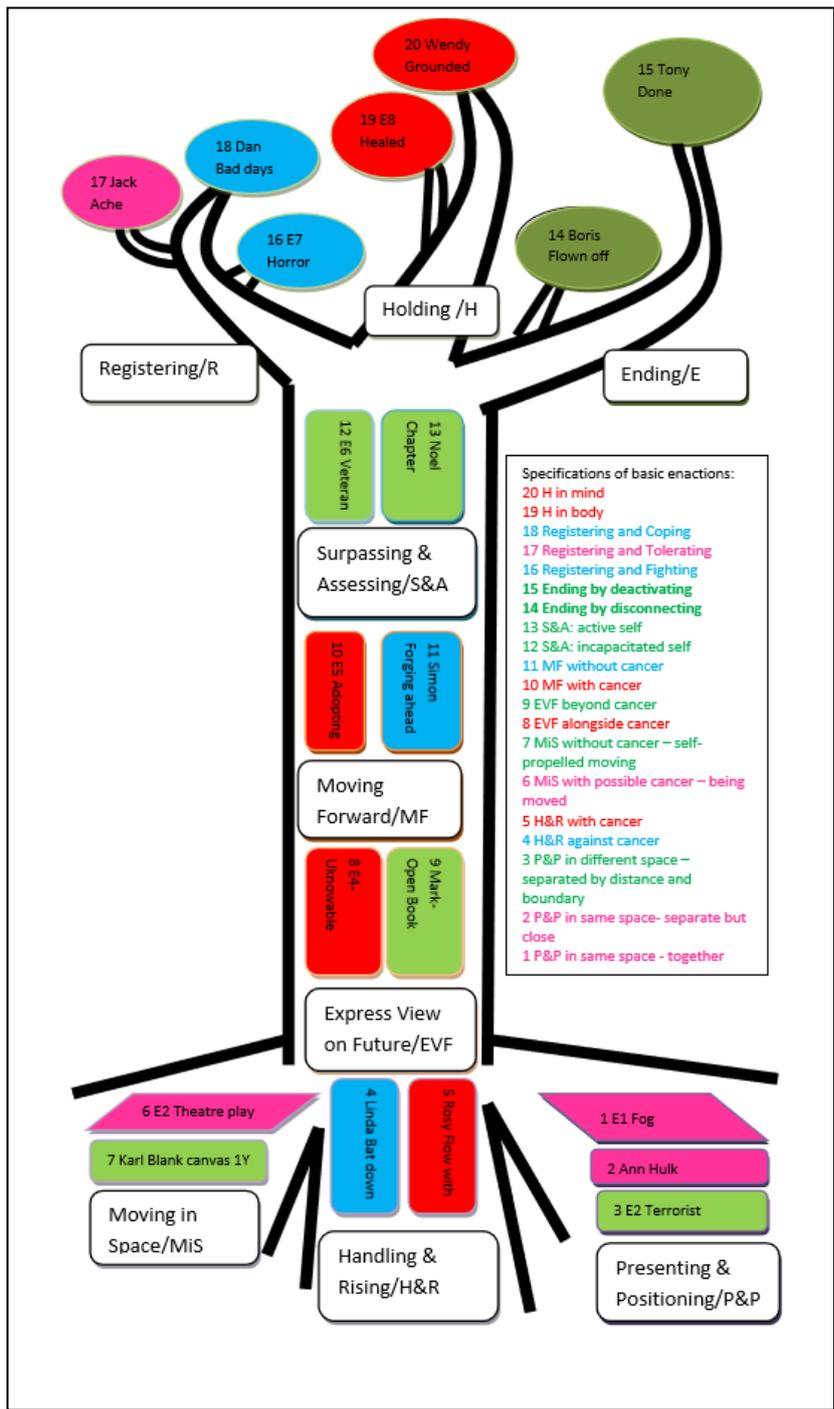


Figure 24: Four types of self-cancer comprehendings

Key:  
 Active interrogative: red      Active dominant: blue  
 Passive interrogative: pink      Passive dominant: green

Engaging with cancer can be seen as engaging with mortality, or with death. Yalom (2008) points out that for some people engaging with the finitude of life makes life meaningful, while for others it makes life meaningless.

What stands out in this study is that 8 out of 12 research participants expressed a 'dominant' stance and avoided engagement with cancer. No doubt a myriad of factors may have influenced this difference, fear of loss of meaning perhaps being one of them. Based on my overall experience of listening to the participants I suggest the crucial role of people's general outlook on life. Seven out of the eight who took a dominant (distancing) stance not only had an engineering or management related professional role, they also spontaneously referred to psychological management tools which they applied to dealing with cancer. These approaches were pragmatic, e.g. delegating, not investing in what you cannot change, researching and weighing up facts.

The interrogative stance, which entails an engagement with cancer resonates with the concept of ownership. In the literature review I referred to Karnilowicz (2011) who sees ownership as a psycho-social concept, while McGrath (2004) sees ownership as part of the spiritual dimension of living with cancer. The latter I see best reflected in the stories of participants Rosy, Wendy, Ann and E, perhaps less in Jack. Like the pragmatic participants above, these more spiritually inclined participants revealed their stance well beyond their approach to cancer. All made references to always having lived in an awareness of death. Even if one wishes to live with such awareness, it is not easy to exchange a general, perhaps more intellectual thinking of mortality for a real felt sense of mortality (Frommer 2005). If self seeks to continue, then it is perhaps to be expected that individuals who already took an existential stance in life pre-cancer will actively engage with cancer when diagnosed, as it brings about a felt sense of mortality that makes life more real and meaningful. Engaging with cancer and the risk of dying may perhaps also generate a sense of safety if one already has a spiritual mindset. It may

conjure up what O'Donohue (1997, p.114) describes as "When you are in rhythm with your nature nothing destructive can touch you."

In conclusion, as Table 10 shows in terms of space-time liminality (discussed in 8.4.3.1), 10 out of 12 research participants', and all eight of the case study participant's experiencings can be defined as liminal. Focusing on the relational understanding of liminality (discussed in 8.4.3.2), this decreases to the experiencing by four research participants and the experience of the case study participant expressed in 5 out of his 8 metaphors.

Table 10: Spatial and relational liminality

		Spatial liminality				
				Registering	Holding	Ending
		Up to 2 years		3 years +	3 years +	3 years +
		Early		Late	Existential	Negated
liminality	Active interrogative	HR EVF MF	Rosy –Flow with E4-Unknowable E5-Adopting		E8-Healed Wendy- Grounded	
	Passive interrogative	PP PP MiS	E1-Fog Ann-Hulk E3-Theatre play	Jack-Ache		
Relational	Active dominant	HR MF	Linda-Bat down Simon-Forging forward	E7-Horror Dan-Bad days		
	Passive dominant	PP MiS EVF SA SA	E2-Terrorist Karl-Blank canvas Mark-Open book E6-Veteran Noel-Chapter			Boris- Flown off Tony-Done

In the above exploration I have argued that the wider self seems to find an expression in individual's comprehending of a 'dominant' or 'interrogative' self vis-à-vis cancer. In the next section I will further focus on how the comprehendings of self vis-à-vis cancer emerge in a dynamic relationship with participants' wider self and transactions in their medical consultations.

#### 8.4.4 Dynamic outlook

In the previous sections the analysis was focused on the body-schematic aspects of embodiment. Occasionally vignettes were used to expand on specific points. However, these vignettes also included how the present comprehendings of self emerged in relation to the wider self and transactions with consultants. By attending to these contextual aspects of the occurring metaphors, a more dynamic understanding of participants' comprehendings opens up. In the subsequent sections these aspects will be focused on and further discussed.

##### 8.4.4.1 *Self vis-à-vis cancer as an enacting of the wider self*

As has already been indicated (8.4.2.3. and 8.4.3.2) participants often made the connection between their self vis-à-vis cancer and their previous self. That there was a continuation of self was not just implied but often put across with passion, for example:

“I’m a person with issues but and also I’m the person I have always been... and seek to continue to be” (Rosy)

Reflecting on change of self, Dan chooses a slightly less pointed shell for his present self to express that he has softened but is “not completely rounded, that would mean being dull” which is not how he knows himself.

What participants' reflections on change or sameness in relation to their previous self mean, is explored below.

Eight out of all thirteen study participants refer to drawing on *previously accomplished coping skills* of their wider self in dealing with problems which they now apply to their experience of cancer. Within this group personality

differences create further nuances. Based on their reflections, which are summarized in the text between brackets, I distinguish participants who cope with cancer by:

a/ 'organising their self and others':

{ Organise thinking and put more than one mind on the job  
(Mark-Open book – details in vignette D)  
Putting trust in available care and adjust habits if needed  
(Noel-Chapter)  
Focus on what is in your control and make action plan  
(Tony-Done) }

b/ engaging in focused behaviour

{ Being methodical and orderly and keeping busy' (Simon-  
Forging ahead)  
Setting goals and routines (Dan-Bad days – details in  
vignette B) }

c/ exerting psychological control over emotions and thinking

Cutting off emotion and living according to a plan (Karl-Blank canvas 1Y)

Accepting life as it is and putting up with it (Jack-Ache – details in vignette B)

Keeping thought of life threat at bay (Boris – details in vignette E)

Two participants refer to the *values* they hold as a wider self, rather than to coping strategies. Having been diagnosed with cancer does not challenge those values, on the contrary it confirms them and the thought that cancer may have been caused by not living according to those values is not far off. Living closer to their long held values is seen as the way forward in living after cancer:

Rosy (Flow with) has always valued graceful living (getting on with life but with trust in God, realistically and loving). Living according to these values she experiences as the way forward and is also the best protection against cancer.

Wendy (Grounded) has always lived in awareness that life is finite and sees cancer from that perspective

Three participants report having been changed by the cancer experience. The growth thus gained puts them in a better place to take the wider self forward.

Ann (Hulk) has always been searching for purpose but struggled to find it before her diagnosis. Cancer has been 'a wake-up call; life is worth fighting for; not fritter it away'.

Linda's (Bat down) experience of going through cancer on her own has created a clearer sense of identity and independence (see details in vignette C).

E (Unknowable) feels an increased ability to trust people and wonders whether this is based in the care received by the medical team.

In the previous section it was discussed that 'cancer is always there' in some form for the majority of participants. Comprehending their relationship with it is in itself an overcoming of vulnerability. Some participants also name their increased sense of vulnerability but turn it around into a position of strength by using their experience for the benefit of others (Mark, Simon, Boris, Noel).

In conclusion, in their comprehending of self vis-à-vis cancer, the participants in this study in more or less explicit ways and often with pride refer to the continuation – surviving – of their self, either as a seeing through or as a positive development from the way they were before cancer.

Having considered the dynamic between the present and wider self, the exploration of the data will be concluded by considering if and how the self vis-à-vis cancer is enacted in the transaction with consultants.

#### **8.4.4.2 *Self vis-à-vis cancer enacted in transaction with consultant***

For cancer survivors any meeting with their consultant is important. In this section I have chosen to look into the transaction between survivors and consultants at two specific points. First, the moment which I have described earlier as the emergence of the 'autobiographic cancer self', and secondly the surpassing of patienthood.

Following on from the description of the structure of the autobiographic self as expressed in Mark's Open book and E4's Unknowable metaphor (8.3.4 and 8.4.2.2), what stood out in the comprehendings of Mark and E4, was their explicit re-positioning in relation to their consultant. Without depreciating their consultant's expertise, at that moment in time they establish themselves on a peer level regarding the understanding of their cancer and express this in relational terms: the consultant is no longer the protagonist in E4's metaphorical play, while Mark recalls addressing his consultant quite informally in the corridor. As cancer itself cannot be addressed, I wonder whether acting out this changed mental position in relation to cancer, can only be 'lived', 'acted out', 'enacted' in relation to the consultant, who is the closest representative of cancer. In both these cases, the participants seemed to have an experience of their consultant that afforded them the ability to think and/or act in a manner that supported the establishment of a more confident self vis-à-vis cancer.

When E6 was coming up to three years post-diagnosis, no doubt, it was with the best of intentions that his consultant used the expression 'don't consider yourself a patient anymore'. Yet at the time this made E6 feel incapacitated. In the research literature clear and factual communication by clinicians about the reduced likelihood of recurrence when reaching certain milestones (e.g. 3, 5, 10 years) is presented as a crucial and powerful factor in enabling survivors to move out of the liminal stage between illness and health (Wilson et al. 2007). Research shows that such medical information 'affords' certain survivors to be able to move beyond the world of cancer, but equally that it

does not have the intended impact for many others who report an ongoing sense of liminality (Scott (née Blows) 2014). In vignette A below I aim to shed further light on this topic by comparing the response of E6 to responses recalled by Simon and Dan to similar messages. I consider how their metaphors occur dynamically in relation with their wider self and in transaction with their consultant.

### Vignette A: Occurring and affording of the end of patienthood

Vignette A: Experience of E6 – Simon – Dan

**E6:** *“Today (2y8m post-diagnosis) I had a doctor’s appointment to discuss the results of a scan. He told me the cancer is not going to come back. He said ‘there is no need to see yourself as a patient. He smiled and said ‘we have done well’. I expected he would say there was no cancer activity to be seen but that he would keep monitoring me. I expected him to encourage me and to say I was doing well. I **did not expect** him to give the ‘all clear’ because they normally only do that after five years. I am wondering now whether this has anything to do with the benefits system.” I feel **like a war veteran in a wheelchair, without medals.***

Background: *At diagnosis E was given a prognosis of one year. During the past three months E re-established a sense of autonomy towards clinicians (Unknowable metaphor) and took ownership of cancer (Adopting metaphor).*

**Simon:** *After the seventh of eight planned chemo sessions the treatment was put on hold but then (shortly after finishing treatment) **unexpectedly** Simon was told that he was “all clear and discharged”. This was **“like sticking a pin in a balloon”**. He felt “he walked in with cancer and out without cancer”. It was hard to sink in but he felt “I got my life in front of me ... I am not gonna die in the next few months”. He wanted to tell that you can “get to the other side of cancer”. But it also **made him feel “empty... What do I do now? ... Where do I go?”** There were still check-ups to go to – “still going down that line” - “it could come back” – so not completely discharged, “not a closed door”.*

Background: *At diagnosis Simon never thought he could die / ‘got on with it’*

**Dan:** *About 3 years post-diagnosis: “Somebody told me **which I thought was quite cruel at the time** and now I realise was absolutely brilliant, true ... was you have to learn to stop being a cancer patient”. – “... it takes you over “ ... “you have to appreciate fact ... if there is no recurrence within three years you’re probably going to be alright” ... “you have to leave some of that behind you ... you have to move on to the next bit”. Four years in, the oncologist said “I think you’re going to be all right” ... only then did the mental tension go... “I had another scan, another colonoscopy but I knew then that I was fine”.*

Background: *At diagnosis: “all consuming” (see appx.G0)  
Treatment was a psychological struggle.*

All three participants recall a great shock when they received the message that they were no longer considered to be a cancer 'patient'. Their comments draw attention to the following:

The shock is partially due to the 'unexpectedness' and this is linked with 'cultural knowledge': an 'all clear' is expected around five years, it is not expected shortly after finishing treatment.

Three years seems too soon (E6 and Dan), but Dan seems to be able to accept a similar comment from his oncologist at four years. Taking into account that E4 (Unknowable) and Mark (Open book) were respectively 2 years 5 months and 2 years 8 months post-diagnosis when their conceptualising of self vis-à-vis cancer evolved around taking a personal stance towards clinicians and cancer, one could imagine that, at about 3 years, this stance is still quite fragile and can easily be overrun by a medical expert's message.

In contrast to Dan and Simon, E6 (Adopting) had recently taken ownership of cancer as a coping strategy. As discussed in 8.3.6 this clashes with the 'no patient' message and leads to an incapacitated sense of self. The idea of interdependence between cancer and self has also been explored by Batistatou (2004) in a story about cancer told from the perspective of cancer-cells. In this story cancer-cells bond in an affectionate way with their host and come to realise that when they stop negotiating and take over, their host dies but they die too. As imaginative the idea of adopting cancer or cancer befriending their host may be, some survivors may need all the creativity they can muster up to counter-act medical information that challenges the thought of survival (e.g. E receiving a one year prognosis).

The warmth with which Dan recalled his oncologist saying at the right time, in the right tone, "I think you are going to be all right", is an example that suggests that clinical assessments that are spoken tentatively, with empathy and openness for the client's autonomy rather than from an 'expert' place, are

easier to receive for cancer survivors than well intended, but too defining statements such as 'you are not a patient anymore'.

Overall, the above examples point to the complexity of the role of oncologists. In a first role, at the early stages, survivors need factual medical information from their consultant. In an age when patients access the internet, even on this level some may need their oncologists to discuss their clinical judgment in relation to other sources of information. But based on this study I want to point specifically to the roles of oncologists in survivors' psycho-spiritual process. As discussed above, about two years post-treatment survivors seem to 'enact' a sense of autonomy in relation to their cancer experience and may seek to use their relationship with their consultants to do so. This means that next to being a physician, consultants are needed to take on a second role, i.e. a counselling role. This could be seen as a diversification of the medical role. It could also tie in with discussions about physicians needing to be knowledgeable about transference and counter-transference (Liechty 2000). It has been suggested that physicians engage more proactively with patients' metaphoric expressions in order to better understand their cognitive and affective illness experiences (Reisfield and Wilson 2004). By the time consultants want to finalise the follow-up appointments, I suggest it may not be their medical evaluation of 'patienthood' that is most important. Survivors are, each with their own strategy, moving towards that point anyway. Their need may be for such conversations to happen not only with clarity, but with empathy and humanity as well. From this perspective the valuable clinical assessment of 'no patienthood' is not about ending a survivor's sense of liminality. This study, together with many other studies, reveals that life after cancer is often experienced as an in-between state. But in what way, to what extent, for how long and whether this is distressing or adds to a sense of meaningfulness, is individually so diverse, that without an exploration of the survivor's outlook and a communication of the clinical judgement in relation to that outlook, the chances of the message being harmful rather than helpful are high. In other words, a third role for consultants to take up and that is called for here implies an ability to step out

of a strict 'medical expert' role. Moreover I wish to suggest that their own existential awareness may be beneficial to their cancer surviving patients.

In a recent article published by the American Society of Clinical Oncology, McFarland and Hlubocky (2019) explore the role of 'The oncologist as therapist'. They encourage oncologists to work proactively with the alliance between themselves and their patients and to engage in meaning-orientated conversations with the latter. However in the description of these roles McFarland and Hlubocky do not address how these therapeutic roles demand less of an expert stance and more of an exploration of the meaning of death and dying in their own life.

In European literature also, medical oncology acknowledges the importance of a patient-centred and holistic approach (Popescu et al. 2014). Not only have programmes been devised to improve oncologists' communication skills; these programmes are now also critically assessed. A core finding seems to be that, rather than focusing on skills, the type of communication that is needed depends on physicians' ability to explore their own lived experience and the context in which they work (Stiefel and Bourquin 2016). This is a development that resonates with the needs I perceive in cancer survivors. The meaningfulness and impact of oncologists' relational and psychological responses to the psycho-spiritual journey of cancer survivors, and the flexibility this demands as described above, imply that it is first and foremost a matter of being, rather than skill.

## 9. Conclusion

In this study I have been concerned with the question “How do bowel cancer survivors, who have no active disease, and are between a few months and 20 years post-treatment, comprehend (i.e. experience, conceptualise, express) their self vis-à-vis cancer? The data explored was gathered from 12 research participants and extended with eight ‘comprehendings’ provided by an earlier case study participant. The form ‘comprehendings’ is used to express that comprehension is understood as an active ongoing process. Further in the text ‘experiencings’ will be used for the same reason. Given the theoretical framework of the study (a combination of interpretive phenomenology and enactive cognitive science), I focused on the metaphorical character of the comprehendings and explored them from five dimensions of embodiment. The emerging insights were developed in the main text but the core findings will be presented below. Together they constitute a brief answer to the general research question.

From exploring the body schematic structure of the 20 metaphorical comprehendings of self vis-à-vis cancer (obj.1) and from ordering those according to a developmental body logic (obj.5), it emerged that four types of self were conceptualised with reference to nine body schematic structures. For these participants, early on a first self vis-à-vis cancer is portrayed as a minimal action-based self that ‘positions’ (1), ‘acts upon’ (2) and ‘creates space’ (3) in a manner that suggests an increasing ability to think cancer as less active and complemented by a self that regains a sense of movement. About two years post-treatment from this comprehended actionable freedom seems to spring an autobiographic or narrative self. This second self expresses a personal view on cancer which introduces a decreased dependency on clinicians. It also changes the time focus from the present to the future (4). This opens up a sense of journeying, a moving forward (5). From the start some survivors cope by connecting, and others by disconnecting from cancer. This becomes very clear at this stage: moving forward may be imagined as widening the gap with cancer, or as travelling

with cancer. Either way, at some point survivors are likely to receive the message that no further medical follow up is needed. From the experience of participants in this study it seems this happens when cancer survivors approach the third anniversary of their diagnosis. Abruptly or gradually survivors come to realise that they have surpassed (6) the point of being a cancer patient. The emerging 'beyond cancer patient self' is a third meaningful change in the experience of self vis-à-vis cancer. For some this seals a gradually strengthened belief that there will be no recurrence and, subsequently, holding cancer in awareness is 'ended' (7) which leads to a 'self beyond cancer'. This fourth self is only emerging under very specific circumstances. Most survivors continue as being beyond patient-hood but live with a degree of ongoing cancer awareness as they 'register' (8) whether there are any signs of recurrence or problems. Over time this experience mainly changes based on familiarity and growing competence in dealing with continuous or late physical, psycho-social and practical stressors. Survivors who take a connecting stance towards cancer, are more inclined to embed their experience with cancer in a wider existential outlook on life and death. Long-term they continue to 'hold' (9) cancer but in a way that transcends illness. Looking out for absent body schematic structures (obj. 3) led to the conclusion that as long as people do not exclude a recurrence, some form of protective activity against cancer will be embedded in their metaphorical comprehending of self and imagery that suggests uncontrollable, scattered cancer will be avoided. I have argued this could be seen as a conceptual expression of the bio-chemical drive for survival.

The idea that there is a non-conscious drive that carries the self forward through the occurring metaphors is part of the theoretical framework of this study, but what stood out most in the data was the intensity with which participants consciously frame the way they comprehend cancer and overall deal with it, as a reflection of who and how they have always been (obj. 2). This was expressed by 10 out of 13 study participants. For eight this means taking forward previously accomplished coping skills. Two participants believe it is about living according to their long held values. The three

remaining participants felt their cancer experience enabled an amendment of previous inadequacies. Whether people refer to coping styles or values, sameness or change, their experience of continuation of self is an important part of their sense of self vis-à-vis cancer.

From examples of positively and negatively experienced transactions with their consultant, it transpires that the impact of the latter's responses on survivors' sense of self should not be underestimated. The establishment of an increasingly assertive self vis-à-vis cancer cannot be expressed directly towards cancer, yet has to be expressed to become real (obj. 4). The relationship with their consultant is the most relevant platform to do so but does not necessarily 'afford' this. I argue that survivors appeal, perhaps not completely deliberately or consciously, to their consultant's ability to respond from a psychological and philosophical stance, rather than a strictly medical one. This cannot be expected to be a given. Further research is needed to understand whether consultants identify with these roles.

The reader should bear in mind that the results of this research emerged from a group of participants who were all white British and able-bodied. They were interested in participating in research, and several expressed a motivation to help others in this way. Only four out of the 20 data sets were provided by women. Having recruited seven participants from the same support group also poses the question whether their shared interest and communication has influenced their thinking and way of being in their cancer survivorship.

With this study I believe to have expanded the available knowledge about cancer survivors' experience of self in the following ways:

Previous studies into the conceptual metaphors of cancer survivors focus on pointing out the type of metaphor (e.g. violence or journey metaphor) and a few explore their body schematic structure. In this study I have focused on the latter but have added understanding by exploring the position of the momentary metaphor in a suggested body schematic developmental path.

For example, the metaphors 'batting cancer down' and 'kicking and fighting (cancer) and running towards the light', may both be seen as 'violence' metaphors. Yet analysing the body schematic structure reveals that in the first metaphor, the focus is on 'handling cancer (with force)' while the second includes an 'ability to move away from cancer into a cancer free zone'. The latter portrays a kinaesthetically more comprehensive functioning, and therefore, I argue, suggests a further accomplished self vis-à-vis cancer.

Although the individual findings were understood from their position in a developmental body schematic logic, this thesis - apart from the case-study included in the analysis - did not focus on individual participants' process of change over time. A brief creative exploration of the steps since diagnosis, as described by the individual participants, was not substantial enough to base conclusions on it. Further research, akin to the longitudinal exploration of the aforementioned case study, would be needed to explore the pace and specific movements of survivors on the body schematic path suggested in the present study.

In response to the dearth of studies into long-term survivorship, this study includes the experience of four (very) long term survivors and revealed three different experiences of self ('ending', 'registering', 'holding'). Further light was shed on these experiences by studying them, together with the experiences of shorter term survivors, from a perspective of 'liminality'. The study confirmed earlier findings that for many survivorship is an experience of sustained liminality. However, the experience of two participants in the study at hand contradicts the idea that moving out of liminality is impossible. Additional light has arguably been shed on liminality by exploring it not only from a space-time perspective but also from a relational perspective, i.e. by exploring the liminal character of the engagement of self with cancer. This pointed out the role of personality. More pragmatically inclined personalities seem less likely to experience 'relational liminality' than those who are more philosophically inclined.

In addition to understanding survivorship in terms of liminality, other research addresses survivorship as a process of recovery or as a process of growth. In this study also, the theme of the experience of 'growth' and 'resilience' appeared randomly in participants' narratives. It would be interesting to explore these experiences from a body schematic perspective but this would require a focus on self vis-à-vis 'previous self' and self vis-à-vis different contexts.

With this study I also intended to bring into view cancer survivors' experiencings that are perhaps less known or accepted by professional health care practitioners. This was enabled through the recruitment of participants outside my hospice counselling practice and through the use of a framework that can hold together data but that is, at the same time, sufficiently abstract to create space for a rich variety of experiencings. I believe the findings of this study are of interest to health care practitioners who care for bowel cancer survivors, or arguably, for cancer survivors in general, for the following reasons and in the following ways:

This study arose from my attempt to delineate a wide range of variations in survivors' experiencing of cancer. The findings show that survivors between 1.5 and 2.5 years post-treatment may have an experience of self that is body schematically structured in any of four specific ways. In addition, three major differences and further specific variations are experienced by survivors who live beyond patient-hood. Knowing these structures will help 'hearing' them and should lead carers and practitioners to a better understanding and empathy.

Revealing the body schematic structure of the comprehendings draws attention to the 'achieved' conceptual handle. That which is 'not achieved' (e.g. 'pushing down cancer' implies one is not moving forward yet) is, however, equally noticeable and shows vulnerability. The metaphorical comprehendings of self throughout survivorship, which, in this way always reveal vulnerability and strength, make this study relevant for practitioners

who seek to balance a professional emphasis on strength as well as on vulnerability.

As this study focuses on self and psychological process, it should perhaps go without saying that the findings, especially the detailed differentiation of the nine enactments, are relevant to the work of psychotherapists and counsellors.

The findings of this study show that the self vis-a-vis cancer restores and/or evolves over a very long period of time, and in a format that does not necessarily disable people's functioning. On the other hand the existential dimension of this process suggests that providing humanistic reflections may support survivors' re-anchoring in life. Most cancer survivors in the early stages seek and receive psycho-social-spiritual support from health care services. Awareness of the wider process of survivorship, as explored in this thesis, I wish to argue, presents health care services with a challenge, but also with a moral demand to be flexible, and to avoid making cancer survivors' requests for mental support dependent on physical support needs. In addition health care services would do well to cooperate with community services to develop initiatives that may serve this purpose, and/or refer to initiatives that are already available.

Finally, the findings have widened my initial understanding of self in cancer survivorship, which was based on a case study, but they have also raised my awareness of the often imperceptible ways in which professional bias risks shoehorning individuals' experiencings into a known frame. I therefore aim to disseminate the findings not as fixed 'facts' but, rather, as 'lenses' for academics, practitioners and survivors to continue the ongoing hermeneutic interpretive process of understanding. To help this process the findings are carried forward, in the practice part of the thesis, in a painted format. Paintings, like other art forms, have a certain power to reach people's pre-conceptual knowing and acting.

## 10. Research art-iculation to aid multiple practices

The practice part of this thesis consists of an expression of the research findings in a painted format. This has been called: an *art-iculation*. In chapter 8 references were made to the paintings when they had brought forward specific understandings of participants' metaphors. In this chapter I specify the wider aims, context and experience of this painting exercise.

It is inherent to a DProf in Health and Social care that the research is instigated by practices of care and care education and contributes directly to these practice fields. Contributing to closing the gap between practice and scholarship from both directions is what I feel passionate about. Artistic expressions have been described as effective in making life experiences accessible for scholarship and in making research results accessible outside academia (Cole and Knowles 2008). In this study creative material was used, as explained in chapter 7, to aid the process of data generation, but participants were not invited to craft their expression. It is at the dissemination stage that this study engages with the domain of arts in qualitative research.

The answer to the question as to how to take the findings back to practice emerged as the research work unfolded. The idea of expressing the research findings in a painted format started as an intuitive thought. This sprung, not in the least, from knowing an artist-painter whose painting style I perceived as potentially conducive to what I wanted to express and with whom I believed a productive cooperation was possible. Yet the resolve to take it forward only came when I understood that it could serve multiple purposes and practices.

Initially I was thinking of using the paintings in my practice of training health care students and practitioners and in my counselling practice with individuals or with groups of survivors. Inherent to art is that it enables reaching out to wider audiences (Leavy 2018). This has now opened up the thought of dissemination to a wider or more general public.

I also became aware of how the paintings could benefit the present research practice itself. In aiming for a holistic understanding and presentation of the research findings, I was conscious of the difficulty of moving from engaging with different interpretive 'lenses' to integrating several 'lenses' (see vignettes). It became clear to me that the next move towards a more "seamless" (Galvin and Todres 2007, p.37) holistic presentation would be helped by using a medium that presents parts and wholeness in a more balanced and non-linear manner and where the focus on one or the other is handed over to, rather than imposed on, the viewer.

Finally, gaining this first-hand experience strengthens my ability to explore and encourage arts based research in my role as lecturer and supervisor of qualitative research in counselling and psychotherapy.

In subsequent sections I present reflections that I deem relevant in preparing for the use of the *art*-iculations in practice. In the first section painting is linked with research as an enactive interpretation. In the second section the creation of the paintings is explored from a relational perspective. In the third section I turn to the health care sector and discuss some differences and similarities between using paintings for educational or therapeutic purposes.

## **10.1 An ongoing enactive interpretation**

As much as the body of literature that explores and explains the productiveness of the relationship between research and art is growing it is not unusual to think of research and art as opposites; the former being factual, the latter fictional. This means that using art in research is only sensible from a research paradigm that sees this as a false dichotomy. This is a paradigm that acknowledges and embraces the uncertainty and interpretive character of research findings and that finds in art a medium that can engage with that uncertainty (Hearing and Jones 2018).

Such a paradigm underpins this study. Data generation and inquiry have been understood as enactive interpretations. The inquiry into participants' metaphorical comprehensions of self vis-à-vis cancer resulted in distinguishing body schematic structures, narratives of wider self, and narratives of transactions with consultants. Although transferring the research findings into paintings for educational or therapeutic use falls outside the 'research part' of this thesis, the process of transferring the findings into painting has to be understood according to the epistemological views that underpin the research. Presented with the research findings the artist-painter cannot but make interpretations which are informed by an untraceable background of old and new knowledge and experiencings. All this becomes part of what Gendlin (2004) would call the implicit. Expressing the implicit understanding of research data through painting is, then, a process of searching for a painted image that resonates with the felt sense of the findings. This interpretation is enactive: it happens in a transaction with the canvas, the brushes, paint and pastes, etc. Painting, as well as the ending of the painting, takes place and form in a process of communication and feedback between the artist and the researcher. 'Enactive interpretation' encompasses more than what is in awareness, but in a process like this, enactive interpretation is also very tangible in a number of ways:

First, over time it became clear that the decision to call the paintings 'finished' could only be made by the researcher. There was an unmistakable feeling about a painting capturing the research findings, or not yet. We, i.e. the researcher and the artist, also discovered that there was not just one way to reach this sense of accuracy, but the challenge was that it had to be inferred by the artist from explanations and reflections made by the researcher.

Secondly, decisions about the size and number of canvasses for each of the metaphors (2 small-sized canvasses of 13x18 cm and 1 medium-sized one of 26x36 cm), about the use of paste in addition to paint, about portrait or landscape format, were made in an ongoing search for the means that best 'afforded' the expression of the research findings.

Thirdly, the painting process could only happen through co-operation. The process entails the absolute interdependence between researcher and artist and may therefore not suit everybody. In the next section I expand on issues specifically related to relational artistic research interpretation.

## **10.2 A relational artistic interpretation of research findings**

Much of the literature on art based research reflects on practices where the researcher is also the artist. A relational dimension has the potential to add a dynamic and richness to the work. However, it also triggers specific ethical and epistemological concerns. Informed by professional ethical guidelines, I most of all believe in transparency, in clear communication with all involved (artist, supervisors), and in making informed decisions. Decisions are never based on a mathematical weighing up of all the pros and cons. They rest, ultimately, on the belief that the process between researcher and artist will produce worthwhile and rigorous work. This raises the question of the formation of the working relationship, the identity of the artist-painter, and the experience of co-creating research based paintings. I now turn to these issues.

A brief informal exploration of the artist's interest in this project was followed up with a written description (see appx.H0) of the rationale and aims, anticipated ways of working, potential challenges and the need to agree a financial arrangement. This document created a focus, a first step in enacting a process that was yet unknown to both researcher and artist.

We both considered the artist's personal experience with cancer (15 years ago) as beneficial for the project. Beneficial also were his professional experience with attending to other survivors' experiences, and the fact of having worked, with the researcher, previously. Both the artist and the researcher felt they were familiar with each others' personality.

A point of uncertainty and reflective attention was whether other stresses in our lives would seek an outlet in the painting process and thus interfere with the research findings. Anticipating that the project would take a year there was the fear that something might jeopardise completion. The biggest uncertainty was also the biggest pull, i.e. the commitment to an unknown process. This uncertainty was exacerbated for the artist by his not knowing the research data beforehand and for the researcher by her unfamiliarity with the art, and the craft, of painting.

A specific aspect of the identity of the artist was discussed and explored with great attention. The painter-artist is also the case study participant whose metaphors, in the work at hand, have been analysed and discussed in parallel with those of the research participants. As it was agreed to respect the anonymity of the case study participant in this thesis, it followed that his name was not mentioned in relation to the paintings either. The artist was asked to paint research interpretations of his own and others' metaphorical comprehendings. After a trial with a small number of paintings we were reassured that, probably because the artist's metaphors expressed experiencings from 10 to 15 years ago, they did not take him back to that time. They were painted from a stance that was not unlike the one from which he engaged with other participants' material.

Art that stands on its own will be created according to the aims of the artist. These may be multiple but it is expected and accepted that the satisfaction of the artistic drive and craft are paramount. When research uses art, it comes with an inevitable tension as another goal is not just added but given priority over the normal artistic goals, even though artistic impact is also expected to be present (Lapum 2018; Leavy 2018). In hindsight, finding an effective way to communicate and paint the research findings required us to allow enough freedom to the artist and to the researcher "to do their thing well". The process towards reaching that point evolved around two issues. The first was about finding out how best to present the research findings to the artist-painter in order to generate 'research based' paintings while also

safeguarding the anonymity of the research participants. The latter was achieved by only sharing anonymised and summarized or interpreted data rather than the recordings or transcripts. The anonymised summaries are included in appxs. F. The second was about discovering how to use structural and textural form to express both the body schematic and the contextual and emotive findings. Three separate paintings gradually took shape for each metaphorical comprehending of self. They were created in a specific order and based on specific information, as follows:

The first painting is on a small canvas and is a textural expression of participants' comprehending of self vis-à-vis cancer. The researcher read out the anonymised summary of the participant's experience and the artist listened while focusing on mood, process and personality, rather than facts or specific images. The artist made attempts to integrate the wider sense of the person in their present stance towards cancer. This painting was strongly led by the artist but usually created for both the artist and the researcher a sense of reassurance that the experience could be captured. We learned that it was not possible to paint a textural impression of the data after attention had been given to detail and data structure and therefore it had to come first.

The second painting is also small and depicts the kinaesthetic and spatial structure of the metaphors with a recurring 'stick figure'. This figure is informed by but not identical to the schematic drawing by the researcher (see 7.4). It is embedded in a context that expresses the overall comprehending of self in relation to cancer. For this painting researcher and artist jointly read and discussed, in detail, the summarised data and the interpretations. This painting was most guided by the researcher in making sure the more exact research findings were accurately presented. This painting was often finished with a sense of surprise and relief. The artist worked with a total focus on the painting at hand without comparison with earlier paintings (i.e. of other metaphors). For the researcher, keeping an eye on the complete data set and their body schematic links could not be avoided.

The third painting is medium-sized and incorporates the stick figure and any other necessary conceptual messages, but aims to balance this with a textural expression of the experience. Finishing these paintings mainly evoked a sense of achievement and beauty. To engage with a felt sense and a conceptual understanding simultaneously is very challenging. So is painting from such a dual stance. In that sense the small paintings, which focused on felt sense and conceptual understanding separately, prepared the way for the combined, medium-sized painting.

At the end of this chapter (Figure 25) the third paintings are presented in thumbnail format as a reminder of the full set of paintings which will have been viewed as part of chapter 8 on the portable data-storage device attached to the thesis. The colouring that frames the pictures refers to the colours that were used to differentiate the 'stepping stones' presented in the discussion of the nine enactive clusters.

### **10.3 Using research based paintings in health care education and practice**

The intention is to use the paintings in educational settings with health care practitioners and in therapeutic settings with cancer survivors. The educational work I envisage to happen in groups up to 15 attendees as this allows for interactive work. The therapeutic work could be individual or in groups. In this final section I briefly outline some aspects of the approach I believe the paintings 'afford'.

Paintings invite, in the first place, visual engagement. Yet, in this case, the paint has deliberately been mixed with paste to also invite tactile exploration. This is also enabled by the small size of the canvasses. One could take this kinaesthetic engagement further by inviting people to mirror the positions of the stick figures and to experiment with the movements depicted in the paintings.

Lakoff and Johnson (1999) pointed out the shared character of human body schemas as a basis for empathy. Motor simulation theories do so by referring to mirror neurons (Gallese 2001; Gibbs Jr 2006). Others such as Gallagher et al. (2002) caution not to reduce inter-subjectivity to motor simulation or shared body schemas. By introducing health care practitioners and students to survivors' comprehensions of self through sensory and kinaesthetic impressions, but to the underlying metaphors and narratives as well, I hope to be able to open up a space where the full evocative potential of the paintings can flow, and trigger what Galvin and Todres (2007, p.37) call "empathic imagination", i.e. a real imagining of the other person's world. It is expected to also awaken their pre-understanding of cancer survivorship. This is an important factor in causing the implications of new insights to be understood and instigating improved practices (Schmitt 2005, p.375) . This inter-subjectivity entails a demand on people's being (van Manen 2007; Todres 2008) and enables not just rational but also actionable knowledge (Galvin and Todres 2011).

In a therapeutic role the focus is on enabling cancer survivors to better connect with feelings and thoughts that are not fully conceptualised or verbalised, and about bringing those into consciousness. Philosophies of movement which consider movement as the basis of thinking (Sheets-Johnstone 2009) would suggest and underpin the practice of inviting cancer survivors to engage in a multi-sensory way with the paintings and the embedded movements depicted in them. Certainly in experiential psychotherapy the integration of body work in talking therapy has been acknowledged for its deepening and expanding effects (Leijssen 2006).

My own research-based understanding of the paintings and their sequence I imagine to remain in the background. However, they will inform my responses to practitioners' and clients' as they engage with the materials and 'enact' their own understandings.

For the purpose of this thesis the paintings have been included in the form of a power point presentation. The suggestion has been made to present them in a video format, in order to reach a wider audience beyond the world of health care services and practices. This is not unimportant in an age when ever more people survive cancer but come across a lot of misunderstanding in their communities and in wider society. Power point presentations and videos are useful tools for teaching purposes as well, although it should perhaps be repeated that it is the actual paintings themselves that are expected to trigger 'empathic understanding' more effectively. When using the paintings in therapeutic settings, it might be beneficial to also present them in a small evocative booklet for further contemplation as people live through this ongoing process, called survivorship.

The paintings are finished but as carriers of understandings of cancer survivorship they are just paused and are now awaiting further interpretation through a variety of professional, academic and personal lenses.



Figure 25: Research-based paintings of comprehendings of self and cancer

## 11. Thinking self during and after research

At the beginning of this thesis I recalled the time when my thinking of cancer survivorship was like looking through unfocused binoculars (1.1.2). It was not the first time I was confronted with an unfamiliar process in my counselling practice; however, this particular gap in my understanding was different as it sparked an invigorating interest in researching the topic. In hindsight I realise that, although I did not share their experience of cancer, listening to cancer survivors pointed to the heart of living: how to fulfil our being in the awareness of death? In other words, sub-consciously, at heart this research has been an exploration of the existential liminality of being. Gaston Bachelard's poetry on 'The Flame of a Candle' allows me to convey how I felt during this early stage of my enquiry. The flickering of a flame is not unlike the way I then felt energized; intensely orientated to what was unknown, i.e. the space evoked *beyond* the flame.

"What delicacy of life in the flame that lengthens and tapers off! Then the values of life and dreams are united" (Bachelard 1988, p.40).

The on-the-job case study, I felt, had given me a head start. The related inquiry into conceptual metaphor theory and the emerging insights from its application, at least initially, functioned as an anchor. In spite of this anchoring, the complexity of my research unfolded, not in the least by the gentle though incisive questioning by my supervisors. Instead of looking through my binoculars, the task at hand became to understand which model they (i.e. the binoculars) were, and to decide, eventually, that I needed a more sophisticated model if I wanted to explore survivorship from the holistic perspective I value. I also needed to find out who else was looking into the issue of cancer survivorship, and who was doing so from my angle? This changed the research experience from 'looking' to 'doing'. Early on it reminded me of tipping out a big box of Lego bricks as a child and feeling overwhelmed as the sight of it almost wiped out my resolve and aspirations. Never did, and do I understand the emotional basis of reason better than in the struggle to get a grip, initially always precariously, on a big, unfamiliar and

unknown experience. Despite there being no real comparison, this early research experience intensified my compassion and empathic comprehending of the research participants' stories of being adrift at the point of diagnosis and during early survivorship.

I became bodily aware of this process of immersion as the research interviews progressed. As described in the main text, the data generation process started as an experience that I likened to 'taking down music notes', but then it evolved into an experience of 'jointly kneading the soil' (6.1.5). It brought to my attention how relational comprehending and embodied comprehending are mutually reinforced. This ultimately rippled into an understanding of the data inquiry process as a 'hermeneutic dance' in which I would depict the researcher with ever strengthening and open wings that absorb and colour the data, and fuel an ongoing process of interpretation. Yet, as I am writing up this personal narrative, the end date for this thesis appears on the horizon. Initially I felt at a loss as how to live and conceptualise this closure. But now, imagining "the hermeneutic wings resting and folding like a cloak" seems to resonate intellectually and emotionally. This image expresses the sense that both the gathered understandings of cancer survivorship and the awareness of their indefinite character now form a cloak around me. This metaphorical cloak holds two notions: closeness, but with a tiny gap between me and the cloak.

The notion of closeness is important. It suggests a sense of owning the explored comprehendings of survivorship and the interpretations that emerged from my theoretical perspective. This intimate knowing conjures up an experience of being 'hands free' and able to give and receive in dialogue with health care practitioners and survivors, as has been described in the practice part of this thesis. The notion of the gap is equally important. First, it is an acknowledgment that parts of participants' experiencings are outside the reach of research or have been sidelined by the specific focus and limitation of the interpretive framework of this study. Second, it is a conceptualisation that conveys how I, as the researcher, experience this

moment of bringing closure to seven years of research. It is to this experience that I wish to dedicate the last paragraph of this thesis.

Life has been good to me during my research time. No major problems occurred. Nevertheless, the length of time which comes with doing a part-time DProf creates a feeling of travelling through a tunnel under a river. I anticipate finding myself on the other bank, and acutely aware of being at a different stage of life from when I started. In the introduction I described how writing a thesis felt like a way of closing many years of professional counselling practice. Yet the research experience brims with theoretical ideas of continuity, as well as professional expectations about taking the findings further, academically, but also into practice. For months I wondered how to capture this energy whilst also admitting that at 57 years of age I might seek to leave the treadmill and strive for a more equitable work-life balance. I do not wish to be blind to the fact that life is finite; a lesson I was reminded of when some potential participants withdrew as they unexpectedly faced recurrence or terminal illness (appx.H1). But then I received a present. It came with a nebulous, sub-conscious sense of significance; a type of feeling which Robert Romanyshyn (2010) encourages researchers not to dismiss. The present, which was a real gift, came in the shape of a bowl made of clay with earthy natural materials baked into it. This material now symbolises my research findings. I have filled the bowl with water and intend to put it down, thereby enacting a tiny gap between me and the research. Yet close enough to invite other people to look into the bowl with me, that is, to look at the research results embedded in the clay, in the knowledge that they are alive, and that what we see is a reflection mixed with our own reflections as we look into the water.



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## APPENDICES

## **APPENDICES A**

### **APPENDIX A0: Case study**

#### **Introduction case study participant**

In September 2004, at the age of 58, Edward was diagnosed with bowel cancer. When later on liver metastases were also discovered he was given a prognosis of about a year. In October surgery was performed and a permanent ileostomy bag was fitted, followed by chemotherapy. The chemotherapy was stopped short of the last session in March 2005. Edward discussed the option of counselling with his Macmillan nurse and attended a first session with myself at the hospice in February 2005.

#### **The idea of conducting a case study**

In June 2006, while for Edward the experience of cancer survivorship continued, the need for counselling came to an end. Referring to Stiles' assimilation model about the process of change in counselling, he had reached the stage where he showed a level of insight that enabled him to see new experiences as intriguing rather than a cause of emotional distress (McLeod 2010). For both of us it was obvious that his experience of survivorship would further unfold and that it would be beneficial for him as a survivor and for me as a practitioner to continue our explorative conversations. We set out to bring previous and new experiences together as an on-the-job case study with the intention to write a joint article and make our understandings available to other practitioners and survivors (Etherington 2001). In other words an action agenda was added to our interest in cancer survivorship (Creswell 2007). Our focus was on contributing to a better understanding of the experience of cancer survivors post-treatment.

#### **Ethical approval**

The transition from a counselling to a peer-collegial and co-authoring relationship and any professional ethical issues related to such a situation

were thoroughly discussed between the two of us and between me and my Counselling Supervisor.

### **Theoretical framework**

By the end of 2006 Edward and I had explored a range of angles to explicate the experience of cancer survivorship and we began to notice how often we turned to metaphorical language to express new and uncertain feelings and thoughts. An article by Tompkins et al. (2005) introduced me to Lakoff and Johnson's Conceptual Metaphor Theory and the embodiment of cognition, meaning and philosophy (Lakoff and Johnson 1980; Johnson 1987; Lakoff and Johnson 1999). Looking at metaphors as an act of thinking rather than as a linguistic description of an already formed thought resonated with that sense of doing, searching, and trying to understand, which I noticed in Edward and other clients as well, as they were trying to deal with their changing relationship with cancer through finding the right words and metaphorical imagery.

### **Case study: underlying principles**

Based on my professional experience with cancer survivors, and my introduction to Lakoff and Johnson's Conceptual Metaphor Theory, I set out to conduct an on-the-job case study from the following preconceptions:

- 1/ Cancer survivorship is an ongoing process that straddles both vulnerability and strength;
- 2/Cancer survivors are the experts on the cancer survivorship process in all its individual and contextual diversity;
- 3/ Metaphorical and non-conscious expressions are valuable keys to understand the way cancer survivors experience and think about cancer, clinicians and their self.

### **Case study: aim**

In this case study I set out to explore and better understand the psychological experience of self and cancer after finishing treatment.

## **Data generation**

Case study data was collected over a period of almost five years and consists of 8 metaphorical expressions at different points in time of Edward's experience of living after a bowel cancer diagnosis and treatment.

The metaphors were not collected at pre-organised research meetings but emerged in meetings that focused on recently lived cancer related experiences. The first 2 metaphors were collected during our client-counsellor contact. Some time after finishing counselling, we decided to continue the exploration of Edward's continuing cancer survivorship experience and to attend more closely to the conceptualisation of new challenging cancer related experiences. It was during this professional co-research work that, subsequently, 6 more metaphors emerged. The way the metaphors were initially recorded varied according to the circumstances of occurrence: 'fog' and 'terrorist' (as counselling notes) – 'play 1' and 'play 2' (directly written by Edward) – 'adoption', 'war veteran', 'horror movie', 'birth sculpture' (written up by Edward after expressing them verbally to me). The methodology I employed emerged spontaneously from my practice. It is in hindsight that I understand that I employed a broad phenomenological approach and an exploration style which was specifically geared towards enabling expression of that which is difficult to speak.

## **Case study: method of analysis**

The method of analysis was informed by Lakoff and Johnson's Conceptual Metaphor Theory. It consisted of highlighting the physical and spatial movements and sensory experiences of the subjects conjured up in the metaphors. Secondly I referred to the subjective meanings that Lakoff and Johnson have found to be captured by these sensori-motor and spatial experiences.

## **Case study: discontinued and preliminary findings**

In 2009 it became clear that Edward's case study could not be accomplished within the context and time we had available and the work was put on hold. This meant that the exploration and interpretation of the data was incomplete:

1. Only five of the eight metaphors were then (i.e. between 2005 and 2009) explored in terms of their body schematic structure. From these findings emerged the view that the metaphors emerged with increasing body schematic complexity. This led to the idea that it might be useful to deliberately look at experiences of self during survivorship from a cognitive developmental perspective. The terms that were used to capture the structure of the first five metaphors were: Presenting, Sizing and Positioning, Movement, Action and Directing. An attempt was made to capture the implied sensory differences between the metaphors but this seemed less useful for distinguishing the experiences. These results (i.e. for those 5 metaphors) are presented in Table 11 below.
  
2. My understanding of the totality of the process up to five years into survivorship I captured with the following metaphor:  
*Surviving cancer is like long-distance running. Runners first take their position in the starting block (E positioned body-self in relation to cancer and clinicians in Fog and Terrorist metaphor), run blindly within their lane (E moves guided by the clinician's script in Play 1 metaphor), then assess their own and others' performances and potential and try to take first position (E acts away from script in Play 2 metaphor) and then acknowledge that they need to take control over this vivid, small runner who seems to stay in their trail (E accepts that cancer is staying and is better owned and directed in Adopted metaphor).*
  
3. The body schemas that structured the experience of self, were also analysed for how they structured the experience of understanding, engagement and time. These interpretations (again only for the 5 metaphors that were analysed between 2005 and 2009) are presented in Table 12 below.
  
4. A discussion of the findings was started with reference to a number of philosophical and psychological concepts. As this work was at an early stage, these interpretations have not been included in this thesis.

In addition to the practical impediments in 2009, it also became clear that:

1. The conceptualisation of self and cancer would further develop and lead to new metaphorical expressions;
2. As a practitioner I had drifted into a piece of research, driven by an interest in the experience of clients, and drawing on previous research training and parallel principles of inquiry in counselling. Yet increasingly I felt a need for a more in depth consideration of methodology.

During the analysis I realised though that metaphorical data analysed from a perspective of embodied thinking and Conceptual Metaphor invited specific modes of understanding that are very apt for health care practice. With reference to the literature consulted during my DProf research, I would summarise those as:

- Detailed, conducive to person-centred care;
- co-considering vulnerability and agency, conducive to realistic humanising care (Todres et al. 2009);
- Existential, conducive to holistic care;
- Patterns and structuring processes, conducive to dynamic thinking;
- Empathic, conducive to actionable education (Galvin and Todres 2011).

### **Dissemination of preliminary case study results**

At a health care conference in 2007, Edward and I presented some of the case study metaphors as a string of visualisation exercises. Attendees' feedback indeed reflected how this enabled them to engage with the material beyond their preconceptions.

### **From case study to research**

When in 2013 the opportunity arrived to further study the psychological experience of cancer survivorship at doctorate level, I thought it was worthwhile to take forward and refine the theoretical framework and methodology of my case study and to let my research theme, topic and objectives emerge from my case study experience:

- For the case study I gathered data up to five years post-treatment but as I felt that the experience would further unfold and change in subsequent years, at the inception of the research project I planned to explore the experience of survivors who were up to 15 years post-treatment.
- What I noticed in Edward's reflections was a post-treatment process of experiencing and conceptualising of self in interrelation with cancer and cancer clinicians. By interrelation I mean that at times it seemed that his view on cancer or cancer clinicians shaped his view of self, while at other times his view of self seemed to shape his view of cancer and clinicians. It seemed logical to put the self during survivorship at the heart of my research topic.
- During the exploration of the case study I acquired a number of impressions about the depth or nature of the differences between the experiences of self over time, about a possible direction of the experiences and about the nature of a possible end result. Those impressions motivated my research but I decided not to use them as a 'hypothesis'. I chose to carry out explorative research, rather than test any case study based hypothesis in relation to the nature of the process of experiencing and conceptualising of self post-treatment.

Edward full-heartedly stepped back from our original plans for a co-authored article and generously gave me permission to integrate in whatever way appropriate the material and reflections gathered at the time. I wrote up a Participant Information sheet and Consent form that explicated the situation (appx.A1). The consent form was signed September 2013.

During the original case study the following shortcuts were used to refer to the five metaphors: Fog, Terrorist, Play 1, Play 2 and Adoption. When these will be discussed together with the metaphors of the 12 other research participants, I will still use the shortcuts 'Fog' and 'Terrorist' but Play 1 is referred to as 'Theatre play', Play 2 as 'Unknowable' and Adoption as 'Adopting'.

Table 11: Case study findings - part 1

*Re-use of metaphor of previous achievement the metaphor gets a handle on the new achievement the metaphor gets a handle on The secondary frustration the metaphor expresses*  
*Sophistication of earlier achievements the metaphor gets a handle on The frustration of the new achievement the metaphor gets a handle on*

METAPHOR	CUT OFF	FOG	TERRORIST	PLAY 1	PLAY 2	ADOPTION
Principal sensory function	-	Visceral	Sight	Hearing	Voicing	Touching
Principal motor function						
Directing between clinicians and self					Self corrects clinicians script	N/A
Directing between cancer and self					Passive	Personalised cancer limits control of self
Directing by self					Reconnecting with past self	Future orientated
Action between clinicians and self				Self supported by clinicians	Self moves clinicians	
Action between cancer and self				Passive	Self mirrors cancer	
Action by self				Passive	Self-propelled movement	-
Movement of clinicians			In stупense	Clinicians act	Clinicians act	-
Movement of cancer			In stупense	Cancer action in script	Cancer action in script	Cancer acts naturally
Movement of self			Frozen	Self moves	Self acts	Self acts naturally
Positioning of clinicians in relation to cancer		Same space Not in view	Separate space Nearby Active cancer would be seen by clinicians	Separate space Nearby Only Active cancer seen	Separate sp Nearby Only active cancer seen	-
Positioning of clinicians in relation to self		Same space Clinicians not in view	In between self and cancer C1 more central than self	Same space In view C1+S away from ca C1 more central than self	Same space In view C1+S together Self more central than clinicians	-
Positioning of cancer in relation to self		Same space Cancer not in view	Separate space Distant Not in view	Separate space Nearby Only Active cancer seen	Separate sp Nearby Only active cancer seen	Same space Touch Inactive cancer seen
Seizing Cancer		Cancer big Through visual inability	Small through distance	Small through absence	Small through absence	Small through child image
Presenting	Self-Cancer Not present	S+C+CI (Blindly) Present in the world	S+C+CI Seeing Present In illness community	S+C+CI Seeing Present In illness community	S+C+CI Seeing Present Centre of illness community	S+C+CI seeing Present CI not present In family context
Time line	End of treatment	+ 0 months	+ 4 months	+ 22 months	+ 22 months	+ 2 years

Metaphors we recover by - K. Vaidyanathan

Table 12: Case study findings - part 2

SUBJECTIVE CONCEPTUALISATION of Cancer, Clinicians and Self as an Understanding, Engaging and Continuous agency

METAPHOR	CUT OFF	FOG	TERRORIST	PLAY 1	PLAY 2	ADOPTION
<b>UNDERSTANDING</b>						
Focus (principal body of metaphor)	Self	Self	Cancer	Clinicians	Self	Cancer
Sense of understanding		Overall Not knowing Overall helming uncertainty	Self slightly more knowable	Relying on clinicians know-how	Personal experience of un- knowable aspect of cancer as source of knowledge	Knowing as your own
Conceptualisation of Cancer		Suggested to be around "ineasy unknown presence" Potentially helping or harming (active or inactive)	Imagined to be out there "retreated oppressor" Inactive (less active) but potentially active	Known to be out there "unpredictable uninvited guest" Inactive but potentially active	Known to be out there More to it than known Inactive but potentially active	Mine "ongoingly unruly child" Negotiating cancer
Conceptualisation of Clinicians		Suggested to be around Uneasy unknown presence Potentially helping or harming (active or inactive)	Imagined to be there Expertise in noticing cancer activity Imagined as protective buffer between self and cancer	Present at centre Expert know-how on dealing with cancer Helping and guiding	Present at periphery At times making unfounded statements about cancer Supportive if through sharing unknown	-
<b>ENGAGEMENT</b>						
Self in its engagement to self		-	-	-	Aligning present self with real (past) self	Taking present self (with cancer) forward into future (forever)
Self in its engagement with cancer		Not knowing relation to cancer - lost "existing" Passive Vulnerably dependant	Victim in Frozen defensiveness "co-existing" Passive Guarded dependant	Prepared anticipation "co-operation" Reluctant Host	Embracing unknown "co-expressing" Rebellious Host	Owning unknown "co-habiting" Negotiating Parent
Self in its engagement with clinicians	Abandoned patient	Not knowing relation to clinicians passively Vulnerably dependant	Unclear about relationship Passively Vulnerably reliant	Self part of community of illness Fun and respect Engaged-more lively Dependant-supported patient	Self central in community of illness Valued conversations Active Inter-action between clinician and patient	-
<b>CONTINUITY</b>						
Time focus		Past	Past (-present)	Present + near future	Past-present+ near future	Present + long term future
Attitude to time passage/change		Subdued	Preserving	Developing pace	Engaging with (no flow)	Natural continuation

Metaphors we recover by -XXXXXXXXXX  
Draft August 2008

## APPENDIX A1: Case study Participant Information Sheet + Consent form

### **Participant information sheet**

#### **Understanding the psychological process of Cancer Survivorship**

A number of years ago we jointly set out to explore and write about the above topic. The material we collected over a period of almost five years consisted of 8 metaphorical expressions at different points in time of your experience of living after a cancer diagnosis and treatment.

The first 2 metaphors were collected during our client-counsellor contact. The other 6 were recorded during our professional co-research work.

The way the metaphors were initially recorded varied according to the circumstances of occurrence: 'fog' and 'terrorist' (as counselling notes) – 'play 1' and 'play 2' (directly written by yourself) – 'adoption', 'war veteran', 'horror movie', 'birth sculpture' (written up by yourself after expressing them verbally to me). We jointly facilitated a conference workshop in which you presented the first 5 metaphors in your own name. We took some notes of the responses of the conference participants.

As you are aware I have analysed the metaphors using Lakoff and Johnson's Conceptual Metaphor Theory. This revealed the changes in your perception of cancer, consultants, self and the relationships between these factors.

At some point it became clear that our research evolved from a professional to an academic piece of work and could not be accomplished within the context and time we had available. The work was put on hold.

As part of my employment Hospice X asked me end of 2012 to complete this study. In order to do so I am searching for an arrangement with a University to pursue this as a Doctoral project.

I would like to include the metaphors you have provided and any reflections and insights gathered at that time. We discussed this end of 2012 and you

gave me verbal permission to use any of this material as I saw fit.

Nevertheless at this point in time I want to ask you formally your permission to use this material anonymously as part of my research. Before you decide, take time to read the following information carefully, discuss it with others if you wish or ask me for more information if anything is not clear.

### **What is the purpose of the study?**

Cancer survivorship has been researched by a myriad of professional disciplines. With my thesis, I aim to contribute to the understanding of how cancer survivors conceptualise their self in relation to their conceptualisations of Cancer and their medical consultants over a period of 10 years. First, I aim to contribute to an understanding of their experience at different points in time. Secondly, I hope to build an understanding of the changes of the experience over time and last but not least I want to explore whether there is a pattern to these changes.

Insights coming from this study I believe will be relevant to both patients and their professional support workers. First, understanding an experience contributes in itself to better coping. Secondly, a more detailed differentiation of the overall cancer survivorship experience should enable a better assessment of a patient's psychological experience of cancer at any point in time and a more purposeful and informed professional response to it.

### **Why have I been asked to participate to this study?**

Including your metaphorical expressions I consider relevant and valuable for 2 reasons:

1/ This wider piece of research has been prompted by some tentative findings following the analysis of the metaphors you provided:

1.1. The cancer experience changes in ways that are psychological, spiritually and socially meaningful. I believe this needs to be understood better.

1.2. The analysis revealed parallel cognitive changes that suggest a logic akin to early developmental processes. If this is a general pattern then it might provide useful clues for assessment of need and provision of support.

Therefore I consider this pre-existing material as the 'founding case study' for further rigorous academic research of the topic.

2/ Having an insights in the cancer experience of one patient at 8 different points in time over almost five years is unique. I will not be able to repeat this with other participants.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw up till the 1<sup>st</sup> of November 2013 and without giving a reason. Withdrawing can be done by leaving a written note to the researcher by email or post. A decision to withdraw or a decision not to take part, will not affect you in any way.

### **What are the possible disadvantages and risks of taking part?**

There are no disadvantages or risks foreseen in taking part in the study.

### **What are the possible benefits of taking part?**

By taking part, you will be contributing to the development of a better understanding of the experience of cancer survivorship which I aim to disseminate in 2 ways:

1. academically through conferences and journal articles
2. professionally through my employment at St. Luke's Hospice and teaching sessions for nurses and other cancer support professionals at Cheshire Hospice Education.

### **What if something goes wrong?**

If you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact my employer (Siobhan Horton, Director of Clinical services at St. Luke's Cheshire Hospice) or my professional organisation (BACP).

**Will my taking part in the study be kept confidential?**

If the metaphors become part of the research material of this Doctoral project and of any subsequent dissemination via conferences, journal articles or educational activities, no identifiable information will be included. The original identifiable written transcripts will only be accessible and stored by the researcher.

We need to keep in mind though that through our joint facilitation of the conference workshop the metaphors could always be traced to be yours. Therefore it is important that you only give consent if you are fine with the fact that I cannot guarantee absolute confidentiality.

**What will happen to the results of the research study?**

The results will be written up into a dissertation and will be disseminated as described above.

**Who is organising the research?**

At this point in time the research is conducted as part of my contract with Cheshire Hospice Education. Sally Jeynes and Siobhan Horton are my managerial supervisors. In the coming months I hope to arrange academic supervision as well.

**Who may I contact for further information?**

If you would like more information about the research before you decide whether or not you would be willing to take part, you can contact me as follows:

Kathleen Vandenberghe - [k.vandenberghe@chester.ac.uk](mailto:k.vandenberghe@chester.ac.uk)

Tel. 01606 555 694

St. Luke's (Cheshire) Hospice Queensway Winsford CW7 1BH

**Thank you.**

Kathleen Vandenberghe, 15<sup>th</sup> of August 2013

## Consent Form

Title of Project: Understanding the psychological process of Cancer Survivorship

Name of Researcher: Kathleen Vandenberghe

Please initial box

1. I confirm that I have read and understood the participant information sheet, dated 15.08.13, for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw up till 1/11/13, without giving any reason and without my care or legal rights being affected.
3. I agree for the 8 metaphors I provided and any related discussion notes to be used as part of this doctoral project.
4. I agree for the material I provide to be referred to in a non-identifiable way during conference presentations, journal articles, educational or professional activities.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## APPENDIX A2: Ethical approval from BU to use case study material

RE: Query re approval case study ethics  
Research Ethics  
Wed 11/05/2016 08:31 'Kathleen Vandenberghe' (kathleen-vandenberghe@hotmail.co.uk)

Hi Kathleen

Thanks for your email.

Sorry for the ambiguity and for not confirming but the consent is fine and you're ok to go ahead to use this data and refer to it in your current study. This was confirmed in consultation with the SSH REP Chair.

Kind regards

Sarah

Sarah Bell

Research Governance Adviser

Research, Knowledge Exchange Office

## APPENDICES B

### APPENDIX B0: Primary Metaphors examples

From: Lakoff, G. and Johnson, M., 1999. *Philosophy in the Flesh. The Embodied Mind and Its Challenges to Western Thought*. New York: Basic Books, p.50 – p.54.

In addition to the examples included in the main text:

**Knowing is Seeing**

**Actions are Self-Propelled Motions**

**Time is Motion**

**Relationships are Enclosures**

**Importance is Size  
or Important is Big**

Subjective Judgment: Importance

Sensori-motor Domain: Size

Example: Tomorrow is a big day

Primary Experience: As a child, finding that big things, e.g. parents, are important and can exert major forces on you and dominate your visual experience.

**Difficulties are  
Burdens**

Subjective Judgment: Difficulty

Sensori-motor Domain: Muscular exertion

Example: She's weighed down by responsibilities

Primary Experience: The discomfort or disabling effect of lifting or carrying heavy objects

**States are  
Locations**

Subjective Judgment: A subjective state

Sensori-motor Experience: Being in a bounded region of space

Example: I'm close to being in a depression and the next thing that goes wrong will send me over the edge

Primary Experience: Experiencing a certain stage as correlated with a certain location (e.g. being cool under a tree, feeling secure in bed)

**Understanding is  
Grasping**

Subjective Judgment: Comprehension

Sensori-motor Domain: Object manipulation

Example: I've never been able to grasp transfinite numbers

Primary Experience: Getting information about an object by grasping and manipulating it

## APPENDIX B1: Primary metaphor resource document (extract)

(total number of entries: 332)

Table 13: Primary metaphor resource document (extract)

<b>Physical domain</b>	<b>Examples</b>	<b>Physical Experience</b>	<b>Primary Metaphor that maps physical and subjective experience</b>	<b>Complex metaphor to which the primary metaphor belongs</b>
Eating		Swallowing	Acquiensing is swallowing	Evaluation / Social Relation
Eating		Digesting	Fully Comprehending Is Digesting	Mind structure metaphor
Seeing	It has vanished	Being visible	Existence Is Visibility	
body motor		Having a shape	Condition of an entity is its shape	
object manipulation	He lost himself in reading	Object possession	Self-control is Object Possession	Subject-Self Structure Metaphor
Sleeping	My computer is asleep - What a sleepy town	Being awake	Activity is Wakefulness	Action
being alive	The phone line is dead - The town comes to life at night	Being alive	Activity is Life	Action
machine like functioning	I had a mental breakdown	working a machine	Normal thought is the Normal operation of the machine	
Reasoning	Give me an account of why that happened	Accounting	An Explanation is An Accounting	Mind structure metaphor
Arriving	Reaching the end, seeing the light at the end of the tunnel, only as short way to go	Reaching destination	Achieving as purpose is Reaching a destination	Local Events Structure metaphor

## APPENDIX B2: Research literature search criteria

In this study the cancer survivorship research literature has been searched by using search engines (BUmySearch, google scholar), databases (PsychInfo, Scopus, Web of Science, PubMed) and academic networking sites (ResearchGate, Academia edu). In addition I used what Bates (1989) has called a 'berrypicking' strategy by including author searching and browsing the field via the internet and by searching the references list of articles and books.

I have used 'cancer surv\*' and 'cancer' as first key words. The latter because survivorship is a times considered to refer to living with cancer from diagnosis onwards. I have used Boolean operators to link these first key words with the key words presented in Table 14.

Table 14: Research literature search criteria

To be directed to:	Key words
overview articles	Review, Meta-analysis, Directions, Systematic, Discussion
studies of colorectal cancer survivorship	Colorectal, Bowel
studies of cancer post-treatment	Post-treatment, No active disease Inactive
studies of self	Self, Identity, self concept
studies of process	Process, Long-term, Life-long, Chronic, Growth, Biographical, Recovery, Transformation, Trajectory Developmental
studies of embodied cognition	Embodied cognition, Metaphor Conceptual metaphor
studies of psychological experiences	Psychological, Fear, Uncertainty

Research literature that focused on the following topics has been excluded:

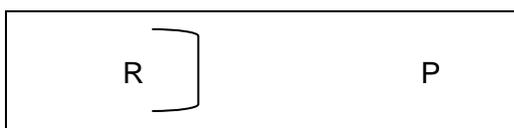
- medical aspects (keywords: genetic, screening, surveillance, tumor, chemotherapy, hormone, \*medication\*, inflammation, immune\*, advanced, surgery, prevention, sexual\*, cell\*, stage, metastatic, medical, particles, biomarker, radiotherapy, fertility)
- interventions (keywords: intervention, care plans, needs, service, programme)
- specific determinants (keywords: \*economic)
- communication and coping (keywords: communication, \*report\*, \*management\*, \*information, self-care, exercise)
- cancer in young people (keywords: \*child\*, \*pediatr\*, adolescent)
- research tools (keywords: online, web\*, scale, inventory, psychometric).
- depending on the inclusion topic, certain tumour groups were excluded from title searches (e.g. breast cancer)

## APPENDICES C

### APPENDIX C0: Body schematic structure of phenomenological 'openness'

#### “Bracketing”

In Husserl's philosophy it was considered possible to transcend (“bracket”) one's own subjectivity and see the world as pure essential consciousness. But as descriptive phenomenological researchers engage with the lived experiences of participants it was acknowledged that during research it is not their subjectivity that researchers 'bracket' but their previous knowledge and the assumption that the phenomenon really exists (Finlay, 2011, p.75). By repeatedly setting aside spontaneous ways of seeing the raw, individuated, concrete experiences, and by instead detecting and drawing out the psychological dimension of the life-world the 'phenomenon' is assumed to come into the open (Giorgi, 2009, p.131). In the Oxford English Dictionary (2019) 'bracketing' is defined as “enclose” and “put aside” which means that this act is metaphorically conceptualised by drawing mainly on a specific form of *spatial* experiencing which I want to present as follows:



#### Bridling

Other researchers, although inspired by descriptive phenomenology, do not always attune to the concept of 'bracketing'. Dahlberg (2006) for example prefers the term 'bridling'. First this term covers the meaning of bracketing but in a more nuanced way; it is understood as an act of 'reining in' rather than 'putting aside'. Secondly, Dahlberg argues that is not just pre-

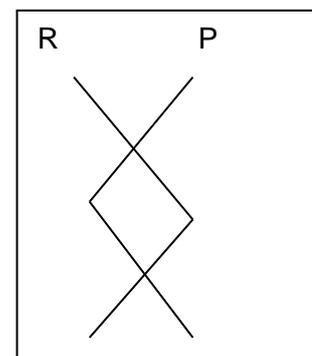
understandings but understanding as a whole that needs to be reined in (Dahlberg 2006, p. 16). A bridle is used “to control the action or movement of something” (Oxford English Dictionary 2019), in this case: oneself. It draws in the first place on a *kinaesthetic* body schema. The spatial consequence of this motor act is ‘keeping a distance’ rather than being in a separate space as is conjured up by the term ‘bracketing’.



### Reflexivity

The possibility or even desirability of ‘bracketing’ or ‘bridling’ becomes questionable if findings are not considered as emerging solely from the participants but from the inter-relation or more accurately, the ‘inter-being’, of the research participants and the researcher (Finlay 2011, p.80). This circular and mutually influencing research relationship is captured by the term ‘reflexivity’.

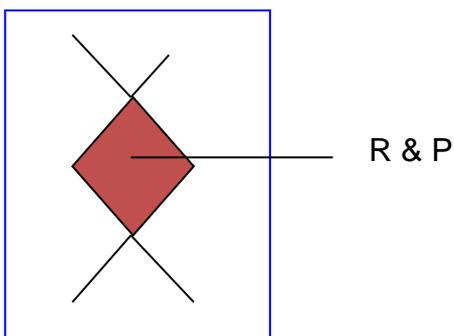
Definitions of the word ‘reflexivity’ (Oxford English Dictionary 2019) centre around an exploration of the “effect” somebody has on something or somebody. Reflexivity explores how one ‘touches’ the other rather than how one can create a ‘separation’ or ‘distance’ (see above). In other words the act that is conceptualised by the term ‘reflexivity’ draws on a *sensory* body schema.



## Empathy and embodied reflexivity

Many interpretive phenomenological researchers go beyond the concept of 'bracketing' and see openness to the participants' experiencing as coming from embracing an open empathic stance (Finlay, 2011, p.77). This implies that instead of focusing on what one does with one's pre-understandings, the focus is on what one does with participants' expressions. Empathy is defined as the "ability to understand and share the feelings of another" (Oxford English Dictionary 2019). Variants on 'sharing the feelings' may be captured by expressions such as 'tuning in', 'feeling with', 'walking in their shoes'. Based on my experience with taking such a stance in my professional practice as counsellor I believe it is important to acknowledge that, as the word suggests, empathy is in the first place an awareness of a sense, an embodied experience, rather than a reflection. In an empathic mode all that I am and think seems to be present and vibrating in the listening, talking, questioning, nodding and leaning forward and sitting back. Without the engagement of my total being I feel I would absorb less of what the other says.

The concept of empathy draws on a bodily experience of sharing, of 'falling together' in the same space, which I represent as follows:

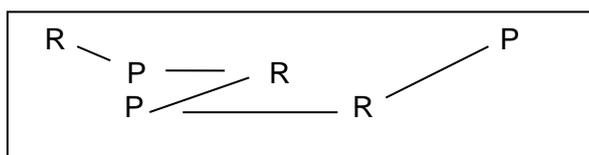


## Alternating empathy and reflexivity with bracketing

Finlay combines empathic openness, reflexivity and bracketing. The tension between openness/reflexivity and 'bracketing' she conceptualises as a dance, more specifically a tango:

“... a tango in which the researcher twists and glides through a series of improvised steps. In a context of tension and contradictory motions, the researcher slides between striving for reductive focus and reflexive self-awareness; between bracketing pre-understandings and exploiting them as a source of insight” (Finlay 2011, p.74).

Finlay's 'tango metaphor' captures the embracement of movement and more specifically a tense and responsive moving forward and backwards. As it is a dance the researcher does not really leave the space of the participant and this suggests that Finlay understands bracketing more as a bridling.



### A reflexive exploration of the relationship between bracketing, empathy and reflexivity during my research

After about three research sessions I started to wonder how I conceptualised my own approach in these explorative sessions. I had a sense that my approach was subtly changing as I became more familiar with the task. I did not understand *how* it changed though. I wanted to make sense of what I felt not in the least because I wanted to assess whether the change was congruent with my methodology.

A first reflection brought to my awareness that I experienced the interviews as a process of taking down music notes on a music sheet, with the notes symbolising participants' metaphors. Yet, the next day, this image felt unsatisfactory and from there developed a sense that I was much more hands

on and I likened my subsequent research experiences to a gardening experience. I likened the generated data to flowers on a plant and the communication with the participants as “hands that jointly kneaded the soil from where the flowers on their plant appeared”.



The first metaphor did not express an awareness of a reflexive involvement in the data generation while the second metaphor did. In the second metaphor my hands are continuously there and they are not still; they need to move together with the participants' hands as it is their joint dynamic that generates the data. This suggests that I am not concerned with actively putting any pre-understandings aside, but they potentially come into awareness in response to the working of the hands of the participants and may be used in a way that is conducive to the emerging of the participants' flowers. Based on this reflection I am inclined to argue that it has been part of my approach not to bracket my pre-understandings but to have them there in the working relationship in order to have them impacted on and changed by the participants' approach. If willingness to change pre-understandings is part of the test of real openness to participants' experiencing, then a stance of bridling, bracketing is difficult to rhyme with this, at least not in the moment.

Where Finlay describes a tango-like relationship between bracketing and reflexivity/openness, the kinaesthetic experience that underpins my gardening metaphor draws more on fine motor skills and is not so much an experience of moving forwards and backwards but an experience of understanding that metaphorically could be expressed as 'grasping'. I wonder to what extent this has been influenced by conducting research that involves the use of material,

like paper, shells or stones, and by experiencing empathy with participants manipulating these objects. With this in mind I believe this section gives a partial expression of the way I have 'lived' openness during my research.

The question I am pondering at the moment is whether there is an experience of 'bracketing' and 'bridling' *within* an empathic encounter. Conceptualising this first of all implies looking into the meaning of the moving hands. My sense of the above metaphor is that the hands are moving but not in a controlling or manipulative way but rather in a way that tunes in with the movements of the participant. This is a responsiveness that goes with and supports the participants' flow. Within this context there is space for an empathic 'bridling' if it is conceptualised as being like a 'sounding board and not a loud speaker', and when it is conceptualised with reference to sensory rather than spatial kinaesthetic bodily experiences. 'Bracketing' within an empathic relating, I feel, conjures up a stance of 'observing', and could therefore be understood by drawing on visual rather than spatial experiences.

## APPENDIX C1: Reflexivity

### Reflexivity as a research method

“appreciates that the researcher actively constructs the collection, selection and interpretation of data and that any results are co-constituted – a joint product of the participants, research and the social context” (Finlay, 2011, p.80).

Figure 26 captures this process well.

The painter in the picture could illustrate the situation of participants during the research session. They enact (partially in relation to me, who is not visible in this picture) how in their mind’s eye they enact their self in situations where cancer and clinicians figure. I look at them enacting their remembered self-enaction but part of what they enact is influenced by our interacting.



Figure 26: Virginia Parker, Triple self portrait

From this perspective rather than wondering how researchers can take their input out of the equation, the attention is more on how researchers can raise their awareness of *how* their pre-understandings, acts of understanding and subjectivity impact on their evolving understandings. By being transparent about oneself and by reflecting on the impact of this on the research process and findings, the findings can be understood in context and the reader is encouraged to further reflect on what might have gone unnoticed, or appreciate what surfaced because of this specific researcher-participant connection. In other words ‘reflexivity’ adds rigour and validity in research (Etherington, 2006, p.37). Reflexivity does not stop at being self-aware though. Once aware one may try to control the impact but it may also be embraced as a lens through which one understands participants’ expressions (Finlay 2011, Etherington 2006, Willig, 2001). In turn participants’ views are

considered as welcome challenges and instigators of change of pre-understandings (Willig 2001, p.10). In that sense 'reflexivity' incorporates an understanding of 'self' as constantly changing rather than as a given that is there to be discovered (Etherington 2006, p.30). For practitioners like me who engage in research, thinking about the impact of practice understandings means that reflexivity also functions as a bridge between research and practice (Etherington, 2006, p.31). Last but not least 'reflexivity' needs to be understood as a hermeneutic continuous process employed at every stage of the research (Finlay, 2011, p.79).

In 'reflexivity' literature more detailed pointers are set out to help researchers to raise their awareness of the myriad of ways in which they impact on their research. One way is of course through the research question, the data generation and analysis methods and the ontological and epistemological beliefs that underpin the study. Although the research approach is intended, "epistemological" (Willig, 2001, p.10) or "strategic" (Finlay, 2011, p.84), reflexivity aims to make clear that the findings are not only enabled but also limited by these choices. Reflexivity also entails an awareness of pre-understandings about the topic of investigation. For example the sampling and recruitment strategy of this study focused on recruiting participants who could challenge my pre-understandings based on the case-study and professional practice (see Chapter 7). "Personal reflexivity" entails a reflection on the impact of one's own values, beliefs, experiences, and social-political-cultural contexts (Willig 2001, p.10). I would like to specify here that this also incorporates more visible aspects such as age, gender, language and the mannerisms that come with professional roles. Finlay, who categorises reflexivity in terms of the level on which it is experienced, captures these factors under "relational reflexivity" and "embodied reflexivity". The latter also draws attention to the impact of the researcher's felt sense and bodily gestures (Finlay, 2011, p.84). Reflexivity also addresses the ethical issues and power relations between researcher and researched (Etherington, 2006, p.37; Finlay, 2011, p.84). "Ethical reflexivity" is probably best incorporated in the way research is organised and conducted. For example

counteracting or carefully attending to vulnerability in participants potentially caused by the research topic, method and venue, is usually (and also in this study) the first methodological task during the data generation process (see Chapter 7). Counteracting may consist of protective actions (e.g. confidentiality, anonymity), support (e.g. in distress), empowering actions (e.g. informed consent, information letter for GP, right to withdraw) and basic respect for humanity (e.g. prioritise attending to need over following planned research schedule and methods). As it was my aim to take a consistent reflexive stance, during the sessions as well as afterwards, I looked out for unintended relational dynamics and how they might impact on the results (see Chapter 7).

According to Van Manen (1997) the process of writing focuses an individual into a reflexive attitude. Based on the personal reflection below I wish to suggest that the experience of the boundaries of our empathy may also contribute to reflexive self-awareness.

*In my counselling practice I experience how my empathic stance triggers a range of feelings on a continuum of comfort to discomfort. Accordingly these feelings translate in actions and words of encouragement, disconnection or perhaps even rejection. In counselling as well as in research they indicate how the participants' expressions bounce off against my pre-understandings. The uncomfortable feelings in particular I use as a 'dowsing rod' for challenges to my pre-understandings. In other words a conscious use of empathy brings into my awareness the pre-understandings which I am attached to and confronts me with the fact that they clash with what participants express. But it also makes the way I use them towards participants tangible. Empathy enables a lived, embodied 'reflexivity'. With raised self-awareness I have a choice whether I let my spontaneous response further flow into words and actions, based on an assessment whether this would encourage or stop participants' expressions. I can also just monitor the feeling and make a reflexive note of its presence and meaning.*

## APPENDIX C2: Body schematic structure of hermeneutic metaphors

In order to build an embodied understanding of 'hermeneutic understanding' I undertook an exploration of the body-schematic structure of some key metaphors that are used to explain the hermeneutic process. Meanings based on the body-schematic structure are compared with the meanings that the terminology intends to reflect.

The term 'hermeneutic circle' and the description of a dialectic relating with the data from different 'positions', speaks of a conceptualisation of the thinking *space* as a circle, potentially a forever widening circle but with the research question and data at the centre and the researcher taking different positions in that circle. When the term 'hermeneutic cycle' is used, the *temporal* aspect of the activity comes more to the fore; the dialectical engagement is repeated with every new position that is taken. Researchers who use the word 'lens' conceptualise the 'thinking' in terms of the bodily experience of '*perceiving*', while others draw on the bodily experience of '*moving*' when they describe interpretation as a 'shuttle-cock movement', a going back and forth between e.g. the whole and parts of the data, the lenses and the data. Discussions about ending the research process often refer to an experience of reaching '*depth*' or '*coherence*' of understanding but the process of hermeneutic understanding is also conceptualised as potentially never ending, an "*opening up a space*" and "*always being on the way*".

So far the highlighted body schematic structure of the hermeneutic terminology, as I understood it, brought to my attention that the dynamic nature of thinking is conceptualised in the usual manner as moving about and taking positions in space (see Lakoff (1991) on Primary Metaphors). However, within this hermeneutic terminology, research data could also be seen as conceptualised in a centralised position, and without further qualification this could suggest that data should be seen as static.

The implied static character of textual data, when these are expressions of participants' experiencing, does not correspond with a phenomenological understanding of participants' experiencing. Dahlberg's (2008, p.94) comment "do not make definite what is indefinite" does not just refer to understanding being indefinite, but also to experience having an 'indefinite' character. Participants' understandings of their own experiencings, just like my own, emerge from a stream of non-conscious responses and have textural dimensions that cannot be captured and that change when carried forward through thinking and talking. In the hermeneutic phenomenology inspired by Merleau-Ponty, 'text' (language and thought) is conceptualised as expression of subject rather than a mere object, is not static but alive through its embedded-ness in embodied experiencing. Hermeneutic terminology however can sometimes be seen to conceptualise the fluidity of thinking, but also as less helpful in conceptualising the fluidity of data. As indicated above, the terms 'circle' and 'shuttle-cock' imply that the data is in a specific place and time that one revisits. They do not capture the notion that data further unfolds with every visit. In search of a more apt metaphor, I came across the picture below (Figure 10 in main text), called 'Flamenco' by Camille Kleinman, which, so far, for me best expresses my enactively embodied understanding of hermeneutics.

First of all by representing the 'dance' metaphor with a picture of a person, interpretation is presented as a process that is generated in and with a 'lived body' and as an embodied experience.

The movement of the person (researcher) through a sea of yet unexplored data (blue), touches parts of data one by one and brings out their aliveness (the person leaves behind a trail of coloured pieces which one could see as fruits or flowers or blood vessels). Together the thus enlivened data take, the shape of wings and spur the researcher into further movement, which in turn leads to wings that further gain in beauty, muscle and span. Different lenses are like different paths which the researcher follows in moving through the

surrounding data, resulting in different colourings being activated in the data. In my view the imagery of 'circle' and 'shuttle-cock movement' conjures up the search for depth, as in a grinding down movement, an aiming to 'grasp' rather than to 'evoke' and 'open up a space'. The 'dance' metaphor offers an image of a path which implies an opening up of an ever widening space. With this one may miss out the message of 'depth'. However, in the metaphorical picture (Figure 10) the emerging colouring and wing muscle in a way suggest both depth and space.

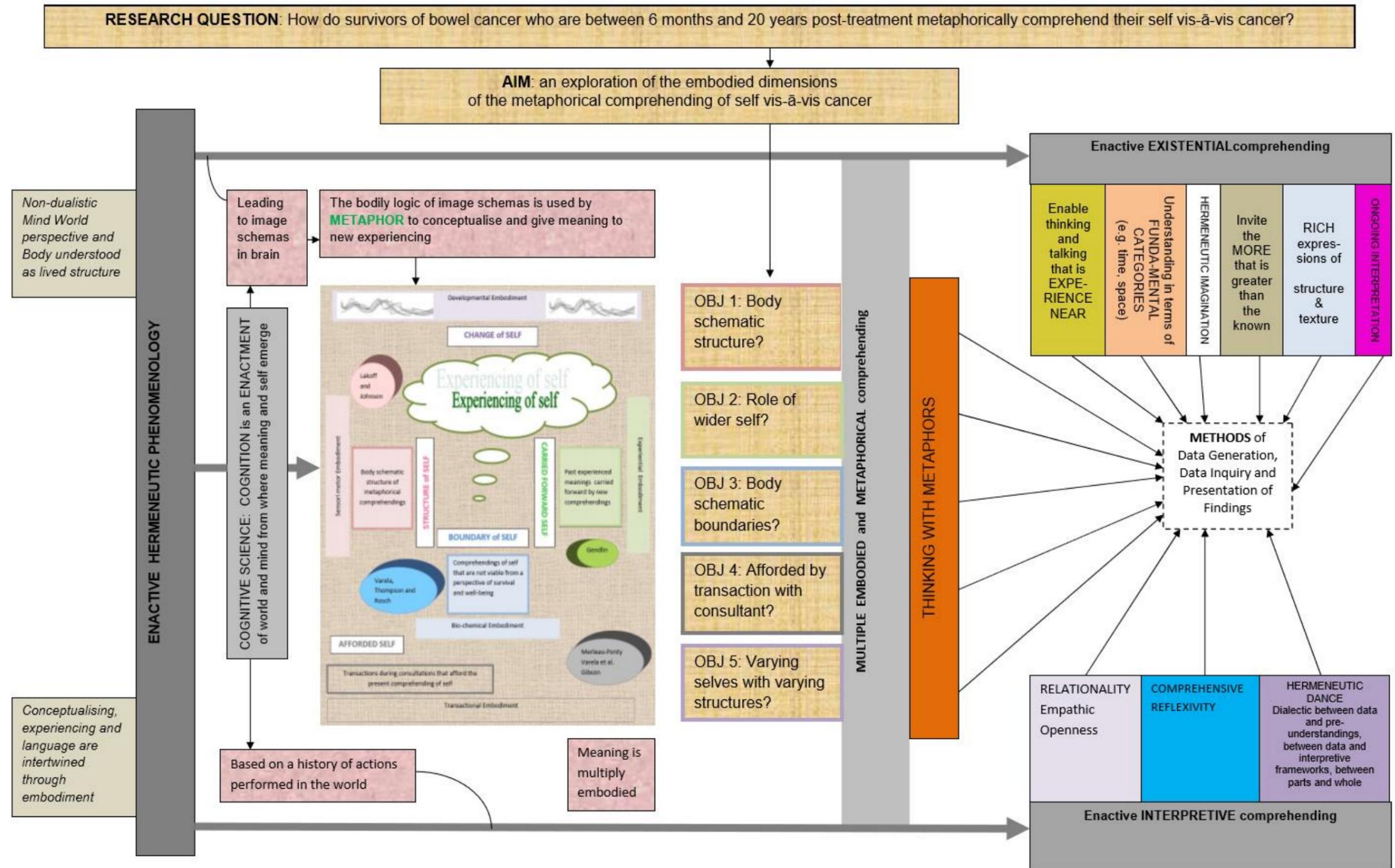
Figure 10: Flamenco – courtesy @ Camille Kleinman



In hermeneutic methodology there is no set system of interpreting. How one explores the data, emerges from previous findings. The enactive view of understanding echoes this in an embodied way by saying that 'the path is in the walking'. In other words interpreting creates the next step of interpreting. As the person in the picture is a dancer (a metaphor for the hermeneutic researcher also used by Finlay, 2011, p 109), the metaphorical equivalent is that the next dance movement is informed by the previous one and its results. Dancing also captures a view of phenomenological research as responding both to intuitive and felt understandings in the moment, whilst also being guided by rational understanding and knowledge of research steps and movements.

APPENDIX C3: Overview research design (master table)

Table 15: Master research table



## APPENDICES D

### APPENDIX D0: Letters of agreement to recruit

#### Letter of agreement to recruit via Hospice social media platform:



9th June 2015

To whom it concerns

I hereby agree for Kathleen Vandenberghe to use information boards, websites and social media of St. Luke's (Cheshire) Hospice and End of Life Partnership to inform the public and potential participants about her research.

The study will be presented under the title "How does the meaning of cancer progress after finishing treatment?" Details will be presented in poster format.

Sincerely,

Handwritten signature of Siobhan Horton in black ink.

Siobhan Horton  
Director of Clinical Services

St. Luke's (Cheshire) Hospice  
Queensway

Winsford CW7 1BH

Handwritten signature of Sally Jeynes in black ink.

Sally Jeynes  
Chief Executive

End of Life Partnership  
Winterley Grange  
Alsager Road  
Sandbach CW11 4RQ

**Letters of agreement to recruit via MCHFT:**



10<sup>th</sup> June 2015

To whom it concerns

I hereby agree for Kathleen Vandenberghe to inform cancer patients who attend the Bowel Cancer Support group about her research. The group is facilitated by myself at the Macmillan Cancer Unit in Crewe.

The study will be presented under the title "How does the meaning of cancer progress after finishing treatment?"

The information will entail a brief presentation and Participant Information Sheets will be handed out to people who are interested.

It has been agreed that this presentation will happen after NHS REC approval has been obtained and on an evening that will be agreed with myself.

Sincerely,

*H Hughes*

Heather Hughes,

Colorectal Macmillan Nurse Specialist

Macmillan Cancer Unit

Leighton

01270 612 047

372

## APPENDIX D1: Information to hospital support group

Information distributed by Heather Hughes, Colorectal Macmillan Nurse Specialist

Kathleen Vandenberghe works as a counsellor at St. Luke's Hospice Winsford but will come along to our meeting to tell us about her research into 'cancer survivorship'. She wants to explore the meaning of cancer for people who are between a few months and 15 years after finishing treatment. If you were interested or you know somebody who might be interested to become involved, a Participant Information Sheet with her contact details will be handed out to take home.

## APPENDIX D2: Participant Recruitment Poster – First recruitment



### RESEARCH

## How does the meaning of cancer progress post-treatment?

Conducted under the auspices of Bournemouth University and  
St. Luke's (Cheshire) Hospice

The Cancer survivor rate has doubled in the last 40 years. This means that more and more people are seeking to rebuild their sense of 'normality' after finishing treatment. Cancer survivors tell us that this is not as simple as it sounds. I aim to expand our understanding of what cancer means for people who are at different times post-treatment. I believe that a better understanding will result in more effective support and will have a positive impact on people's ability to cope.

#### Perhaps this is you?

- ✓ I was diagnosed with bowel cancer.
- ✓ I finished my treatment between 1 month and 15 years ago.
- ✓ I have no known active cancer at the moment.

#### I am specifically interested in:

- Your personal unique experience.
- Your spontaneous sense of cancer rather than your conscious thoughts.

#### What does this research involve?

- A brief introductory meeting and 2 interviews up to 1.5 hours each, with me.
- Exploration of your experience through dialogue, with the use of some creative methods.

#### What will be done with the results?

- We aim to increase the effectiveness of support services by informing health professionals.
- Results will be communicated anonymously to participants, other cancer survivors and their families.
- We will involve patients and public to define extra ways of using the research findings.

#### Interested?

Thanks in advance for contacting me.

*Kathleen Vandenberghe*

*St. Luke's (Cheshire) Hospice – 01606 555 693 – [Kathleen\\_Vandenberghe@stlukes-hospice.co.uk](mailto:Kathleen_Vandenberghe@stlukes-hospice.co.uk)*

## APPENDIX D3: Participant Recruitment Poster – Second recruitment



### RESEARCH

## How does the meaning of cancer progress post-treatment?

Conducted under the auspices of Bournemouth University and St. Luke's (Cheshire) Hospice

The Cancer survivor rate has doubled in the last 40 years. This means that more and more people are seeking to rebuild their sense of 'normality' after finishing treatment. Cancer survivors tell us that this is not as simple as it sounds. I aim to expand our understanding of what cancer means for people who are at different times post-treatment. I believe that a better understanding will result in more effective support and will have a positive impact on people's ability to cope.

### Perhaps this is you?

- ✓ I was diagnosed with bowel cancer.
- ✓ I have no known active cancer at the moment
- ✓ I am close to one of the following three situations:

#### Situation 1:

I finished treatment less than 1 year ago

I did *not* have radiotherapy or chemotherapy

At present I have no or a temporary stoma

#### Situation 2:

I finished treatment about 1 year ago

I had surgery, radiotherapy and chemotherapy

At present I have a stoma

#### Situation 3:

I finished treatment more than 10 years ago

I had surgery, radiotherapy and chemotherapy

I have a stoma

### I am specifically interested in:

- Your personal unique experience.

### What does this research involve?

- A brief introductory meeting and 2 interviews up to 1.5 hours each, with me.
- Exploration of your experience through dialogue, with the use of some creative methods.

### What will be done with the results?

- We aim to increase the effectiveness of support services by informing health professionals.
- Results will be communicated anonymously to participants, other cancer survivors and their families.

**Interested in more information?** Thanks in advance for contacting me.

*Kathleen Vandenberghe*

*St. Luke's (Cheshire) Hospice - Tel: 01606 555 693*

*Email: Kathleen\_Vandenberghe@stlukes-hospice.co.uk*

## APPENDIX D4: Extract hospice website as part of second recruitment

[Home](#) ▶ Volunteers for Research project into Cancer Survivorship required

Here at St Luke's we provide a range of services to help patients, their families and carers live with the changes brought about by life limiting illness. We also invest time and resources into conducting groundbreaking cancer research in collaboration with Universities nationwide.

We also aim to respond to the changing needs in our community.

One of those changes is that more and more people live beyond or with cancer for many years. While this is good news, many cancer survivors tell us that the journey back to feeling 'normal' is not always easy and they rightly turn to us for support.



### This is where we need your help

Kathleen Vandenberghe has been part of the **Error! Hyperlink reference not valid.** since 1999 and she is currently carrying out research into Cancer Survivorship in conjunction with [Bournemouth University](#).

The Cancer survivor rate has doubled in the last 40 years meaning that more and more people are seeking to rebuild their sense of 'normality' after finishing treatment. Cancer survivors tell us that this is not as simple as it sounds. The research aims to expand our understanding of what cancer means for people who are at different times post-treatment.

### How you can help

Perhaps this is you?

I was diagnosed with bowel cancer

I have no known active cancer at the moment

I am close to one of the following three situations:

<p>Situation 1: I finished treatment less than 1 year ago</p> <p>I did not have radiotherapy or chemotherapy</p> <p>At present I have no or a temporary stoma</p>	<p>Situation 2: I finished treatment about 1 year ago</p> <p>I had surgery, radiotherapy and chemotherapy</p> <p>At present I have a stoma</p>	<p>Situation 3: I finished treatment more than 10 years ago</p> <p>I had surgery, radiotherapy and chemotherapy</p> <p>I have a stoma</p>
---	--	---

### What does this cancer research involve?

A brief introductory meeting and 2 interviews up to 1.5 hours each, with Kathleen to understand your personal unique experience  
Exploration of your experience through dialogue, with the use of some creative methods

### What will be done with the results?

We aim to increase the effectiveness of support services by informing health professionals

With the research, we believe that a better understanding will result in more effective support and will have a positive impact on people's ability to cope.

Results will be communicated anonymously to participants, other cancer survivors, and their families.

**Find out more:** [Download the introductory letter](#) - [Download the research project document](#) If you or somebody you know has finished treatment for bowel cancer and correspond closely to the criteria described, we would be very grateful if you would contact Kathleen for more information on 01606 555 693 or email [kathleen\\_vandenberghe@stlukes-hospice.co.uk](mailto:kathleen_vandenberghe@stlukes-hospice.co.uk) Thank you very much in advance

## APPENDIX D5: Extract Facebook as part of second recruitment



**St Luke's Cheshire Hospice**  
9 January 2017 · Like Page

Head of St Luke's Family Support and Counselling Team, Kathleen Vandenberghe, is working with Bournemouth University to expand our understanding of what cancer means to people who are at different stages after their treatment.

We are looking for volunteers who have finished treatment for bowel cancer to take part in this research.

If you or somebody you know has finished treatment for bowel cancer and would be willing to take part, we would be very grateful if you would contact Kathleen on 01606 555 693 or Kathleen\_Vandenberghe@stlukes-hospice.co.uk.

Further details about the research are available on our website: <http://bit.ly/2i6eLTK>

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STLUKES-HOSPICE.CO.UK  
**Volunteers for Research project into Cancer Survivorship required | St Luke's Cheshire Hospice**  
St Luke's Hospice are currently carrying out cancer research into Survivorship in...

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3 2 comments 20 shares

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**Like** **Comment** **Share**

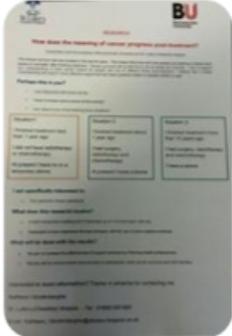
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Most relevant

   
Press Enter to post.

 **Chris Jackson** Please share xx  
[Like](#) · [Reply](#) · 2y

 **Chris Jackson** More details x



[Like](#) · [Reply](#) · 2y

## APPENDIX D6: Email as part of second recruitment

Hi,

As you know I am conducting research into the psychological experience of Bowel Cancer Survivorship. At the moment I am looking to expand my initial group of participants and aim to recruit directly from the public rather than via survivors' relationships with healthcare professionals. I was wondering whether you would be willing to help me with this by passing on my request to people you know, e.g. family, friends, colleagues. This could be done in two ways:

1. By *forwarding* the message below via email to your connections.
2. This message has also been distributed by St. Luke's Hospice Winsford as a Facebook post on 9/1/17 at 17.40. If you are on Facebook yourself, you may prefer to access and share it from there.

Thanks in advance.

Kind regards.

Kathleen

Search for Research Participants

My name is Kathleen Vandenberghe and I work at St. Luke's (Cheshire) Hospice Family Support and Counselling service. I am currently carrying out research into the psychological experience of **BOWEL CANCER SURVIVORSHIP** in conjunction with Bournemouth University.

I am searching for participants who:

- were diagnosed with bowel cancer
- who are not ill at present
- who live in Cheshire, Staffordshire or Shropshire
- who finished treatment and find themselves in one of the following three situations

**Situation 1:** Finished treatment less than 1 year ago, did not have radio or chemotherapy, at present have no or a temporary stoma

**Situation 2:** Finished treatment about 1 year ago, had surgery + radio + chemotherapy, at present have a stoma

**Situation 3:** Finished treatment more than 10 years ago, had surgery + radio + chemotherapy and have a stoma

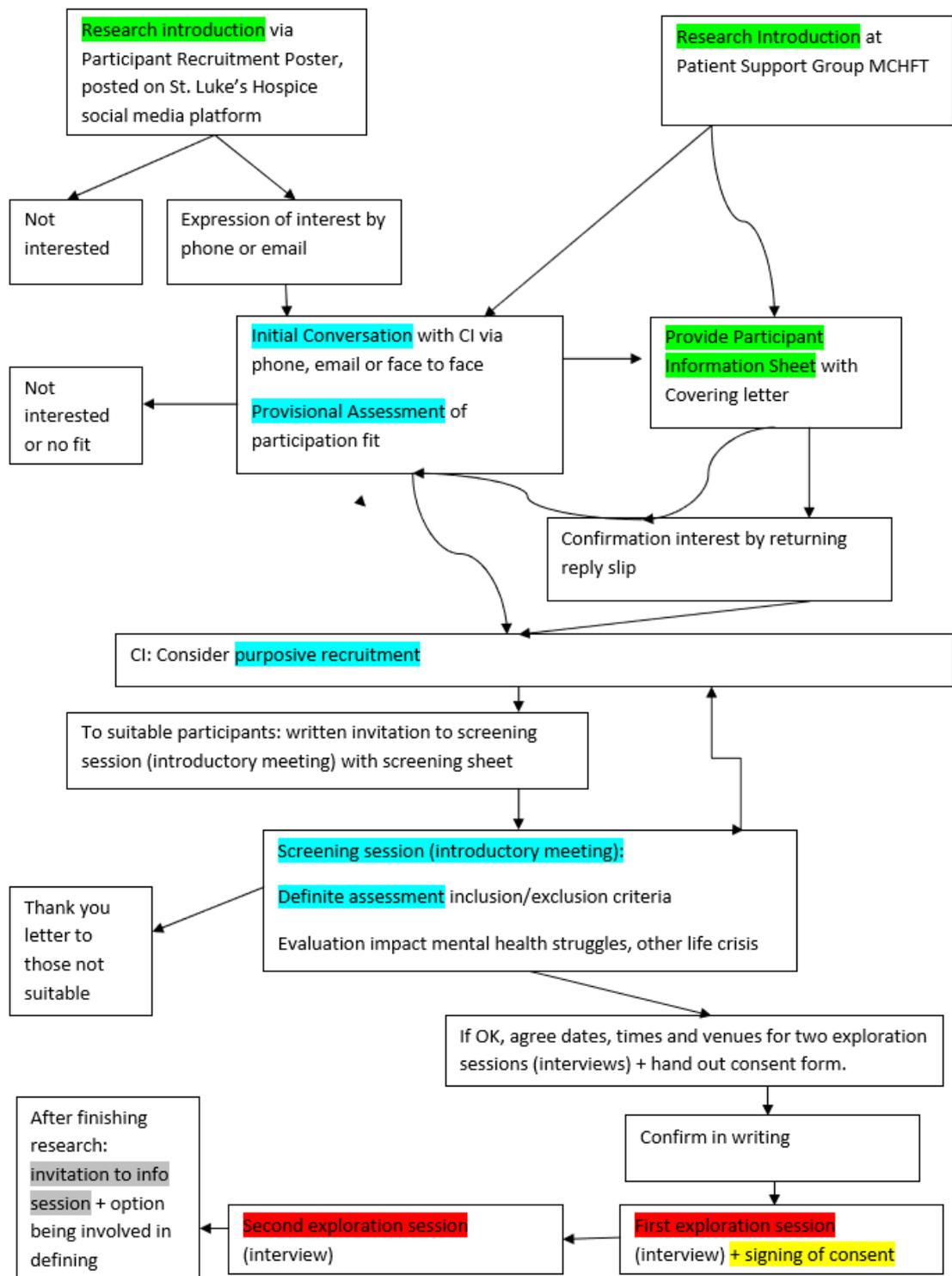
If you or somebody close to you is in one of these situations, I would most appreciate if you would consider participating in my research. You can find more details about the research in the email attachment or by search: survivorship at <https://www.stlukes-hospice.co.uk/about-st-lukes/latest-news/>

If interested, please contact me on 01606 555 693 or Kathleen\_Vandenberghe@stlukes-hospice.co.uk

You can also help me very much by sharing this request with as many others as possible. Thanks.

Kathleen

## APPENDIX D7: Flow chart Participant Recruitment and Research Contacts



## APPENDIX D8: Participant Information Sheet and Covering Letter



Dear,

Following the brief information you have already received about my research I am pleased to send you a Participant Information sheet. In this document I explain in more detail the reasons and methods of this research and what will be expected from participants. It is important that you understand what is involved. Please take time to read it carefully and discuss it with others if you wish.

You may be surprised that this research into cancer survivorship is funded by and conducted from a hospice. Earlier diagnosis and improvements in treatment mean that more and more people live longer or live beyond cancer. Although this is a positive development, it is also a new and unknown journey for patients and health care practitioners. As human beings we aim to make sense of unknown experiences and we search for services and people who can help us with that. It is no surprise that patients who have used the hospice services during treatment, also return for support as they recover. This means that hospices now not only support people in terminal care but also in living with and beyond cancer. By funding this research St. Luke's Hospice management acknowledged that a better understanding of cancer survivorship is needed if we want to offer a relevant and effective service.

If you have any questions about the information sheet, you would like more information or you just prefer to talk things through instead of reading about them, do not hesitate to ring me. If I am not at my desk leave a message on my voicemail and I will return your call as soon as possible.

Thanks in advance for looking into this.

Sincerely,

Kathleen Vandenberghe

01606 555 693 - St. Luke's (Cheshire) Hospice



## **Participant Information Sheet**

### **The title of the research project**

How does the meaning of cancer progress for cancer survivors, after finishing treatment successfully? (Ethics no 15/LO/1397)

### **Who is organising and funding the research?**

This research project is funded by St. Luke's (Cheshire) Hospice, Queensway, Winsford CW7 1BH where I am employed as a counsellor. I will use this research towards a doctorate in professional practice in Health and Social Care at Bournemouth University.

### **What is the purpose of the project?**

I aim to improve our understanding of the meaning of cancer for cancer survivors who have no active cancer and are between a few months and 15 years after finishing treatment. I will pay special attention to make the results useful to professionals who develop cancer survivor support services.

### **Why have I been chosen?**

This invitation to participate has been sent to you as you appear to fit the criteria that have been set for this study:

- You have been diagnosed with bowel cancer in the past.
- You have finished treatment.
- You have no known active cancer.
- You are not currently in counselling with me.

If you confirm your interest by returning the reply slip, I will make contact to arrange an introductory meeting. This will give us an opportunity to clarify this information sheet if needed or anything else that may influence your participation in this research project. In total I aim to recruit up to 10 participants.

### **Do I have to take part?**

Please feel completely free in your decision to take part or not. Your decision will in no way impact upon your access to hospice services.

If you decide to take part it is important that you hold on to this participant information sheet. You will also be asked to sign a consent form in duplicate – one to be returned to me and one for your own records. I need your consent to analyse your information and to include what is relevant anonymously in my dissertation and other publications or presentations.

You can withdraw your participation at any time.

### **What will happen and what do I have to do if I take part?**

Participants will be asked to take part in 2 explorative interviews with 2 to 4 weeks between them. Interviews will take between 1 and 1.5 hours each. They will preferably happen at one of St. Luke's venues (Winsford or Winterley) but alternatives can be discussed. If needed, transport will be organised. Your own transport costs will be refunded.

It is important that you know that you do not need to 'prepare' for our meetings; you should not think about it specifically nor change anything in your day to day way of living.

The general theme of our conversation will be about your cancer experience and what it means for you at the moment. I invite you to come to the sessions with an open mind, relaxed in the knowledge that you neither have to explain or defend how things are for you. They are what they are and that is exactly what I am interested in.

As we go through the sessions I will check whether you are comfortable with the way it is going. You are free to end the meeting at any point.

You can expect me to be sensitive and responsive to the challenges you are living with and to any unexpected thoughts or feelings that may come to you.

At the end of the sessions I will ask whether the hospice's complementary clinic or counselling service would be helpful to you or your relatives.

### **What type of information will be sought and how is it relevant for achieving the research aims?**

This research aims to explore the 'inner knowing' of your relationship with cancer. By 'inner knowing' I mean the sense or the feeling we have of something before we can put it into words. Therefore I will invite you to express your 'inner knowing' in a non-verbal way. This means, I will offer you creative tools and methods that will make this very easy for you to do.

We will then look together at your non-verbal expressions. I will invite you to describe what you notice and be open to any further imagery, thoughts or feelings that may come to you. This will expand our understanding of your experience.

I am interested in understanding why people view cancer in any particular way. To help me do this I would like to ask you about those life experiences that you feel are linked with how you view cancer now. These experiences may have occurred a long time ago or recently. Either way the memory will come spontaneously to you when we are at that stage of exploration.

### **What are the possible disadvantages and risks of taking part?**

You may be surprised by unexpected thoughts or feelings triggered by our explorations. If this would cause distress, I believe that by drawing on my counselling experience I will be able to support you appropriately. Beforehand we will discuss what you would prefer to happen in such an event.

If the interview setting causes any physical discomfort we will make arrangements to resolve them.

### **What are the possible benefits of taking part?**

There will be no direct benefits for you but in taking part you will contribute to the development of better informed cancer survivor support services.

It may be that our conversations will bring about meaningful insights for you; however this isn't the aim of the research. I aim to listen very carefully to you and in the past people have reported that being listened to can be a pleasurable experience.

### **Will my taking part in this project be kept confidential?**

The information that I collect about you during the course of the research will be kept strictly confidential. Your name will not appear in the research. Direct quotes will be anonymised and you will not be identifiable in any reports or publications.

However if something is said that suggests that you, or someone else, are at risk of harm, then I would have to breach confidentiality. In those circumstances I would contact your GP. If possible, I will tell you I was planning to do this.

If you wish to inform your GP about your research participation a letter with the research aims and researcher contact details will be provided.

### **What will happen to the results of the research project?**

The results of the research will be made available to participants, other cancer survivors and professionals. There will be an option for participants to express their views on how the results should be further distributed. Written publications will be available via St. Luke's Hospice website.

### **Will conversations be recorded, and how will the recorded media be used?**

As I will need to study in detail the content of our meetings I will need to record our conversations on audio media. I would also like to take (non-identifiable) photos of the way you have expressed your experience of cancer non-verbally, using creative tools and methods.

The audio and photographic recordings of your activities will be analysed by me.

Quotes from the written transcripts of the audio material or prints of the unidentified photos may be included in the research report to illustrate my thinking and conclusions or used for illustration in public presentations to non-scientific groups, conference presentations, lectures or scientific publications. No other use will be made of them without re-contacting you for written permission, and no one outside the project will be allowed access to the original recordings.

The original recording and identifiable photos will be securely stored and disposed of by myself 5 years after the research conclusion.

### **Can the research setup be adjusted to my personal needs?**

If you feel that through some aspect of your physical condition or any other aspect of your being or life the proposed research setup might be problematic, please let me know and we can look into possible adjustments.

### **Contact for further information**

For any further information about the research, please contact me as follows:  
Kathleen Vandenberghe – email: [Kathleen\\_Vandenberghe@stlukes-hospice.co.uk](mailto:Kathleen_Vandenberghe@stlukes-hospice.co.uk)  
Tel. 01606 555 693  
St. Luke's (Cheshire) Hospice  
Queensway  
Winsford CW7 1BH

### **What if something goes wrong?**

If you wish to complain or have any concerns about the way you have been approached or treated during the course of this project, please contact my supervisor:  
Dr. Caroline Ellis-Hill – email: [cehill@bournemouth.ac.uk](mailto:cehill@bournemouth.ac.uk)  
Tel. 01202 962 173  
Bournemouth University  
Royal London House  
Christchurch Road  
Bournemouth BH1 3LT



## APPENDIX D9: Initial Conversation Schedule



### **Initial Conversation (telephone or face to face) – schedule**

- Take down demographic information: name + tel + gender
- Take down recruitment source (Hospice social media platform or MCHFT support group)
- Reiterate and expand on the aims and methods of the research
- Brief check whether candidate meets main inclusion and exclusion criteria:
  - o bowel cancer (type) + indication of time of diagnosis
  - o treatment finished + indication ending time
  - o no known active disease
- Verify whether participant meets other inclusion and exclusions criteria:
  - o No current clinical, professional or personal relationship with researcher
- Qualify participant's ability to provide "rich data"; assessment if there are physical and personal factors that will severely hinder the generation of rich data.
- Information in relation to next steps:
  - o Provide Participant Information sheet
    - When Sheet with cover letter will be sent out
    - Explore whether adjustments need to be made due to disabilities
    - If Initial Conversation happens in reply to return of reply slip of Participant Information sheet provided at MCHFT support group but without conversation at the time: move to next step
  - o Screening meeting:
    - If relevant: explain purposive recruitment
    - Aims of screening meeting
    - how/when invitation will happen
    - explain function of screening sheet (questionnaire) which will be included
    - inform when and how they will be informed if I cannot include them

## APPENDIX D10: Invitation to introductory meeting + Health and Care Questionnaire



Dear,

**Re: How does the meaning of cancer progress post-treatment? (ethics no 15/LO/1397)**

First of all thank you very much for the interest you have shown to participate in my research. In our previous conversation we concluded that you seem to meet the main inclusion criteria and we talked in approximate terms about the time that has passed since your diagnosis and finishing of treatment.

I explained that I had to compare your position in the cancer survivorship journey with other interested candidates. I can confirm that I am very interested to further discuss your offer to participate.

Please let me know if the following arrangement to come along for a half-hour introductory meeting would be convenient to you:

Date:

Time:

Venue: St. Luke's Hospice, Queensway, Winsford CW7 1BH (car parking available)

Your transport costs will be refunded at 0.45 £/mile. If you would prefer me to arrange transport, do not hesitate to let me know.

The aim of this meeting is to refine some of the information needed to make this research valid and safe. To that purpose it would be helpful if you could fill in the health and care questionnaire included in preparation of the meeting. If you do not know the information, we could ask the health professional service who you think could provide it. In that case please bring their name and address. Our meeting is also a chance for both of us to explore any other issues that might influence whether we move to the next step or not.

I am very much looking forward to meeting you.

Sincerely, Kathleen Vandenberghe



## Health and Care Questionnaire

Name:..... Date of birth:  
.....Gender:.....

Address: Number & street: .....

Town:..... Postcode:.....

Tel:..... Email  
(optional):.....

### Medical information:

Initial diagnosis:..... Date of diagnosis:.....

List all treatments with start date and end date

.....  
.....  
.....

Have you ever had a recurrence?.....

Date of last medical appointment that confirmed "cancer not active":.....

If you prefer that I gather the above information from your GP or other health professional, please provide me with their contact details:

Name ..... Organisation .....

Tel.....

P.T.O.

GP contact details:	Personal Emergency contact details:
GP Name:	Name:
Practice:	Relationship:
Address:	Address:
Tel:	Tel:

*I am asking for Emergency contact and GP contact details for safeguarding reasons. First, as explained in the Participant Information sheet, the research work is not intended to create any problems but if you should experience the research sessions as upsetting I believe I can offer a safe and supportive response or if any physical distress would occur medical hospice staff would be available. Nevertheless if there was a need to contact somebody else or your GP it would be helpful to have these contact details at hand. Secondly, as explained in the Participant Information sheet, if participants express a severe risk of harm to themselves or others it is my duty of care to breach confidentiality and contact their GP.*

*Researchers are recommended to inform participants' present GP when conducting research that is linked to their illness experience. This is merely to provide them with my contact details in case they have any questions about the research or if they feel the research has an adverse impact on you of which they want to inform me. Rather than me informing your GP I will provide you with a letter addressed to your GP that confirms your research participation and includes the Participant Information Sheet. It is your choice whether you want to inform your GP or not.*

## APPENDIX D11: Consent Form



### Consent Form

**Full title of project:**

How does the meaning of cancer progress for cancer survivors, after finishing treatment successfully? (**Ethics no 15/LO/1397**)

Please Initial Here

I confirm that I have read and understood the participant information sheet for the above research project and have had the opportunity to ask questions.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason and without any negative consequences. In addition, should I not wish to answer any particular question(s) or work with any particular creative method, I am free to decline.	
I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the research report.	
I agree for the interviews to be audio-recorded and for creative work to be photographed in a non-identifiable way.	
I agree for the transcripts and photos of the data I provide to be referred to in a non-identifiable way during conference presentations, journal articles, educational or professional activities.	
I agree to take part in the above research project.	

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## APPENDIX D12: Introductory screening meeting schedule



### Screening meeting – schedule

1/ Discuss information given in the screening sheet (questionnaire).

2/ Qualify information about present cancer status:

“At present no known active cancer” - Please indicate the sentence that best qualifies this statement

0 correct – date last check-up: .....

0 probably not but having investigations at the moment

0 some activity but no treatment planned for now (monitoring)

0 some symptoms which at times make me wonder but medical investigations detect no cancer

0 some symptoms which at times make me wonder but I have had no medical investigations

0 other

3/ Assess presence of mental health problems, learning disabilities, other life crisis and whether these would interfere with the generation of data.

4/ Discuss concerns and questions of potential participant

5/ Decide whether to go ahead with research sessions based on whether the candidate

- meets inclusion criteria
- is sufficiently able to provide rich and relevant data
- is interested

6/ Prepare next step: 2 exploration sessions with 2 to 4 weeks in between them

- Discuss Consent Form
- Organise exploration sessions: dates + time + venue + transport

7/ Refund transport cost for this screening (introductory) meeting

## APPENDIX D13: Letter to GP



Surgery Address  
Hospice

Date

Dear Dr

Re: Participation of <Patient Name and Address>.

In research study: "How does the meaning of cancer progress post-treatment?  
An exploration of survivors' metaphorical and embodied comprehension of their  
interrelated experiencing of Cancer, Clinicians and self post bowel cancer.  
(ethics no 15/LO/1397)

I am writing to inform you that your patient has volunteered to be enrolled into the  
above research study.

This research project is funded by St. Luke's (Cheshire) Hospice where I am  
employed as a counsellor. I will use this research towards a doctorate in  
professional practice in Health and Social Care at Bournemouth University.

The purpose of the study is to improve our understanding of the meaning of cancer  
for cancer survivors who have no active cancer and are between a few months and  
15 years after finishing treatment. I will pay special attention to make the results  
useful to professionals who develop cancer survivor support services.

Participants will be invited to an introductory meeting and two interviews of maximum  
1.5 hours each. Through dialogue and with the use of some non-verbal expressive  
tools we will explore how they experience and perceive their relationship with cancer.  
At the end of the study participants will be informed about the results. For further  
details I have enclosed the Participant Information sheet.

If you have any questions regarding any of the above, please feel free to contact  
me..

Yours sincerely

Kathleen Vandenberghe,  
Head of Family Support and Counselling Team St. Luke's Hospice  
Researcher  
01606 555 693  
[Kathleen\\_Vandenberghe@stlukes-hospice.co.uk](mailto:Kathleen_Vandenberghe@stlukes-hospice.co.uk)

cc. Participant Information sheet



St. Luke's (Cheshire)

Queensway  
Winsford  
CW7 1BH

## APPENDIX D14: Ethical considerations (extract NHS Ethics Application)

**A6-2. Summary of main issues.** *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

My thinking about ethical, legal and managerial issues has been informed by the Department of Health Research Governance Framework for Health and Social Care (Department of Health 2005), the Research Ethics Code of Practice of Bournemouth University (Bournemouth University 2014), the BACP Ethical Framework for Good Practice in Counselling and Psychotherapy (British Association for Counselling and Psychotherapy 2010) and their ethical guidelines for researching counselling and psychotherapy (Bond 2004). I have further been guided by Beauchamp and Childress' Ethical Framework (Beauchamp and Childress 2009) and ethical reflections in qualitative research textbooks (Holloway and Wheeler 2002; Silverman 2011). Guided by these frameworks I have considered how best to conduct this study in a way that is beneficial, doesn't harm and respects participants' autonomy, expertise and diversity.

### **Beneficence:**

At the start I had to decide whether I would explore cancer survivors' psychological journey with cancer or whether I would research the role of some aspect of counselling in that journey. As a counsellor I believe the latter angle would also be a worthwhile project, but I have chosen to research the psychological experience of cancer survivorship in its own right as it will make this study relevant to a much wider group of health care practitioners and therefore potentially yield benefits for more cancer survivors.

I will add an 'embodied enquiry' (Todres 2007) to my rational exploration of data. This means I will not only rationally analyse the data, but will also attend to the feelings, imagery, metaphors that are triggered in myself when I tune in with or empathise with my participants' expressions. I have chosen this approach as it adds depth to the way we understand people's experiences.

Research aims in the first place to be beneficial to a wider group of people through dissemination of results, but I hope it will also be beneficial for the individual participant, i.e. by having a respectful listener to their feelings and thoughts about personal experiences (Holloway and Wheeler 2002).

Participants will be reimbursed transport costs but will not receive any other payments. If a need for psychological support transpires during the research sessions, this will be offered through the hospice, which is a free service. I believe this arrangement preserves the integrity of the research results and of our humanity and professional duty.

**Nonmalificience:**

Participation in this study will not impact on cancer survivors' access to hospice services. During the research participants' wellbeing, dignity, rights and safety will be attended to with care. In any written or verbal communication I intend to be sensitive to people's situation, potential vulnerabilities and cultural diversity.

I also decided not to take on participants if they are in counselling with me as well – even if the counselling sessions are separate from the research exploration sessions. Power inequalities easily emerge from researching clients in your own care (Holloway and Wheeler 2002). I consider this an unnecessary risk.

I have been debating whether to allow past counselling clients as participants. On the one hand these survivors may have a heightened interest in participating as a form of 'giving something back' or to 'contribute to research that aims to improve understanding of cancer survivorship'. On the other hand there is perhaps a possibility that the contextual similarity between research and counselling, will cause past explorations to interfere with the present. Therefore I will not systematically recruit past clients, but if needed through lack of other participants I will evaluate the appropriateness of inclusion on an individual basis.

I will follow the Research ethics code of practice of Bournemouth University that says "The confidentiality of information supplied by participants must be respected, except where the requirements of professional practice determine. Any limits to confidentiality must be explained to participants." Although I will not engage with my participants from a counselling role, the fact that this research will happen within the hospice context, means that I shall adhere to my professional policy regarding the legal and statutory limits of confidentiality and inform my participants accordingly. Notes, tapes and transcriptions will be identified with code numbers in order to safeguard confidentiality (Holloway and Wheeler 2002).

**Respecting autonomy:**

Our main tool to do so is writing a Participant information sheet that is comprehensive and gives a true reflection of the topic, style, methods and time requirements of the explorations.

As this research does not involve any medical interventions, I believe it is less important to inform General Practitioners about their patients' participation. Also, from feedback from patients and the public on the draft Participant Information Sheet I have learned that to inform GPs about their patients' participation in this nonmedical research is easily perceived as 'patronising'. On the other hand if the research exploration sessions were to affect

participants' emotional wellbeing adversely I would want GPs to be able to inform me if they feel that is needed. In order to balance these values I have decided to provide a letter addressed to the participants' GP which informs them about the aims of the research and confirms their patient's agreement to participate. However I will hand this letter to the patients for them to decide whether or when they want to pass the letter on to their GP. I have answered question A491 with 'yes' although there was no option to clarify why I have left it in the participants' control. Qualitative explorative research per definition may bring participants to speak in a way that they did not anticipate at the time of signing the informed consent form. Silverman (2011) suggests that informed consent is perhaps best seen as a process of negotiation, rather than a oneoff action. I will take up his suggestion to ask again for consent at the end of each exploration session.

### **Respecting diversity:**

From the inclusion and exclusion criteria it will transpire how I will balance on the one hand respect for the myriad of ways in which people may be different and on the other hand respect for the aims of this study. Only if the consequences of people's specific features are contraproductive to the aims of the research will I consider it ethically justified to decline participants.

### **Relational responsibility:**

Researching cancer survivorship is touching on uncertainty and mortality. When we set out to expose experiences that in their core touch on existential challenges, we owe it to our participants that we meet them midway as fellow human beings. Silverman (2011) reminds us that involving people in research equates to entering a relationship that comes with responsibility. We need to invite data in an empathic manner that makes participants feel supported throughout the process.

### **Research quality:**

This research is funded by St. Luke's (Cheshire) Hospice. In keeping with the Research Governance Framework for Health and Social Care this hospice strives for a high quality research culture and encouraged this study to be carried out under the auspices of Bournemouth University.

## APPENDIX D15: Ethical approval NHS, R&D MCHFT and BU

### Extract Favourable ethical opinion NHS



**NRES Committee London - Bromley**

Level 3, Block B

Whitefriars

Lewins Mead

Bristol

BS1 2NT

Telephone: 01173421390

Fax: 01173420445

05 August 2015

Mrs Kathleen Vandenberghe  
Fir Tree Cottage  
Napley  
Market Drayton  
TF9 4DS

Dear Mrs Vandenberghe

**Study title:** How does the meaning of cancer progress post-treatment? An exploration of survivors' metaphorical and embodied comprehension of their interrelated experiencing of Cancer, Clinicians and Self post bowel cancer.

**REC reference:** 15/LO/1397

**Protocol number:** N/A

**IRAS project ID:** 159615

The Proportionate Review Sub-committee of the NRES Committee London - Bromley reviewed the above application on 05 August 2015.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Miss Georgina Castledine, nrescommittee.london-bromley@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

#### **Ethical opinion**

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

#### **Conditions of the favourable opinion**

A Research Ethics Committee established by the Health Research Authority

## Approval R&D MCHFT



Research & Development Office  
Leighton Hospital  
Middlewich Road  
Crewe CW1 4QJ  
Tel: 01270 278095  
Email: charis.emmett@mcht.nhs.uk

Mid Cheshire Hospitals   
NHS Foundation Trust

Mrs Kathleen Vandenberghe  
Fir Tree Cottage  
Napley  
Market Drayton  
TF9 4DS

29/10/15

**MCHFT ID: 2015353.4**

**REC REF: 15/LO/1397**

**Title: How does the meaning of cancer progress post-treatment?**

---

**An exploration of survivors' metaphorical and embodied comprehension of their interrelated experiencing of Cancer, Clinicians and Self post bowel cancer.**

Dear Kathleen

Thank you for your completed application sent with the requested documentation. I am pleased to inform you that from a research point of view Mid Cheshire Hospitals NHS Foundation Trust is happy for you to undertake the research in line with the protocol you have submitted.

I must remind you that the National **Research Governance Framework for Health and Social Care** is the framework used by the Trust for our research management and governance. As our local Principal Investigator, you are responsible for the conduct of the project at Leighton Hospital (MCHFT). In particular, you must ensure that the participants are properly treated, informed consents are obtained and that data is protected. At some point your paperwork for this project may be monitored and so, it is important that you keep everything secure, especially documents relating to consent from participants in your research.

If there are any changes to your research or any difficult incidents arising from the research, please contact Charis Emmett (Research Management and Governance Lead) immediately on 01270 278095. Equally, if you have queries about conducting the research in this Trust, she will be happy to assist you.

---

I look forward to hearing the outcomes of your research and receiving a copy of the study report. Good luck with the project.

Yours sincerely,

Charis Emmett  
VICE-CHAIR MCHFT R&D COMMITTEE

## Extract Letter of Access MCHFT

From:  
Human Resources Directorate  
Mid Cheshire Hospitals NHS Foundation Trust  
Leighton Hospital  
Middlewich Road  
Crewe  
CW1 3GE

Date: 28/10/2015

---

Dear *K Vandenberghe*

### **Letter of access for research**

This letter should be presented to each participating organisation] before you commence your research at that site. The participating organisation is Mid Cheshire Hospitals NHS Foundation Trust (MCHFT)

In accepting this letter, each participating organisation confirms your right of access to conduct research through their organisation for the purpose and on the terms and conditions set out below. This right of access commences on 28/10/2015 and ends on 30/08/2018 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from MCHFT. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving confirmation from the individual organisation(s) of their agreement to conduct the research.

The information supplied about your role in research at the organisation(s) has been reviewed and you do not require an honorary research contract with the organisation(s). We are satisfied that such pre-engagement checks as we consider necessary have been carried out. Evidence of checks should be available on request to the organisation(s).

You are considered to be a legal visitor to the organisations premises. You are not entitled to any form of payment or access to other benefits provided by the organisation(s) or this organisation to employees and this letter does not give rise to any other relationship between you and the organisation(s), in particular that of an employee.

---

While undertaking research through the organisation(s) you will remain accountable to your substantive employer but you are required to follow the reasonable instructions of the organisation(s) or those instructions given on their behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by the organisation(s) in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

*L004 - Example letter of access for university researchers who do not require an honorary research contract*

*Version 2.3 August 2013*

*Research in the NHS: HR Good Practice Resource Pack*

Page 1 of 3

## Extract approved BU Ethics Checklist



# Research Ethics Checklist

Reference Id	3915
Status	Approved
Date Approved	21/08/2015

## Researcher Details

Name	Kathleen Vandenberghe
School	Health and Social Care
Status	Postgraduate Research (PhD, MPhil, DProf, DEng)
Course	Postgraduate Research
Have you received external funding to support this research project?	No

## Project Details

Title	How does the meaning of cancer progress posttreatment? An exploration of survivors' metaphorical and embodied comprehension of their interrelated experiencing of Cancer, Clinicians and Self post bowel cancer.
Proposed Start Date	01/09/2015
Proposed End Date	30/09/2017

Summary (including detail on background methodology, sample, outcomes, etc.)

# APPENDIX D16: Public Engagement – Conference poster

Presented at:

*The 8th Annual Postgraduate Conference Bournemouth University Executive Business Centre, Lansdowne Campus, 9 - 10 March 2016.*

*The Changing Prospects for Cancer: 'A Good Survival' Emirates Old Trafford Lancashire County Cricket Club, Manchester, 11 March 2016.*

*The 10th Anniversary Keele Counselling Qualitative Research Conference: "The Creative Researcher", Keele University, 7 - 8 May 201*

**By Kathleen Vandenberghe**  
DProf Health and Social Care BU

## How do cancer survivors "get their head around" cancer post-treatment? Listening to the embodiment of the metaphors they recover by.

**Supervisors BU:**  
Dr. Caroline Ellis-Hill  
Dr. Desi Tait  
Dr. Jan Mojsa

**PRACTICE ORIENTATED**  
Currently 2 million people in the U.K. live with cancer and survive on average for 6 years (Cancer Research UK 2014). The National Cancer Survivorship Initiative promotes research and health care developments (DH et al. 2013). As a hospice counsellor I aim to better understand the meaning of cancer for survivors over time.

**FOCUS: DEEP PROCESSING**  
In the U.K. cancer survivorship support is strongly goal orientated and focuses on a re-making of a "self" that disconnects from the vulnerability of the cancer experience and on the role of people's conscious thinking in achieving this (Bell 2012). In 2005 I was introduced to Lakoff and Johnson's (1999) philosophy and cognitive theory which considers metaphorical language as embodied unconscious thinking. Application to an on-the-job case study revealed that this perspective could inform therapies that would complement the above by considering UNCONSCIOUS THOUGHT PROCESSES, by exploring survivorship as a PROCESS with VARYING EXPERIENCES OF SELF while standing both in VULNERABILITY and STRENGTH.

**AIM**

This study explores how adult survivors of bowel cancer who are between a few months and 15 years post-treatment experience their Self and their relationship with Cancer and their cancer Clinicians.

**ENACTIVE EMBODIED MIND**  
This study is built on a NON-DUALISTIC view on MIND AND WORLD UNITED BY 'A LIVED, EXPERIENCING BODY'. The Enactive Embodied Mind thesis emphasises the flow of our embodied acting in a biological, psychological and cultural world. What and how we think is considered an "enaction" on these different levels. Our visceral responding, our felt-sense of situations, discriminations and patterns, our social interacting are all brought forward into our conscious concepts and language with which we eventually explicate our thinking and meaning making. Cognitive neuroscience suggests that meaning becomes conceptualised when activity in sensori-motor and conceptualising parts of the brain are connected by Metaphor. The way this multi-layered view on embodiment of thinking and meaning making has been explored by Varela (1991), Gendlin (1962), Lakoff and Johnson (2007) will inform this study. They operationalise what Merleau-Ponty (1968) referred to as thoughts and language being a second version of our body. Thinking, feeling, experiencing become one movement and metaphors become one explore how we think with our body. This dialogue between Phenomenology and Cognitive Science contributes to HOLISTIC UNDERSTANDING

**METHODOLOGY**

Cancer survivors' experience of their Self in relation to Cancer and their Clinicians will be explored by listening to their METAPHORICAL CONCEPTUALISATIONS of their experiencing and by shedding light on the BODILY ENGAGEMENT embedded in the picture of the metaphor and at work in the process in which the conceptual metaphor emerges.

**OBJECTIVES**

DESCRIBING, COMPARING and EXPLORING THE MEANING OF the EMBODIMENT - of survivors' metaphorical conceptualisations - of the relationship between the varying conceptualisations

**RESEARCH LITERATURE** – This study differs from most research through its holistic approach. Methodologically it is closest to the work of Gibbs Jr and Franks (2002) who also explored cancer survivorship from a perspective of metaphor and embodied cognition.

**METHOD – metaphorically explained**  
Up to 10 survivors are invited to their local hospice for an introductory meeting and 2 sessions.

**FLEXIBLY STRUCTURED EXPLORATION**  
As the researcher I feel like a gardener attending to a plant. I start with a gentle invitation of both verbal and non-verbal metaphorical expressions of their experiencing of cancer. The flowers on the plants I liken to the metaphorical expressions of my participants. Some metaphors grasp their sense of Cancer, other their sense of Clinicians or Self. Some refer to their present, other their past experiencing. Hence a diverse selection of flowering plants. I invite my participants to express and describe the physical structure of their metaphorical comprehension. Just like a flower has a size, a shape, moves or is still, grows in a direction and takes a certain position on the plant, I invite them to refine their metaphors in such sensory, kinesthetic and spatial terms.



What are the...  
Like flowering springs from the pollination by the bees, I aim to understand how their metaphors are an enaction in a situation they need to make sense of. I check that the metaphors resonate precisely with their felt sense by inviting responses to neighbouring metaphors. Just as one might describe the nature of a seed by differentiating it from the look and function of shells in the soil. I keep in mind that unconscious biological drives co-determine the way their experience is conceptualised and liken these influences to the bigger stones beneath our hands.

**EMBODIED REFLEXIVITY**  
The focus is on the participants rational and emotional responses but always in the awareness that their responses are generated through our joint exploring of their experiencing. Like hands that jointly knead the soil from where the flowers on their plant appear

**Literature cited**

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(\*) Joseph Wajid of Derby, An Iron Forge. 1772.

**RESEARCH IN PROGRESS**

Data Generating: Nov. 2015 – May 2016  
Dissemination: 2018 - 2019

APPENDIX D17: Shells and stones used during data generation



Figure 27: Shells and stones used during data generation

## APPENDIX D18: Flexible use of Research Exploration Plan (REP)

### ***Point 1: Number of sessions determined by research aims, practicalities and researcher confidence***

The participants who came forward during the first recruitment (N=7) round were invited to a half hour introductory meeting and two research sessions. The introductory meeting mainly consisted of a face to face discussion of their diagnosis and treatment steps and aimed to assess whether other life crises would impact on the exploration of their experience of self in relation to cancer. Initially I felt I could only make an accurate assessment and respond with appropriate sensitivity if I met people face to face. Later I realised that my hospice counselling experience made me over-concerned for people's emotional state of mind.

The two subsequent research sessions lasted between 1 and 1.5 hour and were organised about 4 weeks apart. In the first session participants took a first person perspective, in the second session a third person perspective. Initially I thought that asking participants to take more than one perspective in one session was too intense and therefore the first seven participants were invited to two sessions. Another reason for organising two sessions was that during 'pre-research experiences' (PRE) I noticed that metaphorical expressions during the first session sometimes triggered new experiencings that brought about new metaphors in a follow-up session.

At the start of the second round of recruitment I evaluated the necessity of three face to face meetings. This was triggered in two ways. Recruitment via the hospice media produced three people who lived further afield. Covering that distance three times would be impractical either for them or for me. The analysis of the first set of data showed that the first session mainly generated insight in the relationship between self and cancer. This was core to the topic of this study which made me decide to leave this unchanged. The second

session enabled a richer expression of the experiencings of self. This was equally relevant and needed to be preserved. As was intended, in the second session people also explored their earlier cancer related experiencings in more detail. This entailed reflections on the time of diagnosis and all consequent treatment steps. The latter I felt could be omitted as this was not the focus of this study. I decided to limit the exploration from a third person perspective to an inquiry in their sense of self and sense of cancer at the present, pre-diagnosis and at the time of diagnosis. Research literature has indicated that the severity of the impact of diagnosis influences the later psychological recovery process. By condensing the third person perspective exploration I could meet participants for one session. Also research practice itself had increased my overall confidence and I did not longer feel the initial concern about combining two perspectives. I also felt that the introductory assessments could happen with sufficient care and accuracy via email and/or telephone contact.

After reducing the number of meetings from three to one I had five more sessions with five different participants. In the original plan I would have had nine sessions with only three different participants. After a supervisory discussion I concluded the new approach would not compromise the generation of relevant data, was practically more manageable and five participants would enrich my research more than three.

***Point 2: Planned type and order of techniques of secondary importance to achieving the generation of rich data and participant well-being***

As was described in the main text it was part of the Research Exploration Plan (REP) to start with a technique that had the power to evoke a basic aspect of the implicit experience of cancer (e.g. asking “how big is it?”), before moving on to positioning cancer in relation to one’s body and the room, moving to a verbal description of the creative expression and using this as an introduction to a verbal metaphorical description; followed by a general

conversation about how the experience was linked with experiences in their life-world. I expected that in most cases the proposed order and explorations would feel comfortable and effective but at the start I wondered whether it was essential to go through all the steps with every participant. From my case study and my practice I knew that verbal metaphors held the richest information. The storyline embedded in every verbal metaphor exceeds the non-verbal spatial metaphorical information. This meant that if participants did not fully engage with the creative expression of their experience but immediately used elaborate verbal metaphorical descriptions, their input could still be considered as being rich and complete. I concluded that including all the steps and keeping to the prepared order was secondary to the aim of eliciting the richest data.

The choice of the methods used to explore participants' conceptualising was informed by PRE. I wanted to be and felt I was primarily in tune with a stance of openness towards my participants and their experiencings. As a consequence I gave myself permission to let go of the prepared explorative methods and to engage any other method that seemed a better fit. In that sense I empathise with Dahlberg's advice (2008) not to fix beforehand the methods to study the phenomenon, be it that this exposes the complex relationship between being 'rigorous' and 'responsive'.

The order and range of approaches was also secondary to the well-being of the participant. Although the materials had been chosen based on positive experiences during 'pre-research experiences' I was prepared for unexpected rejections and was confident that any conversation would hold valuable clues to the embodied character of people's conceptualising. Participants' personal and conceptual style, preferences and abilities needed to be respected at all times.

## APPENDIX D19: Details introductory stage of explorative sessions

As explained in the main text the introductory stage of the explorative research sessions entailed three tasks. How these tasks were attended to and why is laid out below.

### ***Task 1: Ethically reflexive exploration of research venue and research relationship***

Prior to the sessions I had reflected on the meaning of the research venue. It was my aim to meet participants in a venue that was conducive to open up survivorship focused experiencing and thinking. In the Participant Information sheet (PIS) I had expressed that the research sessions would preferably happen at one of the hospice venues but that alternatives could be discussed. I was concerned that if people no longer talked much about their cancer experience at home, that surroundings full with references to their family might inhibit free exploration. Aware that the hospice might be associated with dying it was clarified in the PIS covering letter that long term cancer survivorship is part of the support offered by hospices (appx.D8). At the start of the research sessions I checked out how participants experienced coming into the hospice. This was followed with information and negotiation of practical issues (venue facilities, transport costs, use of recorder and camera). Receiving informed consent was not a one-off action but rather a process (Silverman 2011) that started as a verbal discussion pre-research, then the consent form was handed out minimum 24 hours before signing and consent to continue and/or use the data was asked again at the end of the sessions. At the time participants still had the right to withdraw data till the end of the research project which I found one of the most challenging ethical requirements. The dilemma between increasing knowledge and respecting rights is very tangible at this point (Holloway and Wheeler 2002). Other relational issues (confidentiality and its boundaries, support in case of distress, info letter for GP, participants' control over session duration) were also addressed at the start. Having clarified the research context, bringing the research topic into the room became the next task.

### ***Task 2: Guiding participants towards expression of research topic***

Based on 'pre-research experiences' (PRE) I was aware that participants do not always find it easy to focus on their survivorship experiencings. This may be because they have not fully been 'rationalised'. It is not uncommon for people to dismiss subjective experiences that they struggle to understand (Petitmengin 2006). Cancer patients have also been found to restrict themselves to 'positive' talk about cancer for normative reasons (Wilkinson and Kitzinger 2000) or to deal with overstimulation (Salander 2012). Therefore I was conscious that an inviting, organised and transparent manner was paramount if I wanted participants to re-value an exploration of experiencings that were not clear, taboo or potentially upsetting. I was also aware that especially early survivors might be concerned that talking about their experiencings would cause them to become upset. By putting across that my counselling experience prepared me to support people in distress, I aimed to re-assure my participants and induce a relaxing explorative state of mind.

In the process of clarifying for myself the difference between relating to cancer survivors as a researcher, or as a counsellor, I arrived at the following conclusion. Both my counselling and research approach is underpinned by the view that understanding emerges in relationship (see Chapter 6) and that consequently the relationship with clients and participants needs careful attention. In addition researching cancer survivorship is touching on uncertainty and mortality. When we set out to expose existentially challenging experiences, we owe it to our participants that we meet them midway as fellow human beings. Silverman (2011) reminds us that involving people in research equates to entering a relationship that comes with responsibility. We need to invite data in an empathic manner that makes participants feel supported throughout the process. Both for counsellors and researchers the use of self and the relationship with participants is conducive to the generation of rich material but during research, generation of data is an aim in its own right for the researcher while in counselling it is a pathway to offloading, insight, change etc.

At the same time it has been highlighted that counsellors and other therapists who engage in reflective enquiry and search to understand more about their service users are 'doing research' (Finlay 2011, p.6). Although research does not aim to create benefits for participants it is not unusual for research participants to experience having a respectful listener to their feelings and thoughts as valuable or therapeutic (Holloway and Wheeler 2002; Dyregov 2004). A not unimportant difference is that in counselling the client is the demanding party while in research this is the researcher.

The participants' focus on survivorship could also be interrupted by other experiences that are at the forefront of their mind and this is where the REP proved helpful. Participants were informed that their expressions would be guided according to this plan and they were reminded (mentioned in PIS) that this included the use of non-verbal methods.

In order to focus participants on the research topic, my input and guidance was emphasised. The next task was to communicate and engage another layer of my researcher stance, i.e. my openness to their experience and holding back of my own.

### ***Task 3: Taking a receptive researcher stance***

Participants were explicitly encouraged to give themselves permission to take an open, non-critical, explorative stance towards their own experience of cancer. I anticipated that by focusing on an empathic connection with my participants' expressions my personal views and pre-understandings would be activated but trusted that this awareness would be productive (see Chapter 6). I communicated to the participants that it was part of the research process to be as responsive as possible to their input ("despite the prepared plan and methods, I will respond in the moment to what is expressed" – "any questions I asked were not to be heard as 'questioning' what was expressed").

## APPENDIX D20: Reflexive notes with regards to data generation

In listening and observing the participants I kept into awareness that their and my thinking and behaviour was influenced by a range of factors other than the experience of self and cancer. The four notes below illustrate an ethical reflexivity concerned with participants' behaviour that seemed to indicate a negotiation of safety and/or power in the research relationship. The fourth note also addresses the impact of my pre-understandings of survivors' experience of cancer. These examples raised my awareness for the importance of active empathy and hermeneutic imagination in the interpretation process (see Chapter 6)

**Note 1:** Although participants had been informed about the topic of the research and the use of creative methods, some responses increased my awareness that a 'rational' agreement does not exclude that some participants need more time to fully engage with the process. This has consequences for the meaning of their expressions. For example presented with the A1 sheet of paper a participant held it up in front of him like a newspaper for about 15 minutes and resisted changing the form or position. Although this could be a genuine expression of his experience of cancer, this did not resonate with his story. It felt like a protective act and as the story of his life unfolded I realised that taking control and holding back had become second nature. It was good to see how this participant protected himself as he felt was needed. In terms of the use of the research data it points to the importance of understanding the expressive data within the interactional context of the research interview or session (Potter and Hepburn 2005) and to check whether participants are using the material to express their cancer experiencing or are using the research tools to regulate their feelings and the relating with the researcher. In other words, to use hermeneutic imagination and to ask the question: "What is really said?"

**Note 2:** At some point a participant asked me to switch off the recorder because he wanted to speak off the record. At the time I was merely aware

that this meant I would not be able to use the unrecorded data, afterwards I realised how this experience spoke of the participant's consciousness that the aim of the research was for the information he shared to be passed on to the public domain even if this was in an anonymous manner. With his question this participant asserted himself and challenged the implicit power relationship between researcher and participant. It also opens up the question to what extent his need to take control and his need to help others impacted on the recorded description of his experience of cancer (Willig 2001, p.22).

**Note 3:** At the point of taking a photo of an expression of the experience of cancer with a sheet of paper one participant commented "this could be a spoof". Although made in a jovial tone it raised my awareness that in addition to having their consent for an explorative approach and being as transparent and responsible as possible about my intervention in the introduction, I needed to stay vigilant for participants feeling exposed or unsafe in their engagement with expressive material, throughout the sessions. When the researcher has to attend to the recording equipment participants are suddenly reminded that they are in a research setting and as Willig (2001, p.23) puts it "although rapport can be established quickly between interviewer and interviewee, it can also be disrupted suddenly when the interviewer's role as researcher becomes salient".

**Note 4:** On several occasions I have used the sculpting with paper exercise with hospice clients. It caught my attention that a lot of survivors I met in a clinical setting 'crunched' the sheet of paper while almost all research participants 'folded' it. I noticed that I felt disappointed about the 'folding'. Further reflection exposed an unspoken professional agenda, i.e. my conviction that there were many more survivors that were struggling than was acknowledged by the hospice and the wider health care sector. This now is no longer a point I have to prove but a thought that I hope I will be able to shed light on by the time I complete the data analysis. It may be that the 'folding' is a sign of being more at ease with the post-cancer experience. Yet in listening to my participants I also heard in a myriad of ways how their

contribution to the research is driven by a wish to help other people. In other ways they are not inclined to present their self as in need of support but as having an understanding of cancer that may be useful to transfer to me in order to pass it on to other survivors who may be struggling more than they do. An orderly presentation of their experience makes sense from this perspective.

## APPENDICES E

### APPENDIX E0: Summary of Ann's research data

#### Session with Ann (13.4.2017) - Summary (7.5.2017) based on transcript

For Ann, the time of diagnosis felt like “a black hole”, an *unknown* that she expressed by choosing a dark stone for that time. She felt “quite threatened” and says “I felt as if there was a conspiracy to end my life”. She describes herself as very emotional at the time, in turmoil inside which was not really seen by her family who took an attitude of “mum will handle it.”

Ann only needed surgery. Surprised she says “I didn't think they would act so quickly.” Ann thought there would be time for reflection and felt “railroaded, no control” into the decision. She felt in a “state of flux... disbelief but also a bit of panic underneath ... because my mind went blank. .... I couldn't detach myself and think (or ask questions)”. “I got the impression it was a no brainer I would have the surgery.” She is aware that they have a 62-day pathway for cancer treatment and it leaves her with the question “did I have the operation for me or was it for the people around me?”

At the time of the operation she says “I would have given anything for the next breath.” She felt very anxious. As Ann has a pessimistic outlook she imagined things to go wrong.

Also nowadays Ann worries about “what is going on and has the operation gone wrong”. This is triggered when she can't go to the toilet which in turn is triggered by emotional upset. Her overall expression though is: “I'm so glad to still be here.”

Ann feels she is not very clear about her feelings about cancer. “I accept it as part of me. I am *still figuring it out*.” On the one hand she explores with the sheet of paper how these questions are hanging over her, “touching on my heart”. This figuring out is also expressed in a rather positive way when she chooses an intricate shell to express her present Self. The shell captures that she is still curious about why she got cancer, “what impact that is going to have on my life, how it will shape the rest of my life.” Up to today Ann says she is still trying to answer “Why me?” She searches for answers in a range of domains: is it a chance thing? – is it because I have not looked after myself enough? (Put on a lot of weight, poured myself into raising the children) – is it caused my years of anxiety and depression? – is it genetic (mother had IBS) – did God allow this to happen to teach me about trusting in him?

Ann sees cancer as real (not just a thought) but as latent. It triggers fear but it is a fear “you're able to overcome.” She is not afraid e.g. of it coming back. She compares cancer to the Hulk, as a big thing with the emphasis on “thing”. It is a “monster” that is “alongside her”.

Cancer has been “a bit of a wake-up call”. Where in the past her focus (also due to her battle with depression) was on “just keep going on, if not for myself for my family ... and for God”... there is a slight shift now towards action. “There is so much need in the world that I’ve got to get into gear and sort of do something positive to help the situation.” Her motivation seems rooted in several aspects: “to give back in some way.”, the realisation that “life is finite”, “I feel that each day is more valuable to me” – not fritter life away”, as her diagnosis has coincided with the “empty nest” she is aware that her sense of meaning and purpose linked with raising children has come to an end. This sense for action is expressed non-verbally when she repositions the sheet of paper from her lap to her feet, indicating that this symbolises wanting to do something. She suggests doing a sponsored walk, something that pushes her physically. She is “looking for a way forward”. Ann is writing a book about finding peace in a turbulent world and trusting in God which takes fear away. She considers this writing in the first place as a catharsis.

The transition Ann seems to explore is also expressed by her pointing out that she was diagnosed with cancer while living in a new house called “wind gather” while she is now in the process of moving to another house, called “rose cottage”.

In the background is Ann’s experience of self with depression since she was 40. She was hospitalized five times. She left a high powered job to raise her children. She feels this took away her self-identification and self-esteem. She wonders whether she has had too much time to think as she acknowledges that her fear has not been about real issues (in contrast to cancer) but about thoughts in her head. She says “I’ve always known that I will face health challenges in my life.” Her depression started around a dispute with neighbours but developed in an extreme anxiety about the state of the world and that bad things would happen. She talks about “having lost the battle with the neighbours” and having a “battle with depression.”

Ann does not express a strong sense of change of self. The people around her treat her “just as me” which she finds a bit strange (as if it hasn’t happened). She also had always thought something physical would happen that would make her think this (life?) was “worth fighting for”.

For Ann her GPs have been the most important people, she feels “cared for” (non-verbal: shapes paper into a heart). They sent her for the screening test and are also now readily accessible. Non-verbally she positions them in the room but at a distance. She reflects on the fact that she has not thanked them for sending her for the screening.

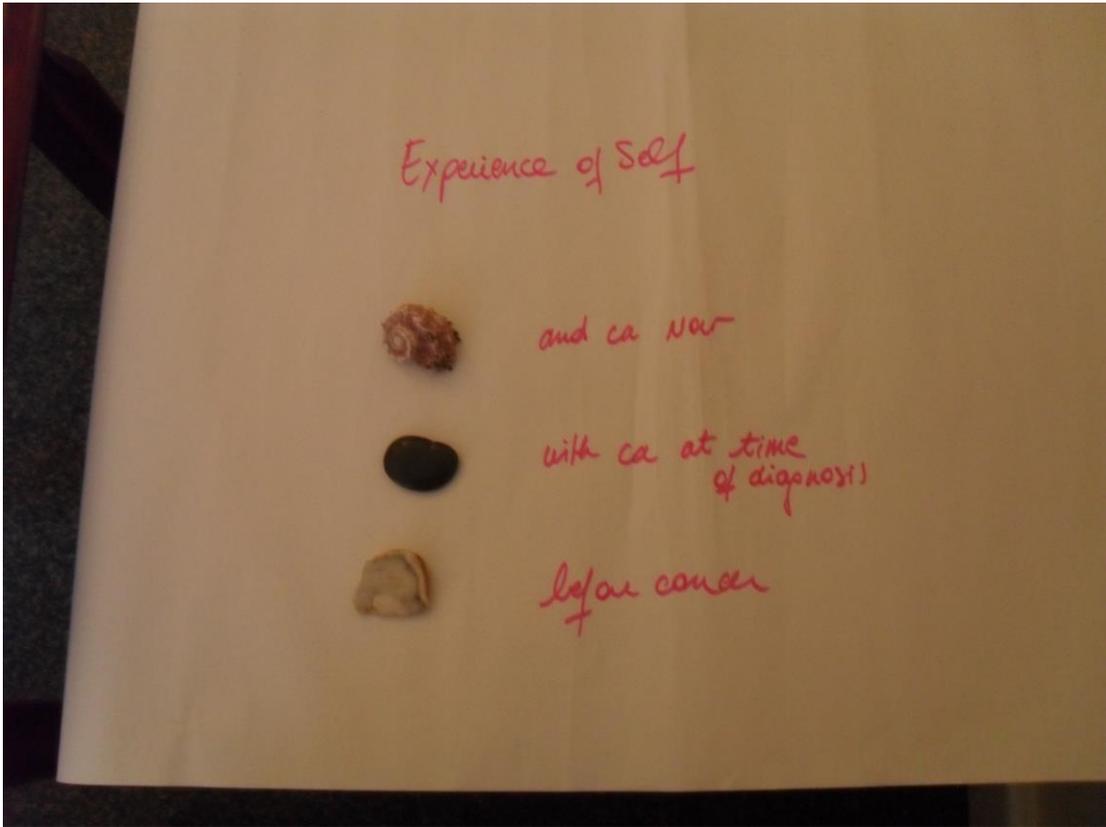


Figure 28: Ann's expression with shells & stones

# APPENDIX E1: 'Individual file' (example: Ann)

Table 16: 'Individual file' (example)

**PRESENT -- 'The Hulk alongside Ann'**  
Time post diagnosis: 6 months - post treatment: 5 months

**SPATIAL KINEASTETIC SELF**

Metaphorical conceptualising:  
"So glad to still be here", "I accept it (cancer) as part of me"; + "Got to get into gear" – "Looking for a way forward" – moves 'cancer' from lap to feet – appeal of sponsored walk"

Body schema: **PRESENTING & POSITIONING - alongside Thinking of MOVING**



**THINKING**  
Regained ability / Questioning Mode  
"Still figuring it out / Why me? (considers genetic, psychological, religious reasons)

**TIME FOCUS**  
*Present xx*  
*Future x*  
(intrigued)

**AUTHENTIC SELF** – Cancer has empowered Ann to express her authentic self (Writing a book on finding peace in a turbulent world and trusting God which takes fear away).

**PRESENT self that points to PAST self:**  
PRESENT: "Cancer was "a wakeup call"  
"Life is finite; everyday valuable, not fritter it away" + "life was worth fighting for" + "so much to do in the world" – Chooses a 'spiral shell' for present self in relation to cancer because it is 'intriguing'.  
PAST: Anxiety and depression and did not know what life was for but "just keep going on, if not for myself for my family ... and for God" ... + exacerbate with "empty nest"  
  
PRESENT: "give something back"  
PAST: religious  
  
Situational change: moving house from 'wind gathering' to 'rose cottage'  
  
*Self that sees life as something that is 'given' with a purpose that needs to be found (Psycho-spiritual)*

**TIME OF DIAGNOSIS / biographical disruption:** "a black hole", "conspiracy to end my life", "an inner turmoil", a dark stone represents this time:  
  
"I've always known that I would have health challenges in my life."  
  
**START TREATMENT:** only needed surgery; "railroaded into surgery"; "mind blank", "state of flux", "could not detach myself and think", "panic".

Present Meaningful medical events: less medical contact – worries about changes in bodily functioning (has not sought reassurance from MIM).

**CINICIANS**

Reaction metaphorically + meaning	Ann's action
GP At some distance but in room (caring and accessible)	Aware of not thanked them yet
MIM Ann knows she can ask them her questions	Not contacted

*Enacts thankfulness based on principle of life has been given*

**CANCER**

Metaphors	Hulk - monster, a thing <b>Alongside self</b> Real but latent : Part of me	Sheet in shape of 'question mark', "still figuring it out" "why me?," Not clear about feelings about cancer: Questions are hanging over her, "touching on my heart"
Level of threat	Capability of harm	
Feelings	"fear you are able to overcome"	Not clear
Uncertainty	Knowable through scans: No fear/no expectation of return	
Understanding		Not established
Having Control	Not cancer but fear	
Acceptance	Reality of diagnosis	

**CANCER IS PRESENT as a big "thing" Co and Self in some space but not engaged (alongside)**

## APPENDIX E2: Interpretation of chosen shells and stones

### 1. Representation of cancer

Ten out of the twelve research participants chose an object (shell, stone, wood) that was spiky or square, big and mostly dark to represent cancer at the time of diagnosis. 'Harmful' seems the best description. Objects chosen to represent steps from diagnosis to finishing treatment decreased in size. Cancer in the present was represented with a rounded, small stone or shell by 11/12 participants. This conveyed a feeling that cancer was seen as 'less harmful', 'less threatening'. Most objects had a lighter colour which may represent cancer being 'better understood' or feeling 'cleared, with less illness'.

Tony engaged in the exercise differently from the others. Only one stone was chosen to represent cancer. It was neither big or small and rounded. If this were to be interpreted in terms of his experience of cancer, it may express his wider narrative that from the start cancer was experienced in a very factual way. He fully trusted that it could be removed. This was supported by only needing surgery. The one stone may speak of being less affected but may also suggest that if I had met Tony earlier in his survivorship that the body schematic structure of his metaphorical comprehending would have been structured as it is now or that he moved through the steps quite quickly.

Wendy's choice of stone was also slightly different: triangular and less sharp. This may be related to the amount of time that passed, i.e. 20 years, a characteristic that also may have played a role in Tony's choice, who was more than seven years post diagnosis. Dan who was diagnosed about 10 years ago was the only one who chose a piece of wood, but explained that this was because it suggested growth which he saw as the essence of the threat of cancer

## 2. Representation of self

Not all chose an object to present their self at the time of diagnosis. Those who did chose something small, blank or woolly. This gave the impression of a diminished sense of power. The process towards the present was presented with objects that gradually got bigger. The self at present was unanimously presented with objects that were smooth and 'beautiful' (e.g. heart shaped stones, nicely patterned shells). Where the body schematic structure of the metaphors and expressive space and kinaesthetic 'sheet' exercise allowed for a differentiation of the participants, this is not reflected in the objects they chose to represent their present self vis-à-vis cancer. There was perhaps one exception: 10/12 chose a 'big' stone or shell while 2/12 choose a remarkable small, beautiful one. The latter were Ann and Linda, the only participants who had not reached the second anniversary of their diagnosis.

APPENDIX E3: Individual primary metaphor work document  
(example)

Table 17: Individual primary metaphor work document (example)

Summary Rosy	Metaphor	Primary metaphor	Meaning
...			
Pat expresses in several ways that cancer is present for her, e.g. She puts it on the table and comments "It is never far away."	never far away	Emotionally intimacy is proximity	cancer is present
Positioning cancer high up does not resonate for Pat, because that would mean " If it was up there I would have put it on the shelf and forgotten about it."	not forgotten		
In conclusion "uhm, up there is when I feel good and everything's great. And I seek to achieve that. But down there and close by is the reality."	down there and close by		
But she has folded the sheet a few times and says "But I do not allow it (fear) to take over" ...		2/Processes are motions through a linear sequence of locations	but she does not let it impede on her forward focus
"because that is compromising the way forward".		6/Suspension of Action is The Stopping Of Movement + Good is Forward	
She concludes "it is there but it is also contained". ...	contained		cancer is present but contained
"(cancer) impinges on my blank sheet (life without fear) ...	Cancer impinges on my blank sheet but it is contained	Imperfection is dirt	
She also point out though that the folded paper "keeps lifting up, you see, now and again" and ...		Being in control is being above / Moves now and again	
(Doing it differently here) means I am happy to go with the flow (of what cancer brings)...	go with the flow of what cancer brings	Circumstances Are Fluid	willing to engage in the circumstances as they present
I am bald and I'm wanting to keep an open mind about the things that arise." ...		accessible to awareness is out	
"not setting things in stone."	not setting things in stone		
...			
"When issues do come that mean I have to step out of my comfort zone ... grasping the moment and not allowing that (the uncomfortable feelings about) the challenges) to spoil that."	stepping out of my comfort zone	States Are Locations (interiors of bounded regions in space) + Acquiescing to a situation is taking an object	willing to engage in the circumstances as they present

## APPENDIX E4: Group primary metaphor work document (extract)

Table 18: Group primary metaphor work document (extract)

Body schema	Rosy - Blank Canvas - Present Conceptualisation of Cancer	Mark - Cancer stored - Present Conceptualisation of Cancer	Noel - A chapter in my life - Present conceptualisation of Ca	Rosy - Present Conceptualisation of Self in relation to cancer	Mark - Present Conceptualisation of Self in relation to cancer	Noel - Present conceptualisation of Self in relation to cancer
ARRIVING / reaching destination		Approaching the ending (it is getting to back of the garden now)	Have arrived (it is in the past)		VM (... And forgotten about it) I AM FREE FROM	
Sequence		I make sure the appointments happen (a bit like adoption - although adoption is more about going on a journey)	I make sure I can get an appointment if needed			
PURPOSEFUL ACTION – directing					VM (... In such a way)	
PURPOSEFUL ACTION - Force (agent, recipient, not)		LOW PROBABILITY inactive but potentially accidentally active VM "90 % happy that it will not come back"	ABSENCE OF ACTION		VM (folded it ....)	"a lucky escape" (due to the fact that he went for medical advice in time)
POSITIONING (position of self towards clinicians or towards cancer)		S & CA SAME SPACE BUT SEPARATE + POSITIONED BY SELF Ca in back pocket - stored on my computer - at the back of my garden	S & CA NOT IN SAME SPACE - Another era in life - Have escaped ca - in the bin	S & Cancer in same space but patient tries to keep self and cancer separate : "Cancer impinges on my blank sheet (life without fear), but in the small parts that it does (impinge) it is contained"	CA IN CORNER OF MY LIFE - NVM puts it in his back pocket - VM "like the memory on a computer" - VM "It is getting to the stage where it is down the end of the garden" - VM/NVM "If I had an elastic band I would ...."	
RELATING	S & Cancer in same space but patient tries to keep self and cancer separate : "Cancer impinges on my blank sheet (no fear), but in the small parts ..."			S & Cancer in same space but patient tries to keep self and cancer separate : "Cancer impinges on my blank sheet (life without fear), ..."		

Body schema	Rosy - Blank Canvas - Present Conceptualisation of Cancer	Mark - Cancer stored - Present Conceptualisation of Cancer	Noel - A chapter in my life - Present conceptualisation of Ca	Rosy - Present Conceptualisation of Self in relation to cancer	Mark - Present Conceptualisation of Self in relation to cancer	Noel - Present conceptualisation of Self in relation to cancer
<b>MOVEMENT ON A PATH but not self-propelled (moved by external forces in a positive (Eplay1) or negative (Jksurgery) way</b>						<b>cancer was a phase in my life</b>
Time is movement in space			"Ca is a chapter in my life" - "a phase"			
Time is movement in space					Past is in Present - VM "Not possible to let go off it" because people ask about it...	
<b>MOVEMENT IN SPACE (by clinicians or by self)</b>		LOW PROBABILITY MOVEMENT VM "90 % happy that it will not come back" EXPECTS NO MOVEMENT	<b>NO MOVEMENT</b> The cancer is "static"			
<b>LOCATION (experience of space)</b>	<i>Cancer impinges on my blank canvas</i>	<b>S &amp; CA SAME SPACE + EVERYDAY SURROUNDINGS</b>	CA & S NOT IN SAME SPACE + IN EVERYDAY SURROUNDINGS "Ca is a chapter in my life" - "a phase" - NV+V "I put it down. ...	<b>The non-cancer space has to be established on a daily basis by patient.</b>		
<b>MOVEMENT (OBJECT) MANIPULATION = controlling</b>		NVM - I could probably have expressed that by folding the sheet in a way that it wouldn't unfold."				
<b>PRESENCE: who and type of environment</b>		<b>ALWAY PRESENT BUT STORED VM</b> "it is in the background but never disappears"	<b>IN THE PAST</b> "Ca is a chapter in my life" - "a phase"		Self is more present than cancer; cancer present is conceptualised as in a corner	Cancer is not present in the present

APPENDIX E5: Plutchik's 'wheel of emotions'

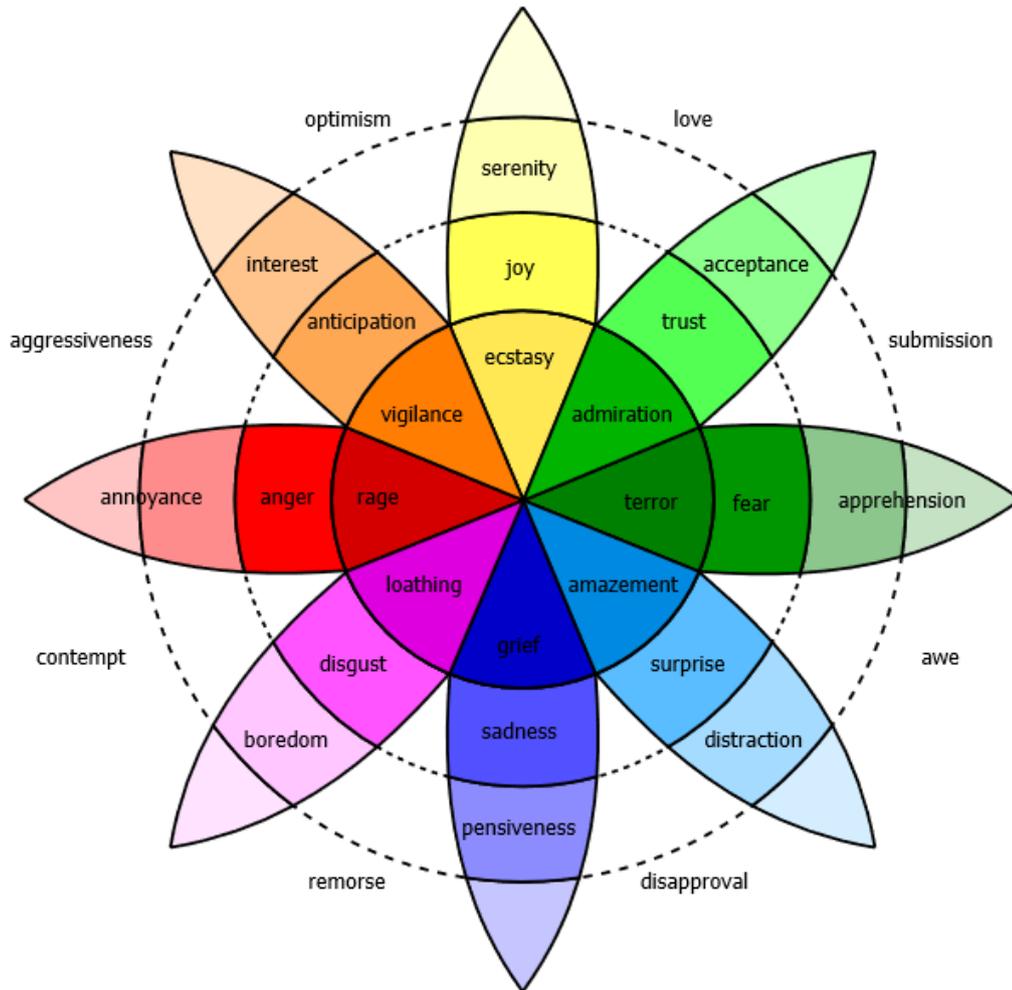


Figure 29: Plutchik's 'wheel of emotions'  
(Plutchik 1980)

## **APPENDICES F**

### **APPENDIX F0: Case study data E-fog**

#### **E's experience of survivorship April 2005**

#### **Counselling notes 04.2005: paraphrasing of client's communication**

#### **Title formulated for DProf thesis: Fog, the only place where I can 'be' (shorthand: Fog)**

'My consultant has decided to finish my chemo earlier than I expected but somehow suggests this is a positive. My personal experience of the treatment and my beliefs about my cancer are not taken into account. It leaves me with an enormous sense of uncertainty and I feel abandoned. My family takes on board the medical view that 'I am doing well' and I feel as if I live in a different world from them too. My world is a place where I am cognitively and emotionally not clear. I live in a foggy place. But, I set out to engage with this place. It is the only place where I can be.'

## APPENDIX F1: Case study data E-Terrorist

### **E's experience of survivorship August 2005**

#### **Counselling notes 08 2005: paraphrasing of client's communication**

#### **Title formulated for DProf thesis: The terrorist has left the country (shorthand: Terrorist)**

'It is five months since the chemotherapy which followed surgery was finished. I have just been for a first check up appointment keen to hear a medical view on the "shadow on my lungs?" that had been noticed months ago but nobody had mentioned since. The consultant's response was brief. I was told not to worry about the shadow because the cancer is believed not to be active. When I came home I switched the news on and there was talk about terrorism. I thought this is what my cancer is like: a terrorist that has been known to live in the country and now has left but perhaps will come back.'

## APPENDIX F2: Summary of Linda's research data

### Session with Linda 15 05 17 – Summary based on transcript 17 04 17

When Linda thinks back to the time of diagnosis she recalls it as “a slap in the face”, “it blew my head off” and it took her “a long time (months) to get over the shock”. Linda recalls how “we don't realise straight away what it's all about”. When it turned out after surgery that she had stage 3 cancer and it was in her lymph nodes it made it “real” and “not just a wake-up call”; she says I was “beside myself”.

She links her intense reaction with two experiences: 1/the fact that she “didn't see it coming”. She had not been prepared: she “didn't have symptoms” and only went for a check because her identical twin had been diagnosed with a non-cancerous polyp, 2/ “I never had hardship – mum is very protective.” Linda chooses a sharp shell for cancer at the time of diagnosis, something that “hurts”, “stabs you in the heart” (especially as she thought of her children), she was left “heart-broken”.

She felt “time stood still” for her because her future was so uncertain. “I felt a little bit dazed – like I was “watching in”, “on the outside looking in”. “I was biding my time somehow”. “Couldn't look back because that was sad and I couldn't look forward because that was scary. So you're stuck.”

She eventually chooses a very opaque stone for her self, representing that her self was gone. My “old self was gone completely”, “I could not have described myself”, “I couldn't look at photographs – found it hard to go back (before diagnosis) because I felt like that had gone.” “My old life had gone – and this was the new me now and that's what I had to get my head around” because “I was convinced this was going to be my fate.”

Despite all that “because I've got young children, you paint your smile on and get on with your day”.

Looking back at the diagnosis she says “I feel very lucky – someone must have been watching over me to push me to do it (go for a check), considering the stage as well.”

Linda talks about her treatment on the one hand as “a very long process but you don't realise that initially”. “You're just on a treadmill – and the times of waiting you've got to crack on.”, “get my head down and get on with treatment.” She did not struggle much with chemo physically but the ongoing negative medical news (tumour markers were rising during chemo, nodule on lung) was very stressful. Linda feels she struggled mainly mentally: “I felt stuck”, “in limbo”, “just exist – I felt I lost my identity”.

Although she was looking forward to the end of chemo, she likens the feeling to that “apprehensive feeling on New Year's Eve” (what will the year bring?).

Only one year after diagnosis (one year ago) she had the first positive news when her first blood results came back as all right. "After a year of thinking it's curtains – there is no feeling like it – the relief!", "I never experienced before." "I was high as a kite", "it made that whole year worth it." "Someone had given me a lifeline again", "it blew my socks off". The positive news was later followed up with a positive scan but that (to her surprise) did not have the same effect, although it added to the feeling that "she had turned a corner".

Linda expresses her present experience of cancer by crushing the sheet of paper in a ball and positions it close to her. This expresses several aspects: By positioning the cancer close to her she says "I carry it with me (it is close to me and not on the floor at my feet). It is not on her shoulders because that would suggest she says that she experiences it as a burden and that is not really the case. More accurate is that "it doesn't weigh heavy on my heart but it's always there", "always in the back of my mind (daily think about it)" By crushing the paper she expresses her hate of cancer: "I want to break it" (cf. at time of diagnosis it broke her heart) because of my "feelings of fear – hating it and the effects it's had".

But crushing the paper also expresses her attempt to exert some control over it. She specifies "I know I've got no control over the illness itself" but I aim to "control over how I deal with it, so it's a case of keeping it together really". Linda gestures with her hands that initially Head and Cancer were on the same level, while now she feels that with her Head she is "a little bit above it – can bat it down a little bit". "I am a little bit on top of it. I can close the door on it if I need to; have control over where I put it." "It is not overshadowing me". "I don't let it stop me getting on with life."

Her ability to feel in control is different in the daytime than in the evenings. As she has gone back to work she feels she "can get on with my day" (cancer is further away). But at night she often has a "cogs going feeling", "my space is closing in".

Linda puts a lot of words towards expressing how she considers having no real control over cancer as an illness: "It's mapped out", "It's out of my hands", "if it is down for you it is". For cancer at present she chooses a stone that is slightly less pointed than the one she chose to represent cancer at time of diagnosis: "it is not quite as aggressive but capable of hurting (knocking me of my feet) – but not quite at the moment". Keeping all this in mind she describes as "I am cautious", "I am not complacent", "not foolish", "not tempting fate".

Linda feels that she has taken things from the experience of cancer "that are important".

1/ It has changed her perspective on life, more specifically appreciates the tiny things far more than she ever did before.

2/She also says “I feel I’m a different person to what I was before”, “I now have more of an identity than I did before”. She specifies: “I realise I can do things on my own”, “more capable”, “don’t feel I need someone else now”, “It was my fight”. Linda links this with her previous experience “As a twin I felt other people were stronger because they were going through life on their own. I felt I was chosen to be a twin because I needed her.”

3/ Linda also says “I don’t want to waste my time (on things I don’t want to do) because your time is precious”.

When blood tests or scans are coming up, Linda says cancer “becomes more prominent”, “it moves, is overtaking a little bit”. She fears this feeling of it taking over so she “can’t function and the children will notice.”

Her experience with health care professionals has not been so good. Especially with her oncologist she did not feel connected. She was looking for reassurance and did not receive it. Non-verbally she expresses this by crushing the paper sheet and says I “screw it into a ball and kick it across the room”. He made her and her husband “feel small”. Although this worries her in case she needs him again, she also says “If I had to face the oncologist again, I would confront him with his behaviour”. “They’re my bloods and they’re my tumour markers – and I’ve got a right to know what they are”.

She folds the sheet in two to express that she has a team relationship with the colorectal nurses, “I’m one half, they are the other”. Based on an earlier experience she feels some mistrust towards them as they were caring and friendly but regarding the chemo they “told me what I wanted to hear”.

She looks at the future and says “I can’t say for definite what will happen in the future.” Being cautious is “a bit of self-preservation, preparation... I don’t know whether anything would ever prepare you for it to come back.” She also tries to prepare her family in this way. “I do not let them bury their head in the sand”. Although her husband avoids the: “if I wasn’t here conversations”. With her children she sets out to “being realistic without frightening them”, “I plant little seeds” by saying e.g. “Mum’s okay, touch wood”. “I do not say ‘okay but it might come back’ – rather let them know that we’re not quite out of the woods but it’s good.” She is in the process of arranging an extra scan this month, which is two years after diagnosis as she feels she needs the reassurance.

She does not look far ahead, just to the next event. She concludes “I live life in chunks really”.

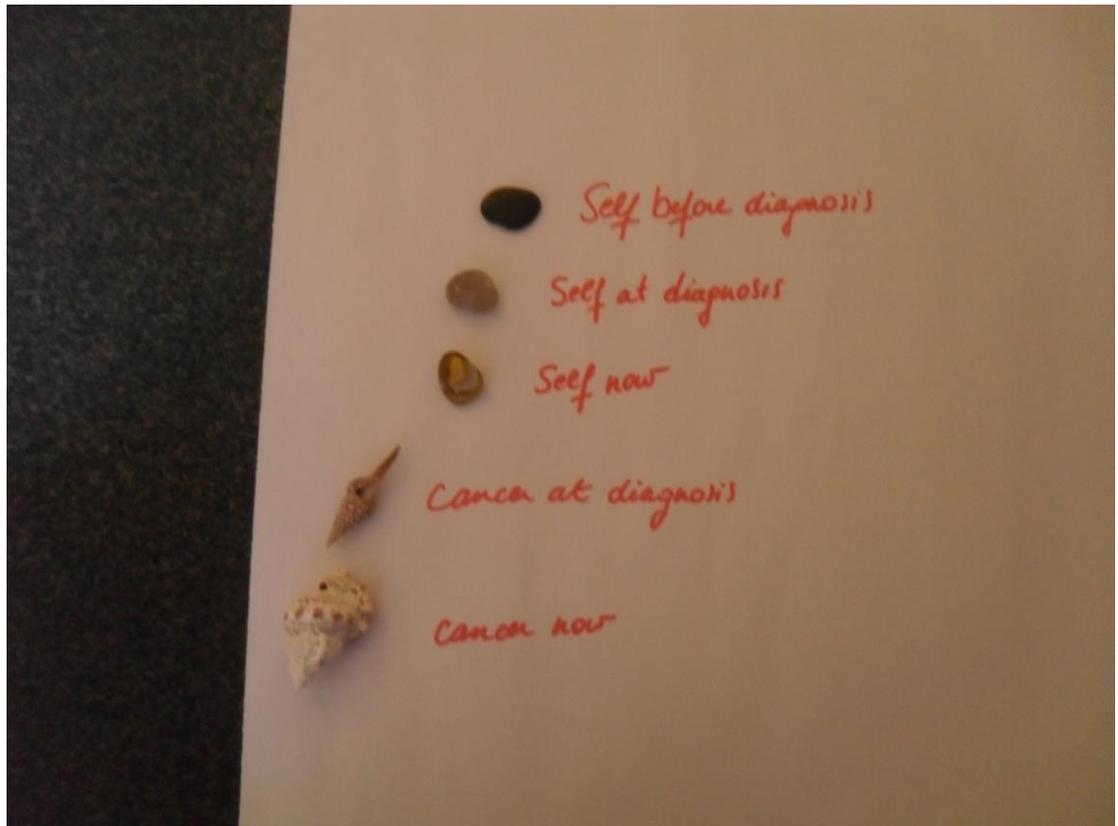


Figure 30: Linda's expression with shells & stones

## APPENDIX F3: Summary of Rosy's research data

### **Session with Rosy 21 11 15 – Summary based on transcript 17 12 15**

Rosy initially sees the unfolded A1 sheet of paper as a representation of cancer before diagnosis. "I knew little about it beforehand so I saw it as a blank canvas." But she goes on saying "I don't feel I want to contaminate it or make it smaller... I still feel it's a blank canvas... with no particular thoughts or no fears. So this (cancer as a blank canvas) is the future".

This becomes further nuanced ... "The logical positive side of me wishes to see it like that." "The emotional, sometimes physical side of it would make me feel fear and therefore it would not be so blank."

Rosy's anxiety and fear has several causes:

First, she feels anxious "concerning being able to cope with everyday life and wishes to do the things I wanted to do before." This partially refers to the stress of living with a stoma.

But secondly, she is also worried of going back to her previous busy life-style. Rosy has a fear that her earlier busy lifestyle may have "contributed to a cancer". Now, she says, "I am trying to pick up the pieces of my life again in full." But, this does not mean she wants to go back to her previous busy life style; She do not want to go back to a pre-cancer feeling of "I'm doing so much, I don't really enjoy anything." On the contrary she states "I do want to go back to what life should be and that's enjoying it, you know, as a Christian... anything we do should be done with grace and I'm so conscious that if I take too much on I'll lose that grace to do it." This resonates with what seems her motto "living in the moment". Rosy picked this up from a radio programme one day she was preparing to go to hospital and felt she needed some support. It spoke to her.

Rosy expresses in several ways that cancer is present for her, e.g. She puts it on the table and comments "It is never far away." Positioning cancer high up does not resonate for Rosy, because that would mean "If it was up there I would have put it on the shelf and forgotten about it." In conclusion "uhm, up there is when I feel good and everything's great. And I seek to achieve that. But down there and close by is the reality."

But she has folded the sheet a few times and says "But I do not allow it (fear) to take over" ... "because that is compromising the way forward". She concludes "it is there but it is also contained". Rosy relates that she does not want to share a hotel room with a friend and that she is aware for this to "be a big thing" for her and uses this as an example to illustrate how cancer (having a colostomy bag) "impinges on my blank sheet ... but in the small parts that it

does (impinge), it is contained.” “I don’t allow that anxiety to encroach too much into my life.”

She also point out though that the folded paper “keeps lifting up, you see, now and again” and adds that this means she cannot always “deal with her body (stoma)... in her normal disciplined way” (e.g. attending to grandchildren in a house without a bathroom lock).

Rosy is aware that she folded the paper in an unusual manner for her “normally I will fold (a piece of paper) very neatly corner to corner and I would smooth it out. (Doing it differently here) means I am happy to go with the flow (of what cancer brings)... I am bold and I’m wanting to keep an open mind about the things that arise.” ... “not setting things in stone.” Later on she expresses that the rough folding means “When issues do come that mean I have to step out of my comfort zone ... grasping the moment and not allowing that (the (uncomfortable feelings about) the challenges) to spoil that.” Later on she adds “I think it also shows how relaxed I am that I, I’ve not folded it so precisely.” “Yes it’s there, it has been but now let’s move on.”

Rosy concludes “you’re never the same again ... However I refuse to allow it to not let me be the same.” She reflects on her attitudes towards problems: “If I have a problem I have to address it practically... not just curl up in a ball and think it will go away.” “When I come up against a wall... my attitude is to face it head on. ... “getting round problems” .

She describes herself as “I’m a person with issues but and I’m also the person I have always been... and seek to continue to be – and that’s probably a fair way of describing how I’ve dealt with having cancer, you know.” “But I’m very aware – from the experience of being diagnosed with cancer that I haven’t got any control really. But what I can control, I try to.”

Having a colostomy bag impinges on cooking, travelling, child care, relationship with partner, underwear I wear etc. “It’s a nuisance at times”, “I really don’t see it as an enemy”, “I saw it as a means to an end to getting rid of the tumour”, “I didn’t think of it as anything but a consequence of that fact that I was diagnosed with cancer.” Rosy recalls that at some point she said to her family:

“I know that I shouldn’t call it ‘it’. It’s, you know it’s taken my life” and I, and I but and I, there were times when I would cry. I would feel so emotional about it because I couldn’t get to grips with this ‘it’. And then we came up with a name funny name.

“... without (the stoma), I wouldn’t be here you know. And so I do feel that you have to get to grips with that side of it. And I found that particularly difficult.” “It helped me to accept it – stage by stage – but it doesn’t happen overnight, you have to get to grips with it yourself.” Rosy feels that other people with colostomy bags sharing their experiences has helped her and the

way she was informed and treated at the time of surgery and her own personality.

Rosy positions herself in relation to the sheet of paper by putting it on the table rather than on the floor. This resonates with her experience of dealing with her stoma “- and when I have anything to hand and I have the space to deal with it, it isn’t a problem.” The bag “governs her day – her weeks” but “I deal with it, I, I don’t feel it gets me down at all (hence it not being placed on the floor)”. The bag she says “governs quite small issues in life really but they’re not to me.”

Rosy’s relationship with her consultant is very clear “no shades of grey”. “I accept that she’s still a big part of my life.” In the present “I’m still dependent on her advice and positive feedback from her”, potentially in the future “if there was anything negative I have faith in her that she would deal with it.”

Rosy folds the piece of paper representing the consultant very neatly to express “the respect I have for what she does and what she has to do and I’m only a very small part of that.” But, it also resonates with the consultant’s precise care and advice (story about stoma popping out).

The consultant is not on a level with cancer because she is not in her everyday life and “I don’t have to relate to her constantly but still very important”, I can trust she is there when I need her. Rosy expresses the importance of the consultant at the time of diagnosis, at present and potentially in future. The importance has to do with her skill but also with her empathy and accessibility.

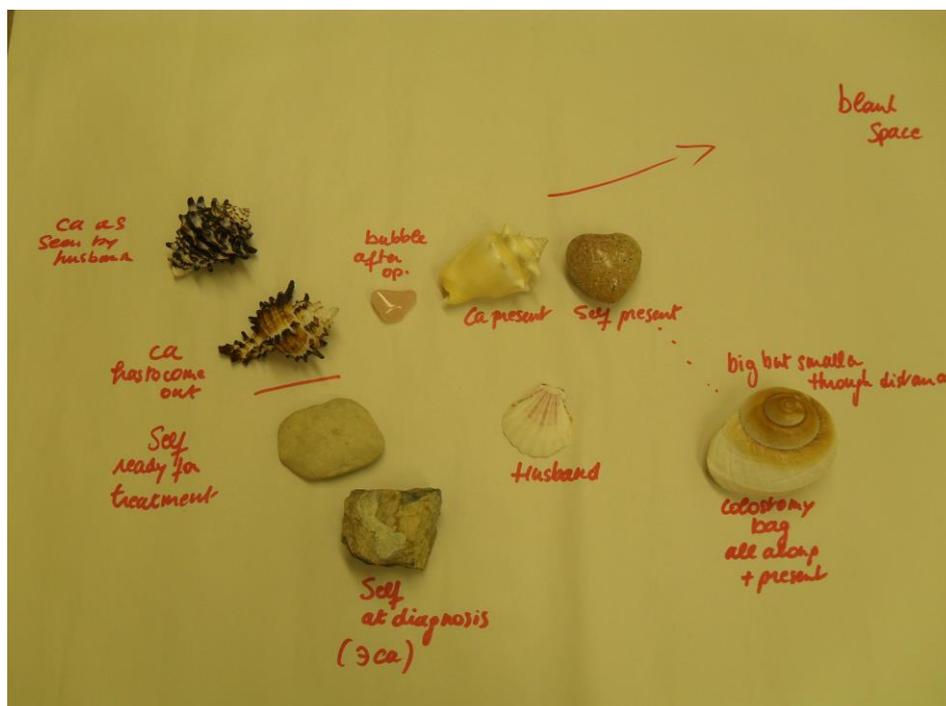


Figure 31: Rosy's expression with shells & stones

## APPENDIX F4: Summary of Karl's research data

### Session with Karl 31 03 17 – Summary based on transcript 23 04 17

For Karl the process of diagnosis started with a sigmoidoscopy during which “they failed to spot the cancer, they missed it.” It was found six months later following a colonoscopy. Karl points out that he “lost six months” and that it may have been in that time that it led to “stage three cancer and cancer in one lymph node which meant he needed chemotherapy.” Once they saw the cancer he says “everything happened from then on, you know, everything went into overdrive.”

Karl refers to the cancer diagnosis as “Cancer to me was like going bang, smacking you round the head with a hammer.” “Cancer is a blunt instrument... it has no care for you, it doesn't care if you are rich or poor. It's a weapon of mass destruction.” He chooses a “jagged, dirty rock” to represent it as it is the “closest to a hammer.”

His diagnosis triggered a strong religious response. He asks (God) “Haven't I done enough (referring to 30 years of struggle with his wife's MS, having had to give up his job and other family stresses caused by both parents dying from dementia and his daughter having breast cancer). Do you have to give me this now? Is this another challenge, what are you testing me for, are you saying I need to be tested?” The unfairness seems to have fuelled in Karl a very strong fighting response towards cancer “What I've gone through in life, this (cancer) is nothing, you ain't going to get me. I'll have you.” “I thought I'll fight you bastard; you won't get the better of me... I'll take this on as a personal challenge to beat you.”

Although his plan to beat cancer was conjured up by a strong emotion, Karl's way of coping he described as devoid of emotion: “... there was no emotion involved, it was a plan, an action plan to deal with it.” Many years ago following a mental breakdown due to the stress of having to combine a high powered job with being a carer for his wife and father, he engaged in a stress management course and therapy which taught him to respond to stress with calm and with making an action plan and live according to a ‘psychology of winning’. His stance is that there is no point in anger, “It's self preservation, it's my brain's way of protecting me, otherwise I would be dead”. In that sense Karl describes cancer as “It's never been a dramatic emotional thing for me. It's just an everyday (thing), just something else, that's my approach to it.” “I've no time to dwell on cancer.” To me cancer was just an inconvenience to be dealt with.”

Karl easily engaged with the plan-like approach of the treatment programme: “once they (medical team) gave me a plan, that was it.” He choose a white stone to represent his self as “prepared, had a plan, I knew” in contrast to a big speckled shell (a bit of a slug, sloth, millstone) to present his pre-cancer self. In the preparation of the surgery the relationship with his surgeon was

crucial “I said to Mrs X .... I will be the best patient you’ve ever had ... anything you tell me I will do ... I’ve got myself fit, ready for surgery. I’m carrying no fat... you’ll find it easy to operate on me... I thought, if I help her, she’ll help me.” Just before the surgery Karl asked for his blood pressure to be taken which was okay ... “blood pressure normal, ready!” and then this almost businesslike approach got a human dimension as he describes how “... there was a tap on my shoulder ... it was the surgeon and she just looked at me and she said, I’m here, and then walked off. I thought, that will do for me. That will do for me. So I was prepped mentally and psychologically. “ ... Later Karl revisits this memory and says “She made a point, just before I went in of coming to me, acknowledging me, and I cried, it was that emotional. That was the most significant thing that’s happened to me in the journey. Wonderful. So I’ll always think of her as my saviour. Because it was human, she cared. If felt not just another patient, so I felt then ‘if she’s putting that into me then I’ve got to give, I’ve got to make bloody sure I survive this and be a good patient.” This meant for him that when he was recovering from surgery in hospital he “wanted to focus (on the medical recovery programme) ... did not want visitors ... I didn’t need any emotional support.” The treatment Karl says was described as “belt and braces approach” as there was one lymph node affected.

Last week Karl got scan results confirming there is no active cancer and his next appointment has been set for the end of the year. Karl says “that’s set me free now... I’ve now at least got another year... I don’t think cancer can come back and kill me within a year if there’s nothing there now ... and if my wife lives another year ... so hopefully, God willing, between the two of us we’ll last until the end of the year.” He expresses his present hopeful Self with a “polished heart stone”. With the sheet of paper he expresses his present experience as follows “I’ve now got to this point – where (previously) that would have been jumbled up with so much going on – now, for the first time I’m back to like a blank canvas where I can get on with my life, if that (the sheet representing life in front of him) isn’t full of all the things, all the pressures...” “For the first time in three years... life is under my control, whereas it controlled me, the cancer.” “I’ve got a fresh start.”

From the following we learn that he does not look ahead that far “I should have at least another year, hopefully I’ll live ‘till I’m 90. But for my sake and my wife’s I’m looking towards the end of the year.” Karl says the unfolded shape of the sheet represents his feel that “(his life) is not a closed book. It is still open.” He positions the sheet on the floor in front (not behind him) of him and near to him (not outside the door) because “Life is still before me.” And “it’s within reach” (not “floating away”), “it’s here and now” (not “a dream”). As it is “nearer, it is more likely it is to happen.”

As for the future he feels that with cancer “everything is ifs and buts”. For example they will keep monitoring nodules found on lung and liver. So far they’ve been benign but if one day they are found malignant it goes from “cure to no cure”. The need for ongoing scans means “it never goes away”. The way he talks about himself and clinicians is coloured by this wish that this

was not the case: "All I want to hear from (them) is a letter saying all is okay (in the best possible way) I never want to see them again."

Karl describes how life to him has been "like going with a bungee thing behind my back, tied to a fence so you're pulling against it all the time ... a big rubber, stretch of rubber tied round and I'm walking against the pressure of this rubber and it winds me back again." Sometime later he summarises it as "An elastic band which gives you so much freedom but only a little amount, then it draws you back."

Karl's life expectancy is on the one hand shaped by the unpredictability of cancer but also by the fact that close relatives have died of dementia. He concludes "you live the hand you're dealt."



Figure 32: Karl's expression with shells & stones

## APPENDIX F5: Case study data E-Theatre play

### **E's experience of survivorship early February 2007**

**Directly written by E during professional co-research work: 02.2007**

**Title formulated for DProf thesis: No guest appearances of cancer in the theatre play (shorthand: Theatre play)**

“Again I have seen my consultant as I have done regularly during the last year. Today I find myself looking back on these visits trying to grasp what goes on. The following image comes to mind: The whole experience is like a theatre play. The consulting room is the stage. The consultant is the protagonist and in each scene one of many principal actors (the patients) stride onto the stage (there around 300 patients at the Christie Hospital on any one occasion) to play their part.

There are also many bit actors, nurses, porters, cleaners (props) etc. From behind the scene you hear the buzz from the back stage workers, moving trolleys, and screens, putting new dressings on the actors, cries of frustration and people agonising over a script they did not want, others crying with joy at theirs... some of course have played their part and left silently through the back stage door, followed by ardent fans who mourn the loss of their hero.

The star of this play – the consultant - has a stable role. The script has become formalised and a bit static amongst the lesser protagonists (the junior consultants). The play has been structured with just two alternative conclusions! During the play the principal actors are taking some freedom with their dialogue; they have rehearsed the official script in a personal way so their scripts slightly differ depending on each of their unique circumstances. I am an amateur stumbling over my lines but the consultant guides me around my mistakes to arrive at the right line – in my case up till now: “come back in a month” – at the right time. With this he implies that the play will have a next showing.

The unspoken but known secret of the play is called ‘cancer’. At this moment we do not quite know “its” role apart from the reputation it has of giving “surprise guest appearances”. Today it has not appeared.”

## APPENDIX F6: Summary of Mark's research data

Session with Mark 09 01 16 – Summary based on transcript 04 02 16

In Mark's case initially the consultant was not looking at cancer yet but from conversations with a relative-doctor Mark was expecting it to be cancer. He also has a close walking friend who was diagnosed with the same illness three months before him. At the time of diagnosis "you have no idea what the future's gonna be. You don't know whether you will be alive in six months time or what." Nevertheless it was "never on top of me ... my response was rather "well the car is broken, it needs to go in and get fixed – you go to the proper service station, they sort it out for you".

In terms of expressing it with the sheet of paper: "I started folding it more or less straight away – I may have folded it in a different shape than today e.g. squares" ( instead of rectangular ). It "never stopped me" because I had to look after my partner who was seriously ill and needed my care. Mark was "finding things to take my mind off it but finding things that were useful, not things that were just a waste of time."

Nowadays Mark says "I have looked at the whole thing and then folded it up in such a way that I've put it away now and forgotten about it". He has put it in his back pocket. It is "at the back of my mind". That is not the same as "letting go off it". That is not really possible because people ask how you are doing. "It is in the background, but never disappears." And when you have a scan, "it brings it to the fore of my mind". He compares it to the memory on a computer, it is there in the background. Being reminded is like "hitting the wrong button on the computer". "I am now 90% happy that nothing is coming back." Mark says he could probably have expressed that by folding the sheet in a way that it wouldn't unfold." It is contained by being in my pocket. If I had an elastic band I would put it around the paper to express the containment." The fact that a relative had the same diagnosis and is now more than 10 years on and well, makes it probable for him to think that it will not come back. Just like her Mark is quite active and keeping fit he believes is helpful. "It is getting to the stage where it is down the end of the garden".

The overall treatment journey with cancer he likens to a "long distance walk", like "walking the coast to coast" from the Lake district to the Yorkshire dales. At first he recalls it being really tough with bad weather and that on manages because of being part of a group; "I wouldn't do it on my own." He compares it to the day after the operation; he was struggling but did keep pushing on. Mark continues the walking metaphor and recalls that once you are out of the Lake district, you see where you are going and you have gentle ups and downs. He compares this to having finished chemo. As long as you are on chemo, he says, "you don't know where it is leading to". When the chemo finished and he had his first year's colonoscopy, he felt he had reached the coast.

At the start of the journey Mark felt he was pushing for the treatment process to start. “ It is about ‘getting in the loop’ because that is when the ‘system with its guidelines about waiting times etc’ kicks in.” From then onwards he felt it is not longer the patient as an individual who is “pushing that”. Mark comments that ‘they’ (hospital) are running behind schedule with the scans at the moment; so he feels he is back to “pushing to keep them back on track”.

Mark concludes that the way he deals with cancer is very much an expression of how he is. He sees himself as somebody who ‘attacks problems’; he aims to “encompass a problem, to have a hold on it”. He describes himself as process-orientated and quick in seeing the wider picture. He has had loads of set-backs in life and just got on with it. His attitude is: Yeah that happened but I need to take a different path now. Like in careers “you get to a crossroads, which way do you go?” From the beginning he was “thinking the ways ahead” by “thinking backwards like in failure analysis” in order to make sense of where he was.

Mark has always talked about cancer, he believes it is about ‘getting the monkey of your back’, sharing with others means “getting more than one mind on the job”. It is part of his professional outlook that, things have to fit, thinking has to be organised. For most of his life, if there is bits and pieces lying around, he’ll make something out of it. And he is always looking to the better things. He feels he has turned cancer into something else and into something positive now by volunteering and helping others. Dealing with cancer is like “effectively folding this sheet in a way so I am not thinking about it”.

Nowadays “cancer is an open book” for Mark while at the time of diagnosis it was in ‘many ways a closed book’. At first the consultant was the only one having knowledge about cancer. Nowadays is confident that he knows a lot about it as well and “ because I know so much about the background to things I could almost talk on, not quite a level playing field with him”. Not quite and in that sense the consultant is also the “guide to the future, he and his team will spot anything that is likely to transpire”. “I am leaving that up to him”, he “has the GPS that shows the pathways”. But Mark is somebody who “makes myself available to a relationship” and “do not stand on ceremony” ( I do not hold back based on hierarchy). The other day he walked up to the consultant in the corridor and said “Consultation went well yesterday, shook hands and off again”.



Figure 33: Mark's expression with shells & stones

## APPENDIX F7: Case study data E-Unknownable

### **E's experience of survivorship late February 2007**

**Directly written by E during professional co-research work: 02.2007**

**Title formulated for DProf thesis: I embrace the unknowable aspect of cancer (shorthand: Unknownable)**

“During the last week I have been thinking a lot about my cancer situation. I have become aware that I do not carry the burden of having cancer. I used to think of being invaded by cancer, but now feel guilty about saying it because it hooks me into being a fraud. People with ‘real’ cancer look awful, thin, yellow. I am not like that. I think I shall never die of cancer, just old age, and then I shall not really believe it.

I know now there are no clear definitive truths about my cancer. My past experience has shown that whatever statements doctors have made about my future health at best they have been a guess. ‘They’ do not know, at a fundamental level, what is going on or what will happen. And neither do I. But I feel OK and I “believe” that I am a survivor.

I’m not even sure that I still want a clear answer, I think I like the confusion, the chaos, it somehow gives me freedom. I am in a comfortable place of knowing yet “un-knowing”. With this I mean I embrace the unknowable aspect of cancer. Instead of being haunted by its uncertainty I find myself stating and elaborating on its uncertainty. I suspect it comes out in my conversations with my doctors. Am I trying to make them see that also for them cancer is un-knowable? I want to know and understand better or more deeply what is going on in every transaction between me and the clinicians. I certainly value our regular conversations.

I have a desire to speak freely about cancer and the effects it has upon me, particularly emotionally. At one stage the shame about my body, which was made even more ugly by a skin, coloured plastic bag glued to my abdomen was overwhelming. It emasculated me and confirmed my feelings of being physically unattractive. Emotionally accepting cancer as a time of learning and a new experience has helped me to be more constructive rather than critical and unsatisfied. I have a sense of being able to be deeply satisfied. I feel I am able to fully live if I should wish & to give all that I have, to hold nothing back, if I want to. And so I am beginning to re write my script.

Trust was a fundamental deficit in my life, which seems to have moved into a credit position. Perhaps a little cautiously, however I am less driven, more understanding, but somehow not less needy, perhaps I have learned how to accept? I feel more at peace with myself and appropriately selfish?

I have also a desire to be truthful, recognising that if my relationships, are to be meaningful and wholesome truth/trust is essential. The necessity to totally trust the surgeons and practitioners whom I was utterly depended upon when I was diagnosed and in recovery may prove to have been valuable in an unexpected way.

I have been privileged to have been through what I thought was “the shadow of, the valley of death” and it has changed me, and somehow has given me permission to be who I really want to be. I have the freedom to live my life as I want without all the constraints of the society to which I have subscribed.

I suddenly realise why my earlier play metaphor feels so unsatisfactory now. It does no longer make sense to see the consultant as the protagonist. I relive my last consultation and decide to turn my play metaphor into an Augusto Boal Forum Theatre play in which actors or audience “stop” the play and intervene with the script where they feel oppressed. The person who stops the play takes the place of the original actor who stays on stage but to the side. I feel it is only right for me to be the star, the protagonist. I want all the attention to be upon me, after all that is why we are all here, is it not? I have a heap of questions ready prepared, to challenge and understand more than to get answers.”

## APPENDIX F8: Summary of Simon's research data

### Session with Simon 16 01 16 – Summary based on transcript 10 02 16

All his life Simon was convinced that “for some reason he would get cancer over the years” caused by previous work conditions.

At the time of diagnosis he was not really concerned; he did not think “Oh, that is the end of the road, I've had it.” He rather “got on with it and got through it”. He likens the diagnosis of cancer and what follows to “cordial at the bottom of the glass, which is then dispensed more and more as water is added.” He also feels that it is other people that are concerned when you tell them you had cancer.

After the seventh of eight planned chemo sessions the treatment was put on hold but then unexpectedly he was told that he was “all clear and discharged”. This was “like sticking a pin in a balloon”. He felt “he walked in with cancer and out without cancer”. It was hard to sink in but he felt “I got my life in front of me ... I am not gonna die in the next few months”. He wanted to tell people that you can “get to the other side of cancer”. But it also made him feel “empty... What do I do now? ... Where do I go?” There were still check-ups to go to – “still going down that line” - which held the message that “it could come back” – so not completely discharged, “not a closed door”.

In response to my invitation to express how he feels by shaping the sheet of paper, Simon expresses that nowadays he has “folded it up a couple of times and put it in a corner. The folding does not have to be “exactly perfectly” because it is not really a problem, it is folded roughly. Getting the size down expresses that is a “small problem” or rather a “small concern” ... the concern about “having to go through it again”. It is living with a risk, one that does not compare to anything else in life. Simon emphasises that it is not living with cancer but “living with the aftermath of cancer”. It is not living with an “illness”. “I've had cancer, I've gone through all the treatment, I've been discharged, so it is in the past ... it is behind me.” It is like a “tall wall, it is everything behind me, the whole world wide – not just bunched up behind me, spread out completely”. At the moment I can still “see it in the corner of my eye but it is going further away from me – like the dispersing cordial.” “It is *not* a wall in front of me, I am forging ahead, trying to spread my wings and push it – no, it rather drifts - I help it to go into the distance”. “Cancer had a place in my life and I am trying to keep it *there* (in that past place).” That suits his methodical and orderly character. In a similar way as things have a place on his wall to ceiling packed bookcase at home.

When appointments are ongoing, letters are kept “in a place for things that are pending, haven't got a home yet”. Cancer is drifting into the distance but I can get to it when I need it. Once finished, they are filed in the proper file.

Referring to his parents' longevity Simon says "I've got 24 years to plan ahead for yet." He makes a gesture that suggests the end of his life is a long way off. He follows his father's advice and keeps busy with an allotment and walking.

Ongoing symptoms are evaluated by talking to others and figuring out whether it is "normal". If cancer were to "crop up" again, you face it then.

Simon has a number of non-cancer related health problems. He considers these as part of aging and does not dwell on them.

When his oncologist told him he was "all clear", he felt a strong urge to thank him and it "made his day", "was a weight of his shoulders" when he could do that. Knowing that his surgeon was a pioneer in key hole surgery, made Simon feel he "was in the right place". He liked his relaxed manner as it made him relaxed. Nowadays he feels he has "filed his oncologist away together with the cancer – he points out that he folds the sheet of paper that represents the oncologist a bit more neatly than he folded the cancer and says when 'filing' him away I would write his name on the file, because he (his oncologist) also "had been careful with him". In his mind he also files it all carefully "so I don't forget".

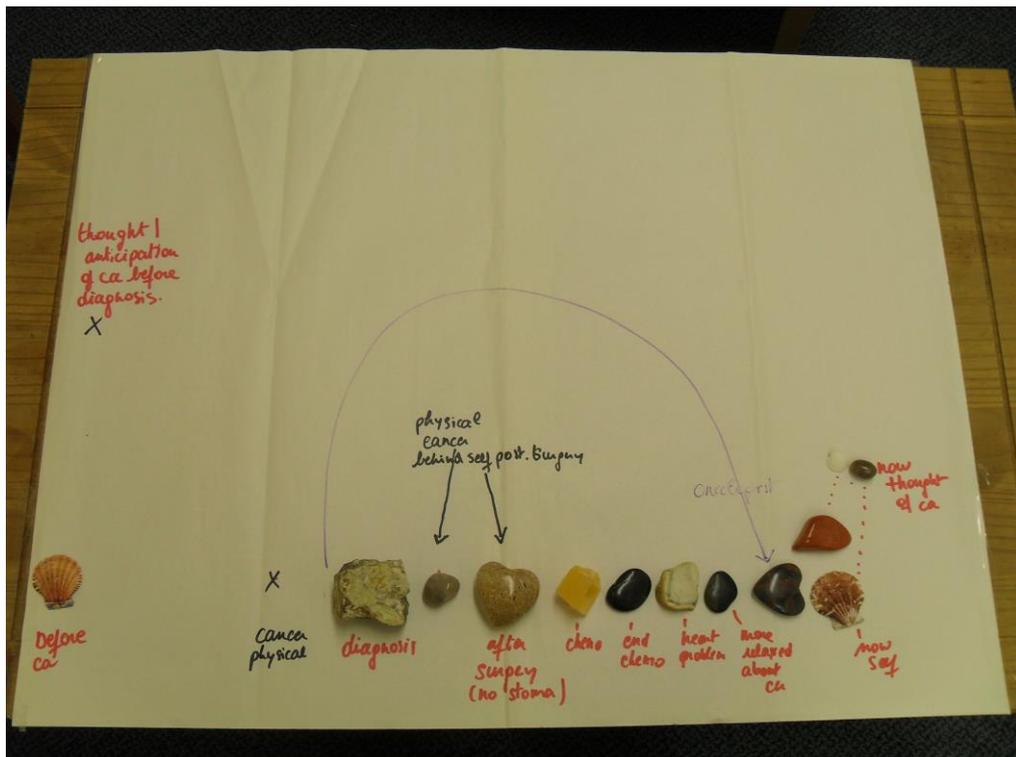


Figure 34: Simon's expression with shells & stones

## APPENDIX F9: Case study data E-Adopting

### **E's experience of survivorship end March 2007**

**Written up by E after first expressing the metaphor verbally to me during professional co-research work: 03.2007**

**Title formulated for DProf thesis: Adopting cancer and accept good and bad times to come (shorthand: Adopting)**

“The role play metaphor has not left me. Today it suddenly dawned on me how exhausted I feel by ‘hosting’ this ‘unwelcome visitor’, this cancer that can come and go as it wishes, that could make ‘guest appearances’. I have a need to shrug of this feeling of being a ‘hostage’.

And as I realise this a new image of me and my cancer pops up: I decide to adopt the cancer. It is no longer a matter of fighting it or adjusting to it. It is a matter of accepting that it is mine. I own it for now and probably forever. Like with a child I accept that I will have good and bad times with it but that is how it is.

This metaphor did not follow from a conversation with my consultant. Perhaps I was influenced by a conversation I had with somebody with adopted children or has the idea that I am nine months beyond the given prognosis shaped my thinking?”

## APPENDIX F10: Summary of Noel's research data

### Session with Noel 28 11 15 – Summary based on transcript 19 12 15

Noel describes how he went to his GP hoping he would “get on the case pretty quickly”. When this didn't happen he rang and asked “can we go and move things on”. They agreed and “that started the trail of events”. He says “I was then on the treadmill” of tests and treatment.

At the treatment stage “everything just goes, it's moving and we move with it, it was predestined from then on”. The aim was made clear by his surgeon, she said “she would try to put me back together again” and “she's done the job”. Looking back Noel concludes “I went from A to B”; “I came out the other end”. The problems along the way he calls “hiccups”, “stoppages”.

The post-op “era” Noel refers to as “a big unknown”, “you don't realise some of the pitfalls”. At first Noel had a temporary colostomy bag. As he knew it was temporary he experienced it as an ‘end-game’ in contrast to the catheter he knew he could have for life be it that also this was reversed after two years. He describes himself as not being an organised person but in relation to coping with his stoma he had to change. I realised “I was in charge of my body” and “had to change my habits”: it is important “to have things at your fingertips” so “you've got a head start”. Otherwise people told him he dealt with cancer in quite a cheerful way, his normal self.

At present Noel describes Cancer as “a chapter in my life”, “a phase” but also “a lucky escape” due to the fact that he went for medical advice in time. He emphasises that he “thinks less and less about cancer” as nobody asks about it anymore. Nonverbally he expresses this by folding this A1 sheet of paper in 8 and makes it small, about a third of the original size. He describes it as “static”, the cancer is not moving. He feels that he could easily say ‘it is in the bin’. It is a phrase he picked up from a friend and that he more directly uses to refer to the situation of a relative who was diagnosed with cancer 10 years ago while for him it is only three years ago. In the session when working with the sheet of paper, his statement “I put it (cancer) down. I don't have to keep holding it anymore” feels more apt.

His belief that the cancer is gone does not take away that there are reminders e.g. when a friend was diagnosed with lung cancer. That “brings it back” but a positive factor is that in meeting “somebody who's got it, you can open up more”. Noel expresses pleasant surprise that his memories related to his cancer journey are “vivid” when he sets his mind on recalling them, in contrast to many other past memories. Scans are another reminder but these come with “a little sort of worry at the back of your mind, because you don't know”.

Noel has experienced non-cancer related health problems for which he takes medication. In his experience this means that instead of “being a walking time bomb”, the medication “safeguards you against things happening” and “gives a different outlook on life”. “You are cocooned”, “you are in a nice little

bubble” and it allows him to “tick off” the risk of a range of potential illnesses. The cancer treatment has “put him back together”. He uses the image of a central heating system as a metaphor for his body. This metaphor explains why he is physically healthier when his blood pressure is under control and not over-pressurising his body-system. He cannot picture what being better with cancer means for his body... “with cancer it is more a progressive better feeling which I can’t picture in my mind”.

Regarding his age, Noel says “I am in the autumn, going on winter”. As a consequence, if cancer returned and he got only five years, he would be okay with that. He is more afraid of brain problems caused by dementia or strokes which he calls “a big hole in the road” rather than a hiccup which he uses to describe his own health problems.

His bowel cancer specialist nurse in the hospital figures very “big” for Noel, she is “up there”, important. This is nonverbally expressed by holding the sheet of paper close to him. Unlike medication she cannot “cocoon” him from ill-health but she “opens doors” both for cancer and non-cancer problems. She is “spot on”, “an ace in my books”. Noel points out how this link is needed also when you are well: “you need someone to fall back on if things don’t quite are as they seem”.

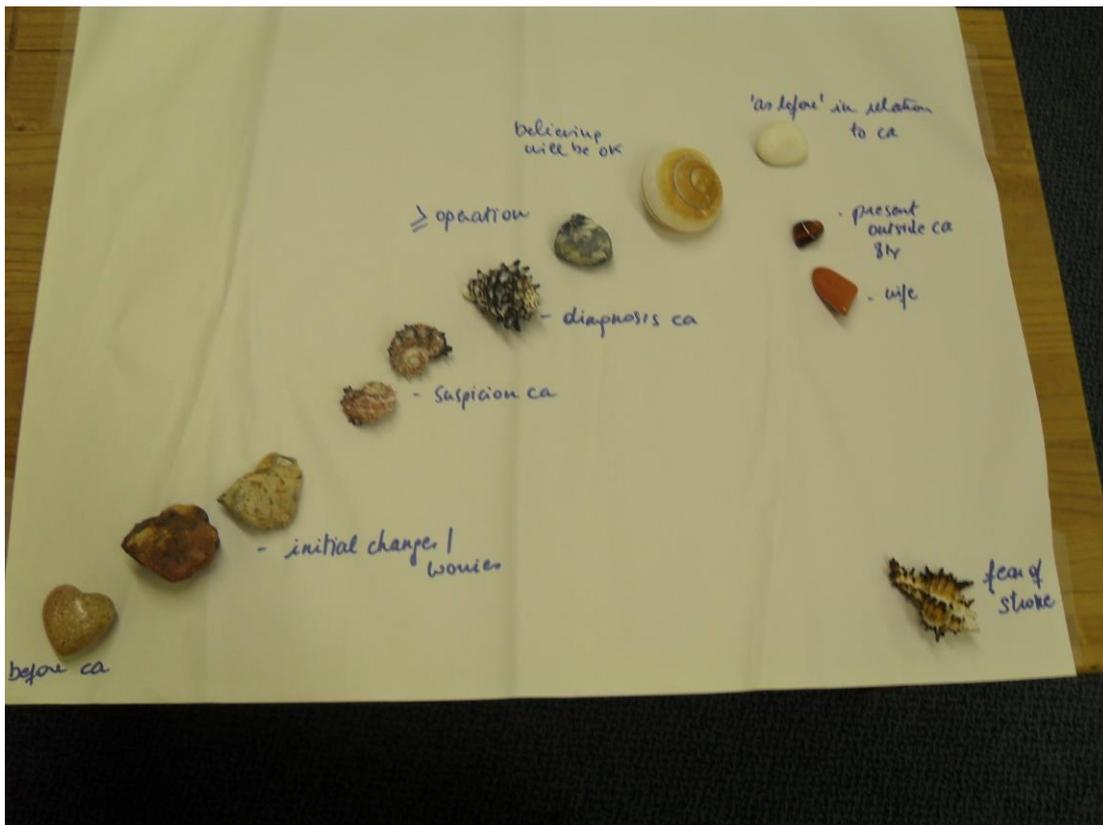


Figure 35: Noel's expression with shells & stones

## APPENDIX F11: Case study data E-Veteran

### **E's experience of survivorship May 2007**

**Written up by E after first expressing the metaphor verbally to me during professional co-research work: 05.2007**

**Title formulated for DProf thesis: A war veteran in a wheelchair and no medals (shorthand: Veteran)**

"Today I had a doctor's appointment to discuss the results of a scan. He told me the cancer is not going to come back. He said 'there is no need to see your self as a patient. He smiled and said 'we have done well'.

I expected he would say there was no cancer activity to be seen but that he would keep monitoring me. I expected him to encourage me and to say I was doing well. I did not expect him to give the 'all clear' because they normally only do that after five years. I am wondering now whether this has anything to do with the benefits system.

I feel 'pushed out of the play'. This is like the end of the war but I have no sense of victory. Is this how war veterans feel? I feel like a sad war veteran – in a wheelchair and with no medals nor statue.

I am sent home. I am cut off from the place where I have tackled and won several battles. I was winning, a hero. With every visit to the doctors it was confirmed that I was winning, that I was a good battler; I felt a "victor". And now there is no fighting anymore. The chance to experience winning is lost. The excitement of winning and battling is lost.

The victory is claimed by the generals. Although he said "we have done well", to me it sounded as if he meant he had done well. I have not been given a medal. My fellow soldiers that have died do get a statue. I am invited to participate in the memorial services and worship them. They seem to be the heroes. How can I envy them for dying? How can I hope to be sent out again? Should I keep up my fighting skills in case I have to go back?

Or can I put my experience to use? Is there a job that will allow me to do something meaningful with the experience of the last years or will this be considered of no value? And what about my scars? People will not want to hear about the war or see my scars. They used to be proof of the fact that I was fighting a hard battle; that I won despite attacks. It made me even better. Now this might turn around. I may make me less suitable; people may see me as weaker than them and consider me unsuitable for anything at all. I am expected to be like everybody else who is not ill. I should be something that I am not.

How will I react to patients who are living with cancer? Will I envy them? Will I hope to be re-diagnosed? Death where is thy victory? (Isiah). The sting is not in death but in life. We should care for the living instead of the dying."

## APPENDIX F12: Summary of Boris's research data

### Session with Boris 09 01 16 – Summary based on transcript 03 02 16

Boris reflects on the different stages of survivorship as follows:

Before you have cancer, Boris says, it is like “the final nail in the coffin” and this is reflected in how others respond when you tell them you have been diagnosed with cancer, “the way others expressed their sympathy almost wrote you off”. He feels the general public does not know how to deal with people who have or had cancer.

During treatment “I did not know whether I was gonna come out the other end” but after the surgery the consultant told him he had it all taken out and did not need chemo. So for Boris cancer is like a piece of paper that is as big as the sheet of paper in front of him (exercise) with nothing on it because the “fear it all had gone”. Or cancer “is a big aeroplane that has flown off forever”, “it is out of the room”, I have “scrunched it up and thrown it away – in the bin, because I haven't got cancer anymore”

But other people, e.g. insurance companies “create consequences that they put in the pot and that causes me difficulties”. This creates “inhibiting regrets”. Or when he is reminded of people who have died he thinks: “Crikey, I wasn't half lucky there.”

Boris needs a regular medical intervention to control a side-effect of surgery, but says: “I don't let that take over”. Once it's done he is “back off again”. When he has an annual scan, cancer does not come into the room with him. Neither does the consultant bring it in. He reflects that it might “walk into the room” if the consultant were to say it had returned.

The consultant he sees as “upon the wall there, a picture with a crown on just saying how good he is” – he imagines it on the wall so that everybody can know his consultant's abilities. Boris would have been okay to stop going for appointments after three years. The fact that the appointments changed from six months to one year made him aware that he probably did not need it at all but it was part of the system to continue up to five years. He felt a fraud and thought other people needed the appointment more than he did.

Boris only had a bag for three months but he feels more should be done to help people who have a permanent bag.

He feels he has “escaped cancer”. “I have come through that (cancer) where other people haven't”. He compares it with another time in his life of which he says: “I came away quite unscathed .... there were quite a lot of episodes like that”.

He also sees himself as being equipped with a personality that “can accept that something is life threatening but can live with it as well and get on with it” The only reason why the awareness of cancer “circles around me”, is because of other people’s reactions. Nevertheless he also says: “I do think you realise with cancer, I never felt before, how vulnerable you are.”

Boris states that he does not do short-term thinking except “if I want something I tend to want to buy it”. “I just want life to go on as it does now”.

In general he sees life as “a time in a hotel room” and when you leave there is “no trace left”. Life is like a “box of years that we are on this earth”. ... he reflects that maybe there is something somewhere (story father, grandmother) ... but for him the hotel room is the best representation of life.

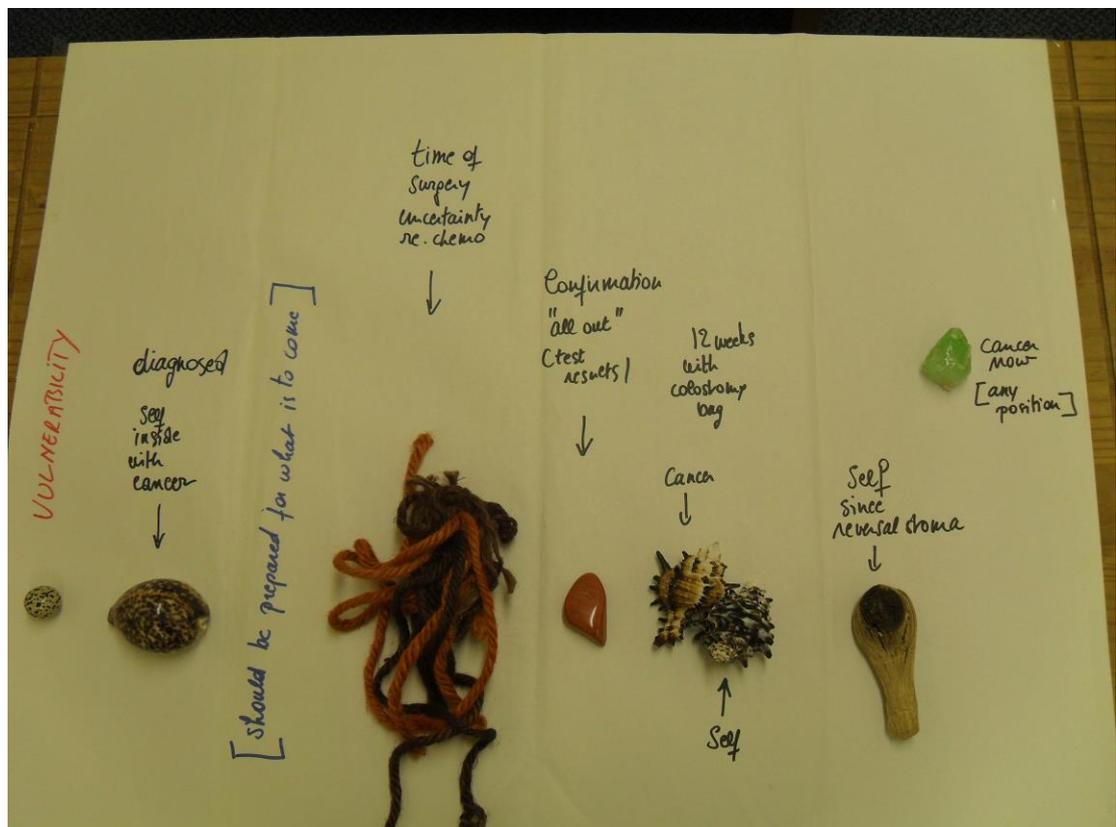


Figure 36: Boris's expression with shells & stones

## APPENDIX F13: Summary of Tony's research data

### **Session with Tony 16 01 16 – Summary based on transcript 10 02 16**

Tony points out that before he was diagnosed with cancer, he felt 'not well' at all. He went in for abscesses to be drained and as soon as that was done he felt 'fit again' but there was the cancer diagnosis to deal with.

Thinking back at the time of diagnosis, he says "I don't think it ever entered my head that I wasn't going to get to that stage that it would be completed." "It never entered my head that I could die."

But he recalls the consultant saying in preparation of the surgery "You do realise this is a serious operation, don't you." In the introductory session Tony mentioned that he got the message that it was urgent as they wanted to operate the following Friday. Nevertheless Tony handled the arrangement of the surgery date in a slightly joking dismissive manner by saying to his wife "I don't think we're doing anything on Friday, are we love", she replied "nothing that is more important than this." His take on it was that "now we know what caused the trouble; we can get on with the job and clear it." He remembers himself as being "interested" (in the process of removing the cancer). He felt confident going into the surgery as he "felt he knew the drill".

Tony likens the whole experience with cancer as having a "really big contract" as he was used to in his professional life. "The consultants are just another department; they know what they are doing." Tony had "full confidence" in his consultant from the beginning and "never moved away from that". His own position or role he expresses with "what can I do to assist? Or in terms of the 'big contract metaphor', he was the material they worked on."

Just after the surgery Tony thought in response to all the technical equipment he was attached to "I am more like a robot than a human being – it amused me". Tony recalls the consultant's words after the surgery "everything went well and it's all been done, and don't think there will be any problem." And "you've gone through it really well". He didn't need chemo and says "I was lucky".

He asked his consultant about the fistulas that were still there as he "was more concerned about these fistula (than the cancer)", within the 'big contract' metaphor, these fistula "had really become the main item as far as I was concerned", while the consultant replied "these are nothing compared to what you've had." The fistula was treated for ten months by district nurses. Tony felt they developed a 'technique' of working together. His role was to be ready by 10 o'clock while during the dressing he was "just laying there". It was his wife's role to help him with that and taking photos of the size of the wound. The nurses did the dressing and at one occasion a student was involved. When the doctor declared it did not need further dressing, Tony clapped his hands and said "Done, finished – we could get on with our lives." He also reflects that he has never seen again one of the nurses – "it was a

stage,... people come in your life and go out of it again.” Physical problems he started to experience after the cancer, e.g. high blood pressure, tiredness... are not linked to cancer at all but just to aging.

As he recovered, his wife became ill and passed away. He copes with his grief by keeping it (their life) open (in contrast to wrapping it up), he continues to do the things they used to do together and tries to keep himself fit.

Nowadays he talks about cancer as “a phase of my life that’s gone and successfully done”. There are “no thoughts of recurrence”. He says “I am not conscious at all of it ... I don’t think about it ... I’ve finished with it.” Non-verbally he folds the sheet of paper in four but describes this action as “I’ve wrapped it up”.

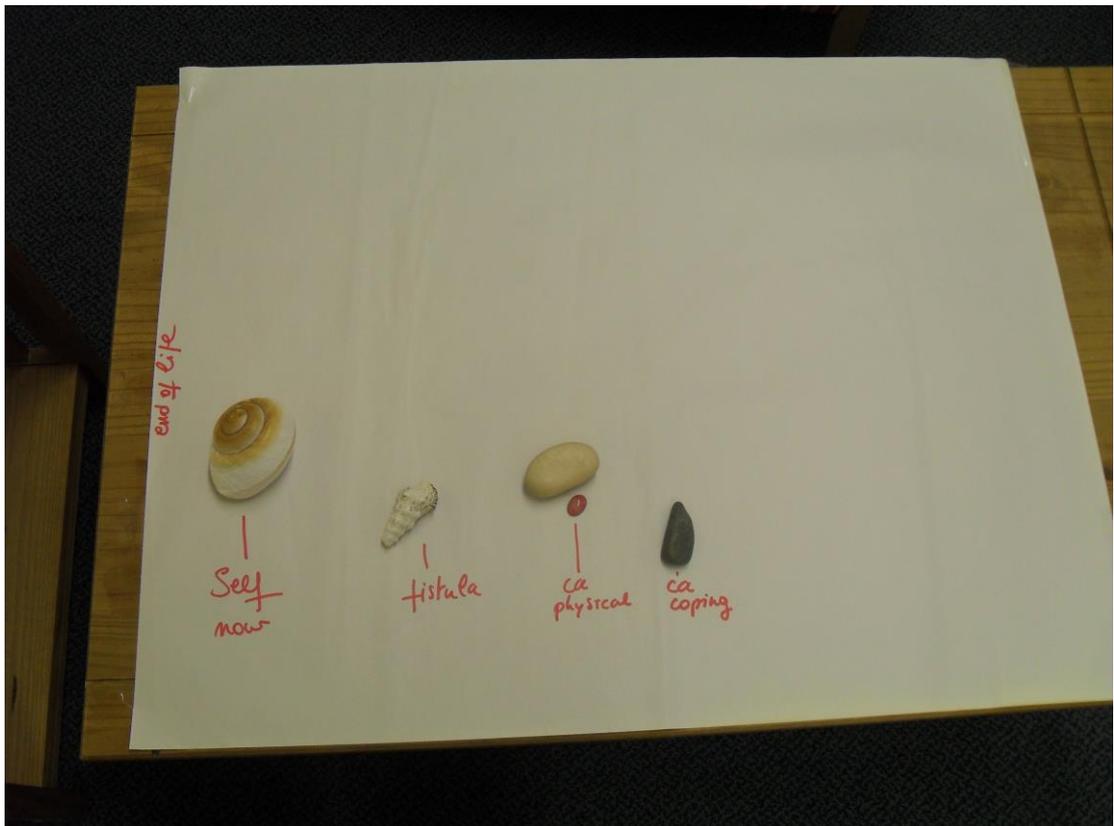


Figure 37: Tony's expression with shells & stones

## APPENDIX F14: Summary of Jack's research data

### **Session with Jack 23 01 16 – Summary based on transcript 20 02 16**

For Jack, hearing the diagnosis could be likened to “the table cracking”, but because straightaway he got the message that they could operate, he very quickly felt relieved.

At present Jack sees his bowel cancer as “something that has been dealt with (he thinks)”. The “table is smooth again – the French polishers have been in.” He convinces himself that “it is gone”, they “fixed” his bowel the way they would fix a broken leg. Cancer is “in a drawer” (like the files with the scan results), “pushed away” and only “coming out when a scan is coming up”. It is in a drawer but “not to be forgotten.” This means that normally he perhaps thinks about it 25 % of the time, if that. But it is not fixed. Sometimes it may be 50 %. It is normally like “a small corner of the sheet” or the sheet of paper folded into four but when e.g. the stoma is playing up, then it unfolds to a half page. Also the thought “did it go” or “am I liable to get cancer” as both parents died from cancer. Since the operation the message has been “you are as fit as anybody else but maybe you are more likely for it to return than another person.”

When the scans were stopped after five years, he felt this was a positive message. At the same time it was reassuring to have something looking after you. Yet this means that you would think about it more as well. Overall Jack felt he would have folded the paper smaller to express ‘cancer’ while he was having scans.

The stoma Jack describes as a “necessity as it is keeping me alive”. But he would prefer it not to be. Having it reversed was never an option. This seems to emphasize that he has no choice in the fact that it “is there forever”. It is there and it's got a mind of its own. It is like having problems with something that is constantly there, he likens it to “being in a business and never have enough money – you can never fully relax”. It being there he describes as it “being in the background”, but “I can see it in the corner of my eye”. It is “within reach” so I can touch it when I want to but not constantly. I could only put it on the floor if it never gave me any problem and that is not the case.

Jack uses the expression “being a victim” as far as he can't do anything about the stoma or the cancer returning or not. But he does not mean victim as in “somebody shot me” – it is just one of those things that's happened. He “puts up” with it and “gets on with life”. A bit like with an annoying boss although you could change jobs.

Jack was diagnosed with a second cancer three years ago. He feels this is ‘more ongoing’ than the bowel cancer or even the stoma. Overall the second cancer he feels takes up rather 50 % of his life and more if there is need to

see a consultant. The Macmillan nurse is the medical person who has been most constant. At the time of diagnosis “she was always there”, “constant”, “mother hen”. He senses her now as “at the back, shoulder height; on my shoulder”. He has very little contact nowadays but feels she is / would be “looking after a certain aspect of my life”. She is important, figures largely when needed but small when not.

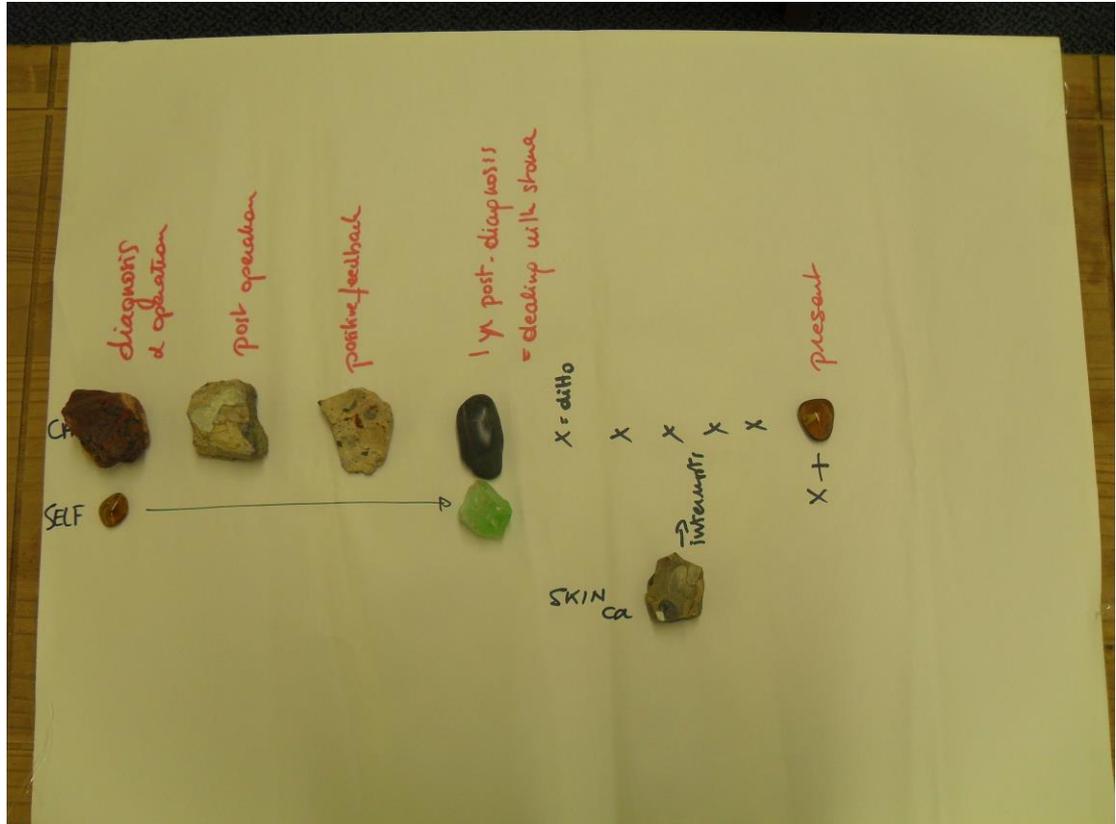


Figure 38: Jack's expression with shells & stones

## APPENDIX F15: Summary of Dan's research data

### Session with Dan 14 04 17 – Summary based on transcript 28 05 17

Thinking of cancer at the time of diagnosis Dan chooses a piece of tree to represent it, describing it as “it isn't a thing, it grows ... and it's danger is in its growth”. About the time of diagnosis and treatment Dan says “the thing I found hardest to deal with was not knowing... whether I was going to live or whether I was going to die ... and knowing that each time I went back to see my oncologist who had the results of the most recent scan ... if it at any single point showed that there was a recurrence I knew I was fucked”. He thinks that the tension was also because he is the type of person who constantly looked into chances of survival.

Early on he points out that despite everything his cancer diagnosis had a “silver lining” because it also led to the diagnosis of another potentially life-threatening illness which subsequently was treated successfully. It was not unimportant that the treatment for this second illness only happened after the oncologist expressed that he thought he was going to survive.

Dan expresses his thankfulness to a family member: “I owe my life really because she is the one who made me go (to the doctors).”

The early impact of the diagnosis he describes as “all consuming ... invaded everything ... concentrating was really hard”. He uses the metaphor “it's like (being) in a room full of sound and it's everywhere ... “ It is very noisy, an intrusive sound, not nice. “It's there and you can't turn it off”.

Dan experienced the treatment phase as “you hand yourself over – it's always the next thing – things are happening”. With a sheet of paper he would make the paper small because the cancer “is in control”. He adds that as a person you are not there – there is too much going on for you to be worrying.

Dan found that “it was always the psychological element (of treatment) that was hard to deal with ... the physical stuff was fine”. . He doesn't believe that being positive helps your chances but he does think it can help you get through it. When a close relative died when he was halfway through chemo, he could not grieve.

Dan expands on how “cycling played a major part in my psychological adjustment”. During chemo he set himself a goal of doing an 80 mile bike ride... “a goal, this is how I cope with things”. He still cycles as this was recommended by his oncologist.

Above anything he had a need for a safe place and that used to be the comfort of being in his own bed. In general he concludes “you need your safe space ... some stupid little routines ... the bigger things tended not to work so well, but the little things worked”.

When the treatment stopped he says “you’re out – you’re (feel) dropped”.

In relation to the noise metaphor he says “It (the noise) gradually quiets down ... and then you can hear and see other things”.

Dan recalls a number of other times since finishing treatment:

-About three years after finishing chemo he found out the guy who sat next to him during chemo sessions had died and “he burst into floods of tears”.

-Another important incident about three years happened: “Somebody told me which I thought was quite cruel at the time and now I realise was absolutely brilliant, true ... was you have to learn to stop being a cancer patient”. – “... it takes you over “ ... “you have to appreciate fact ... if there is no recurrence within three years you’re probably going to be alright” ... “you have to leave some of that behind you ... you have to move on to the next bit”.

-Four years in, the oncologist said “I think you’re going to be all right” ... only then did the mental tension go... “I had another scan, another colonoscopy but I knew then that I was fine”. Compared to now the part of the sheet of paper that represents cancer would have an even more ragged shape.

-Five years after treatment Dan got divorced. This he does not blame on the cancer but he acknowledges that cancer puts stress on relationships. There was also the sense of “you come out of cancer and you say I’m going to change some things”.

In the session Dan folds the sheet of paper in two – at the side a small part represents cancer, the rest himself or life. “95% of the time ... (cancer) doesn’t register anymore”. “I understand it, I know how to handle it, I’ve come to terms to that extent but...” In relation to the noise metaphor ... it has quieted down ... until just occasionally it comes back ...”“But it never really leaves you”. “5% of the time ... occasionally and maybe triggered by something or other ... the bad days come back”. Hence that ragged (not uniform) edge is always there. He chooses a stone that is “small but not perfect”. Dan gives some examples of situations that make it come back: When he went to hospital for his final colonoscopy last summer, that was five years from the previous one ... “god I’m back here in the situation”. Or: read something in the newspaper. Or: someone dying of cancer.

Dan specifies that when cancer comes in his awareness nowadays “It comes from the past” – “It can be very,very vivid” – “It’s not just a memory thing, it’s alive” – “like a disease coming back in a very mild fashion once you’ve had the ...”What is different from the early days is that Dan now has coping mechanisms. “Things kick in to make you cope with it”. He believes that is easier because he is older and more experienced. Therefore it doesn’t come back to really distress him. “I will not panic ... but you sense it again”.

Dan has some symptoms that will never disappear e.g. going to the toilet more often. He describes it as “some sort of residual but they don’t emotively impact me in the same way”. He does not consider this as an experience of patienthood. Experiencing cancer as a patient for him has to do with the noise experience and that is not triggered by the leftover symptoms.

“People talk about the cancer experience becoming a better person, and I know exactly what they mean”. He has moved from behaving ‘badly’ (spiky black shell – rough around the edges) before he was diagnosed, to only a little bit smoother at the time of diagnosis. Post diagnosis Dan felt “so grateful to everybody who’d helped me through the care... I realised you’ve been so selfish, self-centered”. It encouraged him to be much kinder to people. “All those edges have been knocked off. I think that goes back to greater self awareness and greater humility”. But, not completely rounded, that would mean being dull. He chooses a small distinct pointed beautiful shell. He talks of himself as being much nicer and able to build friendships even when this is not straightforward. At the 10<sup>th</sup> anniversary of his treatment Dan did a bike ride to fundraise for a charity. It makes him say “it’s still there but it doesn’t rule my life”.

He is now 11 years past treatment and “they don’t want to see me at all”. The most important Christmas card he sends every year is to his oncologist and surgeon implicitly saying “I’m alive. Thanks”. Otherwise they are in the past. His relationship with them he describes as: not friends, element of hero worship (not equals), utterly trusting, the oncologist’s word was gospel, sacrosanct.

Regarding the future, Dan says: “I tend not to look forward very much, it’s something I’ve never really done”. “I know what I’m doing this year”. “I don’t have a dream”. “Am I going to live as long as my dad, I really don’t know”.

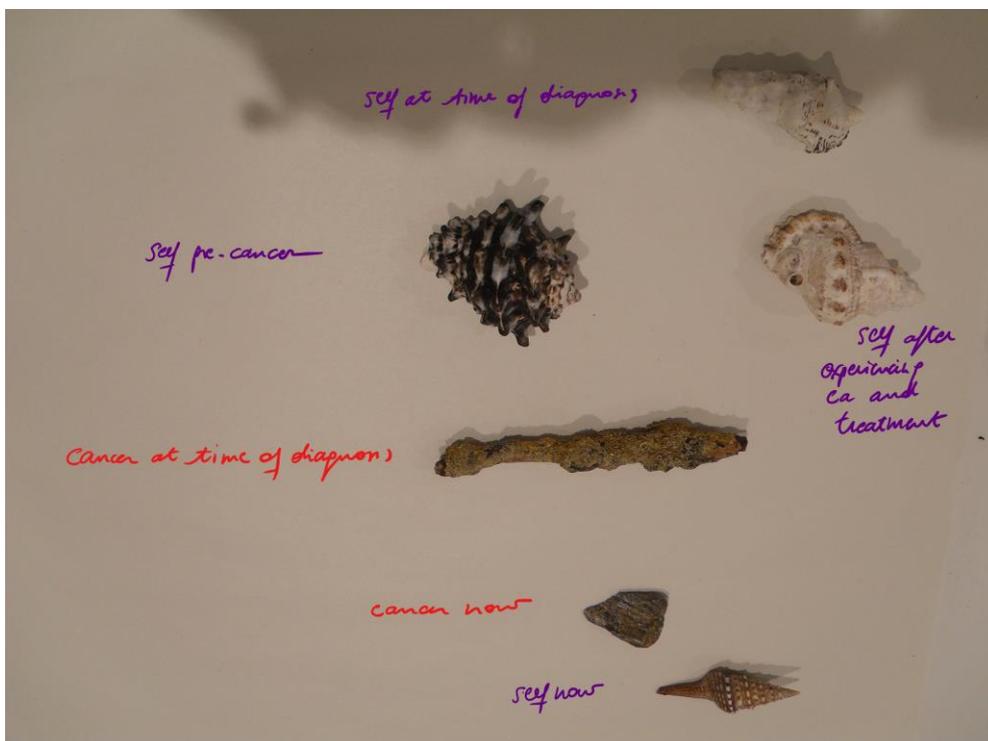


Figure 39: Dan's expression with shells & stones

## APPENDIX F16: Case study data E-Horror

### **E's experience of survivorship April 2008**

**Written up by E after first expressing the metaphor verbally to me during professional co-research work: 04.2008**

**Title formulated for DProf thesis: Like in a horror movie something in the basement tries to drag me down but I kick and fight and run towards the light (shorthand: Horror).**

Triggered by friends becoming terminally ill E tells me about the imagery it evokes in him. Afterwards I ask him if he feels he could write it down. A few days later he hands me this:

“Several people I know have been ill with cancer for many years and are now dying. Experiencing this throws me back to the time that I was preparing for death.

The metaphor reveals itself like this: I find myself jumping off a high building and as I land, apparently safely, I turn to look from whence I have come only to discover the great building is chasing me. Dying is like jumping off a building, the building being my life, my self with cancer, a self that is connected with family, friends and professional carers. Jumping off is letting go – we have to let go in order to go on our journey towards death. But on landing I found the building chasing me, life but more likely the cancer is still close and chasing like the shadow on the heel of Peter Pan.

I did not die and have, not quite reluctantly, to re-engage with life. My friends who are dying now were first diagnosed five years ago. I am beginning to realise that up till now I looked at five years as a place of safety but now, my friends, they remind me it is not. It makes me wonder whether from now onwards – three years after my diagnosis – the chances that my cancer remains in negotiating mood are starting to reduce, maybe become more threatening.

It is as if I have been living in the brightness of a well-lit room, a comfortable home. But now I am wondering what is going on in the basement. Do I hear something? I go down to check. It is dark, the lights do not work, I check hastily, almost hoping there is nothing yet excited by the possibility of something. Things seem ok, but just as I turn my back to the darkness to rush up the stairs towards the light, something (originally in the verbal version E called it “like a bear”) grips my ankle, trying to drag me back. The fear supplemented by adrenalin causes me to fight in panic yet resting in something I suspected was there all the time.

It is like being in a horror movie. I kick and fight and run towards the light. Perhaps I feel free again – for now.”

## APPENDIX F17: Summary of Wendy's research data

### **Session with Wendy 03 04 17 – Summary based on transcript 20 04 17**

Wendy was diagnosed 20 years ago. She struggles to come up with a metaphor of her own but when I introduce the general metaphor of life as a journey, a road, she metaphorically describes that time as “Probably a hairpin bend, a scary hairpin bend along life's, along life's road.”

Wendy remembers that it took a while before she was told for sure she had cancer, but at the same time it was not entirely unexpected: “I think probably at the back of my mind I, it was always there when you go in for a fairly serious operation a bowel operation.”

At the time the search for an explanation was settled as “luck of the draw”. After the initial fear and uncertainty about what would happen next, she remembers being reassured by her oncologist, not in the least by her kindness.

The treatment was presented as “belt and braces”. Wendy describes the treatment phase as a gradual process of recovery over one year both physically and psychologically.

Today Wendy's conceptualisation of cancer at the time of diagnosis is dominated by it being something ugly. She chooses an ugly stone expressing that it “had no purpose in her body”, it was an “alien part of my body”. She chooses the type of stone that if you had it in your pocket you would think “what am I doing with that? ... and “throw it away”.

Her experience of cancer nowadays centres around the small amount of time she thinks about it and consequently she chooses a small stone to represent it. She adds that using the word “not important” would be wrong.

Wendy initially struggles to express her present experience of cancer with the sheet of paper. “I would like to think I'm in control but inevitably there's always a thought at the back of your mind that it may recur.” When we explore where she situates cancer in relation to herself now, she is definite in stating “It's behind me. ... so far away (confident) (confirms: outside the room, in the car park).”

Later in the conversation we return to the sheet of paper and in response to a query of the size of the sheet, the following conversation unfolds: “I would fold it into a very small piece because that's how big I think it is in my life now, even smaller. That's the importance of it in my life at the moment.” When I take a photo she adds: “Tucked away, safe (laughs). ...I put it in my file with the addresses of the ladies I was in hospital with and ...I still keep ... there's a little notebook I brought it with me. ... there were three of us, similar ages and similar stages of recovery. .. we exchanged addresses, ... it's in a folder, it's

there, it's not quite gone away.....” Wendy continues to reflect on what will happen to the notebook when she eventually moves house: “I’ll probably give it a very serious look and I’ll probably move it with me. ... There are certain things you can let go of ... I don’t, I don’t think at this point in time that is one that I, I would let go of. .... Maybe in five years I will..... I don’t know (.) I think (sighs) ... it depends on how, how secure ... I think yes it would go eventually. ... eventually.” I pick up on her hesitance and offer that letting go doesn’t seem to be so clear cut, to which Wendy adds “No, it's not. ....Because it was a, a big thing. ... I think because that’s such a personal thing. ... It’s harder to let go of. Always ... always in the deep dark recesses of our mind. ... It’s a little crutch in a way. ... A little reminder that we’re not eternal. ... my father in law used to say you should live as if you are going to die tomorrow and farm as if you are going to live forever.... ground me, to bring me back to reality.”

Building on the earlier road metaphor, Wendy describes her present experience with cancer as “Yes, I’m still on the road. There might be a warning sign. ... But nothing to alarm me. ... Just wake up and be aware... Almost don’t take things for granted, don’t take life for granted. Life is very precious.” At the very end of the session she repeats “But it doesn’t, it never goes away completely.”

Follow up appointments have long stopped but she remembers that when the colonoscopy appointments came along that took her back a little bit. Nowadays it comes up rarely ...”Occasionally, sometimes you have a ... maybe you have a tummy upset and you think, oh, is it starting again, but nothing that worries me seriously.”

Wendy does not worry about future cancer: “if it happens we’ll face it.” She perceives cancer as “I think it’s inherent within us, and something as stress or situations may trigger cancer cells growing... It’s always there in the background.”

Wendy describes herself as somebody who is able to accept things and be positive and who copes best by understanding. Her attitude to life and death has been shaped by two friends dying when she was young. Wendy’s awareness and engagement with life’s infinity unfolds as she chooses a big spiralled white shell to present herself. She concludes “and that’s what life is, we’re not here for infinity but life is infinite”.

Wendy earlier expressed her fondness and respect for her oncologist. Nowadays there is no contact anymore and she expresses it by folding her sheet of paper in a long thin roll, calling it a long tenuous link.



Figure 40: Wendy's expression with shells & stones

## APPENDIX F18: Case study data E-Healed

### **E's experience of survivorship March 2009**

**Written up by E after first expressing the metaphor verbally to me during professional co-research work: 03.2009**

**Title formulated for DProf thesis: Holding a sculpture of me in a womb-like structure with dormant cancer invisibly arranged inside or around my body and connected to others as they connect to me (shorthand: Healed).**

E talked about wanting a piece of art that captured him as 'being whole – being healed'. I asked E, if you were a sculptor how would this piece of art look? The following image unfolded:

It would have the shape of a person; an embryonic shape but fully grown. The outside of this womb would be in chrome and the inside would be gold or brass plated but rugged. The chrome side comes over the other side but you can see the rugged gold side which represents the cancer inside.

Parts of my body are connected to other people who brought me healing. I am connected to their stomach. I am like an embryo coming to life. It is as if they give birth to me as an adult....

The cancer is permanently held in position. The cancer is 'covered', it is invisible from the outside. I know it is there without having to look.

By turning this image of cancer into a sculpture, it becomes possible to look at it. I can put it in front of me and 'objectify' it. It is also there for everybody to see. But the cancer will be there as something that people cannot recognise as cancer, they will need to ask what it is.

It is important that the cancer is represented by a material that changes. As you touch the gold it becomes shinier.

A few weeks later E met again with his friend sculptor and some further ideas are expressed:

Cancer looks (seen photo at time of diagnosis): clean and shiny, smooth pink and white. Cancer is known but not known. Cancer is silent, not supporting, not defending. Cancer is not an enemy but a part of me. Something that had grown too fast and could easily get out of control.

The lymph nodes: This is the system by which cancer is kept dormant in my body. The support I had from different people: some support was hard cognitive, some gentle, some holding, some demanding etc. As people are attached to me, so is the cancer attached to all via the lymphatic system.

All this is organic – it has altered me and developed me. The sculpture will be of a size to hold in your arms.

## APPENDICES G

### APPENDIX G0: Occurring and affording different degrees of cancer awareness

#### Vignette B: Occurring and affording different degrees of cancer awareness

Vignette B: Living with a low versus considerable degree of cancer awareness  
What's in a number?

Dan 'aware of cancer 5 % of time' versus Jack 'aware of cancer 25 % of time'

In reflecting on the time of diagnosis Dan describes being consumed with checking information on survival rates as part of his personality. His main strategy for coping with stress was setting attainable behaviour goals, e.g. setting out and achieving bike rides of increasing length. He also refers to long-standing psychological issues rooted in childhood. All of this colours his coping with the treatment, which overall he found more difficult on a psychological than a physical level.

Jack merely reports remembering that the initial concern at diagnosis eased when he heard an operation was possible and even more when the bowel cancer appeared not to have spread. Jack talks about cancer as something that happens and is nobody's fault. His approach is about getting on with it; it did not trigger a need for reviewing his life; he was happy with his usual outlook on life.

As Dan says to be aware of cancer only 5 % of the time, he reflects on past communications with his oncologist. At diagnosis it became clear that he also suffered from another life-threatening illness if left untreated. The decision to treat was communicated as based on his oncologist's belief that he was going to survive the bowel cancer. About three years post-diagnosed he was told to accept that he was not a cancer patient anymore. This was at the time difficult to believe. It took another year, when his oncologist said "I think you're going to be alright" for the message to ring true and Dan felt that the "mental tension went". These repeated messages over time that he was free from cancer seem to have 'afforded' a slightly anxious personality as Dan to relax and to live *with a low awareness of cancer*.

Jack's journey has been different. It turned out he needed a permanent stoma and consequently this is now part of his everyday life. Three years ago Jack was diagnosed with skin cancer and although the treatment was successful, ongoing check-ups are needed as he has been presented with more skin irregularities. This has also brought to the foreground that both his parents died from cancer. His surviving Jack captures with the words of his medical team: "you are as fit as anybody else but maybe you are more likely for it to return than another person." In other words, Jack's medical situation does not 'afford' him to let go of cancer to the same extent as Dan can. The risk is more substantial and that rings through in the "25 %". Looking into the dynamic between Jack's self and medical context gives a glimpse into an experience of long-term living *with a considerable awareness of cancer*.

## APPENDIX G1: Specific contribution of case study versus research participants

Splitting Figure 22 into Figure 22a which represents the enactions of the research participants and Figure 22b which represents the enactions of the case study participant, makes it visible how the two sources of data are aligned and do not contradict each other.

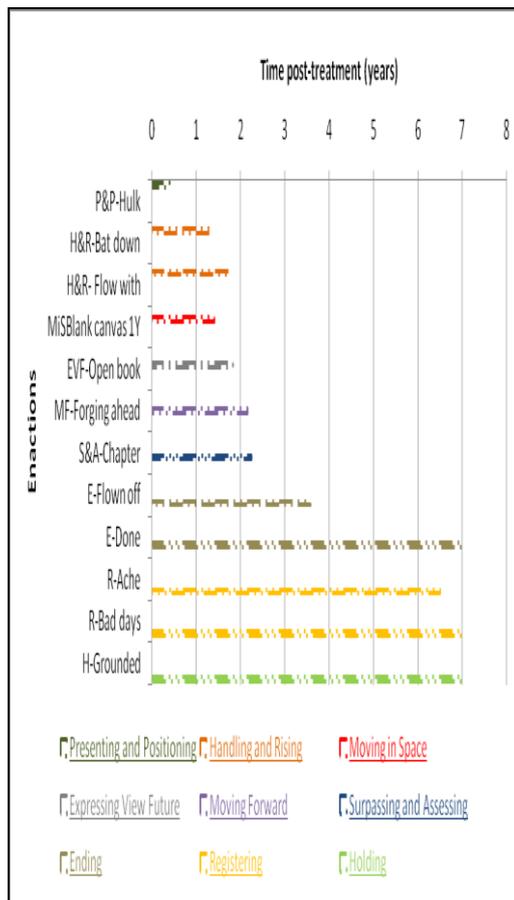


Figure 22a: data research participants

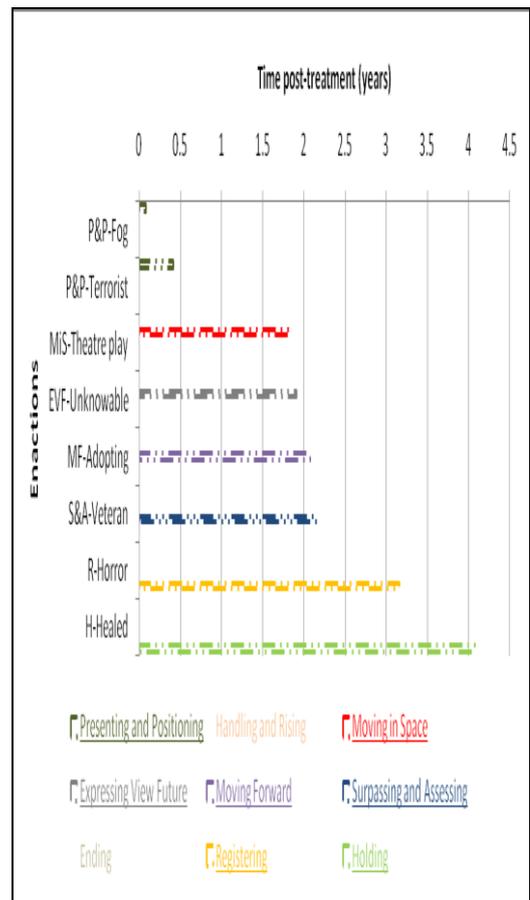


Figure 22b: data case study participant

Based on the discussions of the metaphorical comprehendings in the main text, I wish to point out that:

1. Pursuing further research with a group of research participants who differed from the case study participant (see sampling), has brought to the fore several comprehendings that were not part of the case study participant's experience:
  - Handling & Rising as an enaction in between Presenting & Positioning and Moving in Space
  - Surpassing & Assessing as a positive experience
  - Ending as an enaction in long-term survivorship that challenges the idea that all survivors experience ongoing liminality
  - Registering and Holding also structure the comprehendings of survivors who are over five years post-treatment
  
2. In the group of research participants only three out of twelve, i.e. Ann (Hulk), Rosy (Flow with) and Wendy (Grounded) express a positive intention to engage with and be open to the experience of cancer. This is a position that E expresses in the Fog, Theatre play, Unknowable, Adopting and Healed. Seen in this way the case study participant has certainly added weight to this type of experience of self vis-à-vis cancer. Without his contribution, it might have been too easy to designate the difference as a gender difference. As E is male, other possible causes come to mind, as is discussed in the main text.

## APPENDIX G2: Body schematic process of survivorship as 'movement exercise'

Imagine a Tai Chi - like movement that starts with holding hands over my eyes (Fog), lowering them and sense a presence nearby (Hulk), stretching my arm outwards as putting something at a safe distance (Terrorist). Now pushing both hands down (Bat down), followed by a balancing on my feet (Flow with) followed by a gentle step forward as if taken be the hand (Theatre play). Now a tiny jump into a new space (Blank canvas 1Y), which enables a confident turnaround (Unknowable and Open book) and a walking forward in a new direction (Adopting and Forging ahead) to a point where I stop, turn and look back (Veteran / Chapter). Then a step sideways to the left (Flown off, Done), or to the right, but now a stepping in and out repeatedly (Horror, Bad Days, Ache). The last movement: stepping backwards and embrace the whole (Healed, Grounded).

# APPENDIX G3: Delineations within cancer survivorship

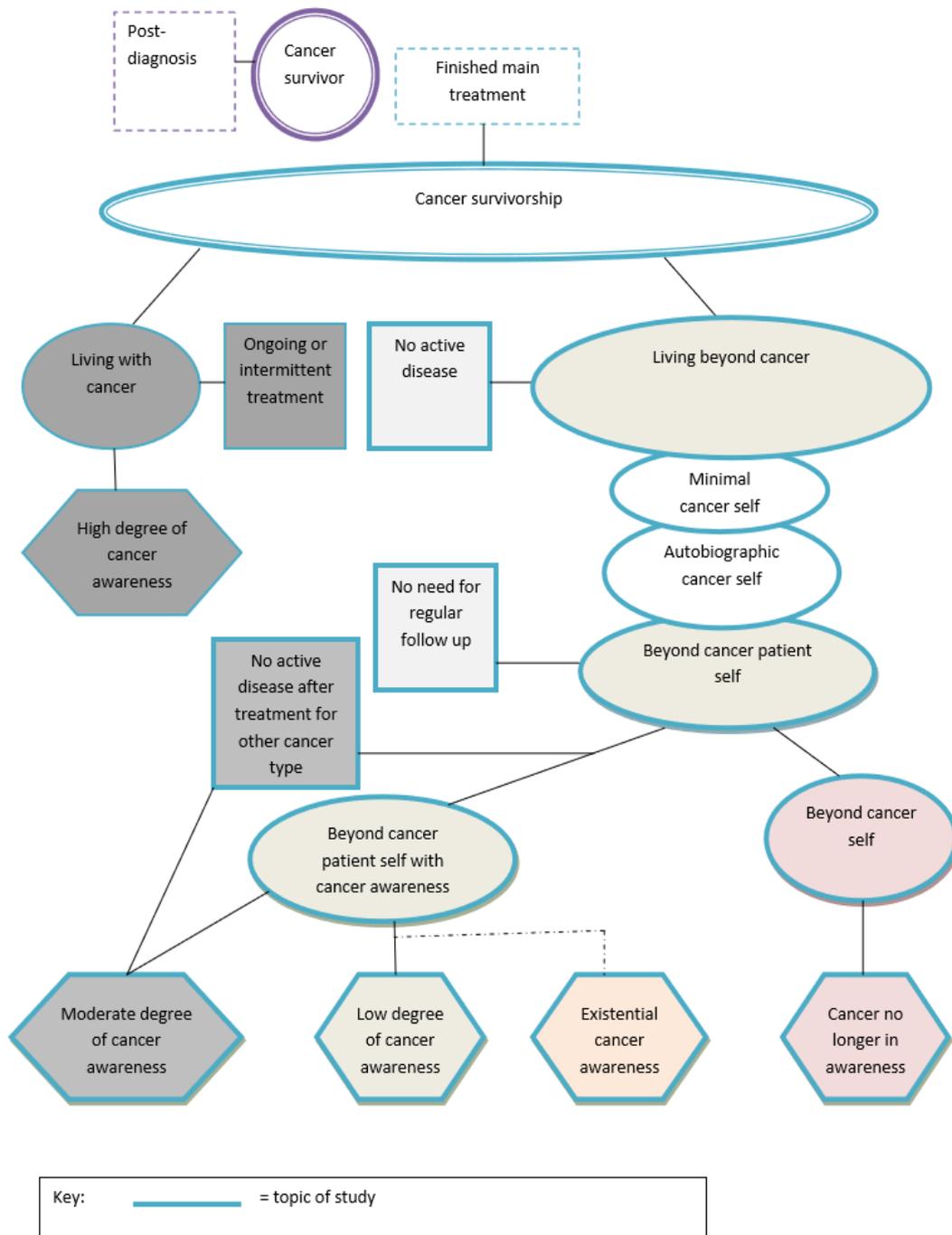


Figure 41: Delineations within cancer survivorship

## APPENDIX G4: Occurring and affording of PTG and self-actualizing

### Vignette C: Occurring and affording of PTG and self-actualizing

Vignette C: Linda – Bat it down:

Linda reveals that she always believed that she was chosen to be a twin because she was not as strong as other people (inauthentic previous self). When she was diagnosed with cancer she was extremely shocked and describes this with expressions such as “I was beside myself”, “my old self had gone”, “I was on the outside looking in” (trauma). Going through cancer treatment on her own gave her an unusual experience of functioning independently from her twin and this experience she has used to alter her view of self (cancer experience turned into affordance for change). She uses words that express a sense of change but also of growth: “I feel I’m a different person to what I was before”, “I now have more of an identity than I did before”. She specifies: “I realise I can do things on my own”, “more capable”, “don’t feel I need someone else now”, “It was my fight”. The fighting still infuses her present conceptualisings of cancer: “I can bat it down a bit, I can close the door on it if I need to”, but also speaks of a person who amidst the struggle stands on her own feet. With the background information, the metaphor expresses not only somebody engaging a bodily experience of exerting force to express and establish some level of control over (fear of) cancer, but a wider self that is exerting capability and autonomy.

## APPENDIX G5: Occurring and affording of resilient self continuation

### Vignette D: Occurring and affording of resilient self continuation

#### Vignette D: Mark

Mark's statement that 'cancer is an open book' is accompanied by the message that he deals with cancer the way he deals with everything. He sees it as a feature of his wider self that he approaches challenges with 'organized thinking'. He brings thoughts and things together to fix what is broken.

When Mark was diagnosed he was the main carer for his wife who was terminally ill. This added to the fact that 'being stopped by cancer' was not an option.

When a person like Mark approaches his consultant and makes an explicit contact which enacts a peer relationship (see main text), what does it mean?

The idea that this is just how he is, risks to underestimate that resilience also needs to be 'afforded' by the transactions with the environment. Resilient people are good at organising such transactions, e.g. Mark explains that as it is important to have more than one mind on a job, you need to talk to people and not be stopped by hierarchy.

I want to argue that what is happening here is not just a resilient man dealing with cancer but a resilient man who is establishing his resilience in that specific situation by skilfully appealing to the consultant to play his part.

## APPENDIX G6: Occurring and affording of negated liminality

### Vignette E: Occurring and affording of negated liminality

#### *Vignette E: Boris*

*Boris, coming up to four years post-treatment, expressed his metaphorical comprehending of cancer as “a big aeroplane that has flown off forever”. Listening to his reflections it transpires that his comprehending is underpinned by interpretations and experiencings of medical communications that ‘afford’ this viewpoint. For example, Boris recalls that soon after surgery the consultant said that “it was all taken out” and “no chemo was needed”. When follow up appointments after three years were changed from six monthly to annual, Boris was further convinced that he was free from cancer. Meeting his consultant for ongoing clinics to deal with a side-effect of cancer, he feels, does not bring cancer back. The communication with his consultant affords him to stay within his framework of being free from cancer.*

*If Boris’s metaphor genuinely ‘works’ then one may expect that it somehow enables a wider self to be carried forward (Gendlin): Boris revealed about himself that he compares life to spending time in a hotel room because there is “no trace left” when you leave. An early childhood experience when a friend ‘vanished’ and a professional career where he repeatedly ‘escaped from’ life threats, seem to support a belief that both life and the threat of death can stop without leaving a trace.*

*When taking into account the moderate severity of diagnosis, his wider self that promotes a mindset that seeks and believes that one can and should move on from any death threat, and medical transactions that do not contradict his view makes it understandable why Boris can really believe and posit that cancer will not return where others might be more hesitant.*

*Tony’s comprehending, ‘successfully done’, is equally based on needing only surgery, transactional experiencings with the medical world and a wider personality and self that supports his negation of liminality.*

## APPENDIX H

### APPENDIX H0: Request and information to artist-painter

Hi -----,

Thanks for your enthusiastic response to my suggestion of you expressing my research findings in the form of paintings – an activity which I refer to as ‘*articulation*’.

In order to clarify in my own mind, and perhaps also in yours, what I am looking for in engaging your artistic talent for the dissemination of my research findings, below I am describing the theoretical and practical context and aims of this approach.

#### AIM

Once I finish my thesis, it is my intention to take my research findings back into practice by setting up workshops for health care professionals and cancer survivors. How to do this in a manner that optimises the chance for the information to be really taken on board and have an impact that makes a difference in people’s actions is what drives my search to present my research findings through paintings. Let me try to explain in more detail the perceived link between art and action.

From our own and other practitioners’ experience we know how difficult it can be to translate new learnings into action, or - to use a word from one of my inspirations, Prof. Todres - for knowledge that is transferred to become ‘actionable knowledge and understanding’, i.e. for it to lead health care workers to change their practice or for survivors to change the way they go about everyday life. Todres points out that it is through the generation of ‘empathic understanding’ that ‘actionable understanding’ is evoked. Consequently the main question at hand is “how will I establish an empathic understanding of my research findings in the attendees of the courses or workshops”?

According to the theoretical framework of my thesis, empathic understanding is generated in relationship. I know we share that perspective and have both put it into practice by taking an interactive approach in teaching sessions. However, empathic understanding is also generated by taking an ‘embodied

approach', which means engaging people's bodily sense and not only their rational sense of the presented information.

In the next section I expand on what I mean with engaging people's bodily sense of information, with engaging an embodied understanding

## **EMBODIED UNDERSTANDING and ART**

In the thesis I address bodily sense in two ways.

First there is the bodily sense that is linked with bodily positions and movement. As you know in my research I focus on the metaphorical expressions that people use to conceptualise, think and reason about their experiences of cancer. A metaphorical expression embeds a bodily position, e.g. a saying like 'living with cancer is like living in a fog', conjures up a bodily experience of standing still, only hesitantly moving as one cannot see in a fog, perhaps just feeling their way, not having a sense of direction and overall not moving too far. A workshop exercise might be for attendees to take on the bodily position that is embedded in the metaphor and have a bodily feel of the metaphor that hopefully leads to an empathic understanding rather than just processing the information rationally.

Secondly there is the bodily sense that is linked with our 'felt sense', our 'gut feeling'. While our 'bodily sense of position and movement' is engaged when we start thinking and talking about our experiences, our bodily 'felt sense' is already active when we are experiencing, in other words it is there before we start to think or talk about it. Remember the first stage of Gendlin's 'focusing' in which he asks to tune in with our felt sense of our present experiencing and then to work stepwise towards a verbal and cognitive capturing of the felt sense. Art has been described as powerful in impacting directly to our felt sense, our gut. In other words when people are presented with an artistic form it is highly likely that they have a gut reaction. If we imagine a painting of somebody who is standing still and not seeing ahead (as in a fog), we may have a gut feeling of and empathic understanding of the uncertainty, fear, loneliness that is embedded in that experience. The idea is that this feeling is evoked more strongly by an artistic expression than by a verbal description of that state of mind, or even by a superficial hearing of the metaphor.

This has prompted researchers to use art to communicate their research findings. It is a trend that is gaining momentum and expanding. More accomplished or more daring researchers also use art during the research, e.g. as a medium for participants to express their experiences. As a novice researcher I restrict myself to the involvement of art at the dissemination of the findings of the finished research. As an aside, I may not have used art

during my researching, but I have asked participants to express themselves with creative material like stones, shells and sheets of paper. As you know the focus of my research lies in the metaphorical expressions people use; one could say this is the art of the mind. As I work from the premise (inspired by Lakoff and Johnson) that thinking and experiencing is inevitably metaphorical, I could say human beings' mind works per definition, if not in an artistic way, certainly in a creative way.

Next I hope to give a more concrete sense of the findings that are in need of 'art-iculation' and what that may involve practically.

## **FROM RESEARCH FINDINGS TO PAINTINGS.**

My research has generated two types of findings. First there are the bodily positions and movements that I have unravelled from the different metaphorical conceptualisations of cancer survivors' relationship with cancer at different times post treatment. Secondly there are the stories about their life, personality, past, future aspirations, views that live in their families, present medical experiences etc that research participants have linked with the way they experience their self in relation to cancer in the present and that contextualise these experiences. These two sets of information have been brought together on what I call a participant's 'individual file'. The bodily positions and movement I have already presented in the form of a 'stick figure' which is positioned in a certain place on the sheet and whose arms and legs express specific types of movement. The storied information is presented according to themes.

The stick-figure (representing the body positioning and movement that is implied in the metaphor) lends itself well to a kinaesthetic empathising but that demands either an active imagining of the position and movement or a real mirroring of it – the workshop attendee will need to actively engage with the expressed movement (as mentioned above). Just *looking* at the stick-figure as an image does not directly evoke a felt sense response nor does it capture the contextual information that carries the 'feel' of the experience. This is where I believe a painting of the findings, including both the data represented in the stick-figure and the contextual information, will have more impact.

If you are interested to co-operate in this project, I anticipate that the following issues, probably repeatedly, will need to be explored:

- what type of canvas, material, paint etc. would work best
- in what order to paint the findings

- from research literature I know that this type of working can create a level of tension between the researcher and the artist – this is not to be avoided but to be explored – it is an aspect of this project that I would like to note and include as part of the thesis as this ties in with my theoretical framework that defines ‘understanding as relational’ – in short it means that there is not such a thing like static findings; every time somebody engages with the findings, they hear the information through their own framework and the meaning changes. This will also be the case for you. On top of it you will bring your artistic logic and feel. And yet all that has to be negotiated with the way I understand the research findings through my framework; otherwise it would not be a dissemination of the research findings.
- how we discuss and explore the findings that I seek to be expressed in your painting
- How we communicate during the process of painting in order to enable both your artistic input to flow and for me to process whether the painting captures the message I aim to put across and any new understandings that may occur in the process.

I am sure there will be other issues that press for attention, but discovering these is part of the project.

Hopefully this description gives you some feel for what I hope the translation of the findings into paintings will achieve but I imagine a true understanding can only emerge from trying it out.

Last but not least, if you are still enthusiastic about this project, I would like to discuss sooner rather than later a fair and mutually agreeable financial arrangement.

Thanks in advance and looking forward to your reply.

Kind regards

Kathleen

26nd July 2018

## APPENDIX H1: In the shadow of survivorship

Hidden in the background of participants' reflections on survivorship, there are these brief research notes that speak of one participant who had a recurrence, one potential participant who became unwell and one who died before the interview. I hope those I met are well, but even that I do not know. On the one hand researching survivorship is an encounter with hope. Yet, I wish to remember those who had their hope crushed.

In the shadow of my research into cancer survivorship

I met you in the car park

Full of beans, the way you were in the session

But now you told me that you had needed further treatment

And were attending the 'fit start' clinic to get well again

Survivorship is capricious

Philip, we were about to meet

When I spoke to you, you said in zest "have to hurry – 79 today"

But that was banter; Only a week later you died

It has thrown me completely

Survivorship is a facade

Jenny, we had planned the session well ahead

Keen to grasp the five year mark

You left a message that said: "I am not well"

I do so hope the five year card did not turn into a cruel joke

Survivorship is harsh