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Doctor of Philosophy

Women's experiences of breast cancer and
Spiritual Healing:
A Unitary Appreciative Inquiry

by

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ABSTRACT

Women's experiences of breast cancer and Spiritual Healing: A Unitary Appreciative Inquiry

The aim of this study was to gain a better understanding of the effects and outcomes of Spiritual Healing in the context of women with breast cancer receiving long-term hormonal therapy.

Background

Spiritual Healing is widely available and used by many but is a neglected area of research. Whilst the exact mechanisms are not understood and healers make no claim to cure, evidence suggested that Spiritual Healing as a holistic complementary therapy could support women whose quality of life is negatively affected by breast cancer and its treatments. After initial surgical, radiological and/or chemical treatments, the majority of women are prescribed hormonal therapy for at least five years, giving rise to immediate and long-term symptoms that compromise their quality of life and force some to take respite from treatment. Spiritual Healing was thought to have the potential to improve quality of life and encourage continued compliance with potentially life-saving orthodox therapy.

Method

This qualitative study used Unitary Appreciative Inquiry to explore the fullness and richness of patients' changing life patterns. An observational study of Spiritual Healing took place in a clinical research facility within a district general hospital, and was given by healers with a nationally recognised qualification. Twelve breast cancer patients, who reported at least one onerous treatment side-effect, self-referred to the study and were given ten Spiritual Healing sessions of approximately 40 minutes' duration each. Data included direct observations noted by healers, patient's daily logs, researcher's field diary and one-to-one semi-structured interviews.

Findings

The effects of breast cancer and its treatments were long-lasting and permeated every aspect of these participants' lives. The physical effect of cancer and its treatments restricted usual activities, leading to low morale and emotional distress. Patients' narratives expressed loss and regret and for all patients fear was a constant companion. Observational data illustrated how the experience of Spiritual Healing reduced physical side-effects, including hot flushes, and afforded a sense of serenity and hope.

Conclusions

This study highlights the potential for Spiritual Healing as a complementary therapy to alleviate many of the distressing effects of breast cancer and its treatments, most notably during long-term hormonal therapy. These findings appear to justify further research to understand the potential value of Spiritual Healing as a complementary therapy to support orthodox medical care.

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Declaration of Authorship

I, Fiona Vera Barlow declare that the thesis entitled: **Women's experiences of breast cancer and Spiritual Healing: A Unitary Appreciative Inquiry** and the work presented in the thesis are both my own and have been generated by me as the result of my own original research. I confirm that:

- This work was done wholly while in candidature for the research degree PhD.
- Where I have consulted the published work of others, this is always clearly attributed.
- Where I have quoted from the work of others, the source is always given.
- I have made clear exactly what was done by others and what I have contributed myself.

Signed:

Date: May 2011

Chapter 1.

Introduction

The aim of this research project was to gain a better understanding of the effects and outcomes of Spiritual Healing. In this chapter, I outline how the study came about and how the original aim was modified to achieve an understanding of the experience of Spiritual Healing in the context of women with breast cancer receiving long-term hormonal therapy to prevent recurrence of their cancer.

I have a long-term interest in Spiritual Healing as a Reiki Master and became interested in trying to gain a better understanding of the anecdotal, positive effects reported by my patients and by Reiki associates. I approached the Complementary and Integrated Medicine Research Unit (CIMRU) at the University of Southampton for support to conduct a study and this broadened the focus to a PhD study of Spiritual Healing. It was not the intention of this study to understand or prove the mechanisms of Spiritual Healing, but to understand any impact that Spiritual Healing may have on the recipients of healing. The contemporary evidence base for Spiritual Healing, which is reviewed in Chapter 2, suggested that it has the potential to act as a complementary therapy and assist patients who are struggling with orthodox medical regimes. In order to investigate these potential effects it was necessary to find a suitable group of patients to receive Spiritual Healing, where a wide range of physical and emotional responses could be observed.

Women with breast cancer emerged as a suitable patient group for reasons discussed in more detail in Chapter 3. Approaching the topic of breast cancer as a woman, a feminist and social scientist, I had expected there to be a body of knowledge about women's 'lived experiences' of breast cancer. Yet in a review of contemporary literature on breast cancer I found that the majority focused either on the medical responses to and explanations for breast cancer, or patients' physiological and psychological responses to particular aspects of the disease and its treatments. The known effects of cancer and side-effects of long-term hormonal treatment determined that this would be a suitable group of participants. However, the missing and key element was an understanding of the whole lived experience, which could not be ignored in the context of this study.

Funding for the study was provided by the Harry Edwards Healing Sanctuary (HEHS). This was founded in 1946 by Harry Edwards, a renowned Spiritual Healer of the time. The aim of HEHS is to provide distant and contact Spiritual Healing to the general public and also to provide training for Spiritual Healers. The Trustees were keen to support research that might enhance the status of Spiritual Healing as a legitimate form of complementary therapy. In this context, my study was seen as the initial exploratory stage of a longer project to identify measurable healing outcomes in preparation for an eventual randomised controlled trial. As part of their funding, HEHS provided healers trained to the required standard, but made no attempt to influence my methodological approach or the study outcomes.

I needed to identify a research method that would capture the full range of any impacts of Spiritual Healing. Although the study was initially set up as a qualitative evaluation study, Chapter 4 describes how I came to use Unitary Appreciative Inquiry (UAI) as my research methodology. Based on Rogers' (1992, 1970) Science of Unitary Human Beings, in which the concept of energy fields is central, this methodology is congruent with the conceptualisation of Spiritual Healing and also fitted well with my feminist desire for a non-hierarchical, participatory research methodology.

Chapter 5 details my method of data collection and how I overcame unexpected obstacles. In particular, recruitment was not as straightforward as I had anticipated, owing to the stated belief by influential medical staff that Spiritual Healing was merely 'hocus pocus'. This came as a shock to me. I had read of resistance towards Complementary and Alternative Medicines (CAM), but did not expect overt animosity and obstruction. As a result, I was forced to revise my method of recruitment and embarked on an unexpected adventure into the realm of the local media. I spoke on local radio shows, gave newspaper interviews, participated in a local television news programme, wrote articles for healing magazines and slowly recruited volunteer breast cancer patients into the study.

Once the study started and I listened to the women's stories, it became apparent that many of the impacts of breast cancer treatments were either not known about or not

acknowledged in the literature. Neither did they appear to be addressed within breast cancer clinics, nor through the normal medical treatment processes. It also became apparent that breast cancer is inextricably entwined in the life patterns of the women. I felt it was not possible to ignore women's experiences of breast cancer and that their voices, expressing their lived experiences of breast cancer, should be acknowledged here. Thus the experience of breast cancer assumed a central role within the study and became equally as important to the study as Spiritual Healing. In fact, it was the understanding of the place breast cancer had in women's lives that allowed holistic impacts of Spiritual Healing to be acknowledged.

So a dual focus developed that has made this research more complex than the original, straightforward question: 'Does Spiritual Healing have any impact?' This research now addresses the holistic impact of breast cancer, its treatments and Spiritual Healing on women's lives. This complexity has presented additional challenges for the development of my thesis, but I strongly believe that the insights the women shared into their lives with breast cancer cannot be ignored. Indeed, my participants all expressed the desire that the findings should inform the care of future breast cancer patients.

The UAI methodology recognises several forms of knowledge and these are presented in Chapters 7–10. Within UAI methodology there is an acknowledgement of 'experiential knowledge', the breast cancer patient's deep knowing of what it is to experience breast cancer and its treatments, including Spiritual Healing. This 'inner knowing' is expressed by the patient using written words and conversations, and captured through what is termed 'presentational knowledge' in Chapters 7 and 8. A synthesis of all the presentational knowledge creates the proposition of a group profile of experience which is presented in Chapter 9. The conclusions are presented in the form of 'practical knowledge' in Chapter 10, which includes practical recommendations for future patient care and for further research into Spiritual Healing.

The next chapter, Chapter 2, gives an explanation of the conceptual framework that informs Spiritual Healing and reviews contemporary literature regarding the effects of Spiritual Healing.

Chapter 2.

Spiritual Healing

'Don't believe what your eyes are telling you. All they show is limitation. Look with your understanding, find out what you already know, and you'll see the way to fly.'

Richard Bach (1972). *Jonathan Livingston Seagull*.

2.1 Introduction

Spiritual Healing has been described as probably one of the oldest paramedical treatments (Walach et al. 2002), with many cultures throughout history handing down healing knowledge (Parkes and Parkes 2005; Miller 1975). Spiritual healers believe everyone has the potential to heal (Schwartz et al. 2004), although some may be more gifted than others, in a similar way to the principle that everyone can draw but not everyone is a great artist.

While Spiritual Healing is known as an energy therapy, the definition of 'energy', in this context, is unclear. Energy medicine has been defined as a therapy based on 'the interactions of the human energy field with other energy fields (human or other)' (Prestwood 2003, p46). Many studies refer to an intervention as 'energy medicine' but the actual therapy could be one of several which include acupuncture, use of magnets, Qigong, Kinesiology, LeShan, Therapeutic Touch, Spiritual Healing, Reiki or Johrei. Indeed most forms of Complementary and Alternative Medicines (CAM) involve some aspect of energy medicine, as the therapist interacts with the patient, although this may not be a prominent component of the therapy (Benor 2002).

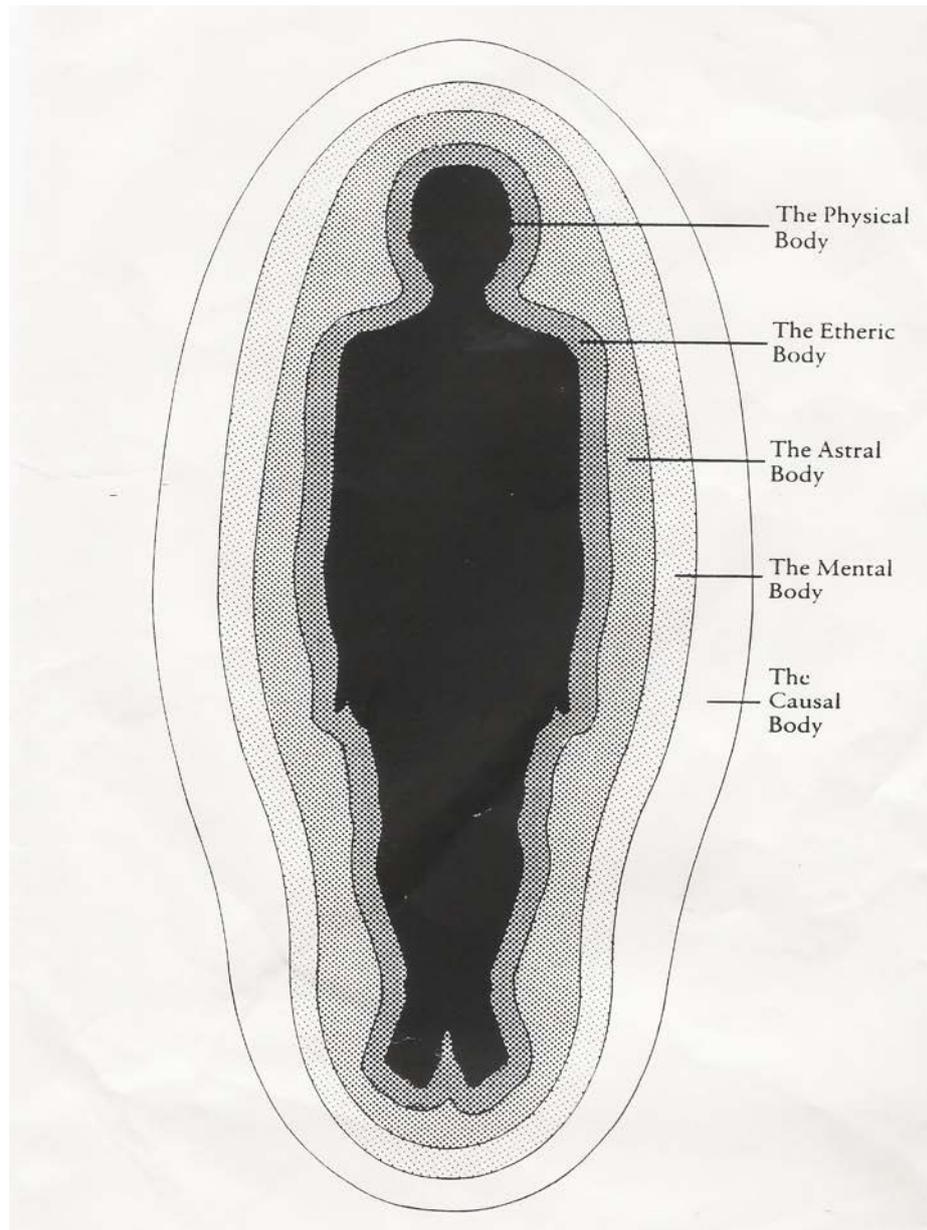
The term Spiritual, as in Spiritual Healing, is presented in upper case to reflect the convention used by the Harry Edwards Healing Sanctuary. Harry Edwards set up the sanctuary as a place of Christian healing, though it is now open to those of all (or no) belief systems and the form of healing offered by their healers contains no overt or covert religious connotations.

The following section defines the conceptualisation and practice of Spiritual Healing on which this study is based.

2.2 Conceptualising Spiritual Healing

While modern medicine is based on Newtonian principles of cause and effect, energy medicine practitioners, including Spiritual Healers, have long claimed that there is a physical body and an energy body and these are not mutually exclusive. The energy body is said to surround and penetrate the physical body and interact with it (Benor 2002). Some claim to see the human energy field as an 'aura', which may explain why it has been acknowledged for thousands of years and is referred to in 97 different cultures (White and Krippner 1997). Within Spiritual Healing the human energy field is conceptualised as 4 layers emanating from the visible energy of the physical body. Within this conceptual framework each subtle energy layer fulfils a different role as shown in Figure 2.1.(P21) and explained below. Spiritual healers claim to channel what they term 'universal energy', also referred to as divine or subtle energy, from outside their own personal energy field to alleviate the symptoms of disease temporarily or permanently, to accelerate recovery and engender a state of well-being and/or acceptance within the recipient of healing (the healee) (Benor 1994; National Federation of Spiritual Healers 2009).

Figure 2.1 The 5-layer Human Energy Body



National Federation of Spiritual Healers', *Training Manual* 2000

The energy layers are detailed below and explain the conceptual link between mind, body and spirit.

2.2.1 The physical body

The physical body is the densest form of energy, a mass of atoms, molecules and cells creating patterns of vibrating energy within a frequency band that can be experienced through our senses of sight, smell, hearing, touch and taste. The physical body is able to interact with other energy fields around it.

2.2.2 The etheric body

Within this conceptual framework, the ethereal body exists within the physical body and extends beyond it. It forms an energy template or matrix for the development and repair of the physical body. The energetic vibrations of the etheric body determine the pattern for the physical body and organs and the state of health of those organs. Disharmony is reflected in the physical body as dis-ease. An illness can appear in the etheric body a long time before it appears in the physical body. Traumas to the physical body are reflected in the ethereal body.

2.2.3 The astral body

The next conceptual layer is the astral energy body that contains the emotional patterns, feelings and vibrations that determine personality and how we interact with others on a personal, social and cultural level. The astral body follows the shape of the physical body but is more amorphous and fluid. It extends between 1 and 3 inches from the body. The astral body affects the physical body. The expression ‘weighed down by grief’ reflects the interaction between the emotions and the physical body. A bereaved person may be seen as physically hunched, appearing smaller.

2.2.4 The mental body

The fourth conceptual layer is the mental energy body that contains the structure and patterns of all thoughts and belief systems that are considered true. It radiates around the whole body, extending from 3 to 8 inches beyond the physical body. The mental body reflects beliefs, concepts and attitudes, and shapes an individual’s perceptions of reality. There is a strong connection between the mental and astral bodies; for example, when a person is anxious they feel emotionally vulnerable. Anxiety can also be reflected in the physical body as ‘butterflies’ in the stomach or sweating palms.

2.2.5 The causal body

The final conceptual layer is the causal energy body that encompasses all the information related to experiences. It reflects and responds to the balance and alignment of all levels. It contains the higher intentions and a sense of right and wrong. The causal energy body contains the desire to increase awareness and a

sense of life-purpose (National Federation of Spiritual Healers 2009; Qumiby Amenti Foundation 2008; Angelo 2007; Evergreen Healing Arts Center 2001; Angelo 1999; Alvino 1996).

2.2.6 The human energy field

These five conceptual energy fields make up one human energy field or aura. The outer shape is believed to be roughly egg-shaped and extend up to 2 feet beyond the physical body. This shape can expand or contract depending on the situation. A person feeling threatened emotionally or physically may have a very small aura, whereas a person feeling safe and loved may have an aura which extends several feet (National Federation of Spiritual Healers 2009; Qumiby Amenti Foundation 2008; Angelo 2007; Evergreen Healing Arts Center 2001; Angelo 1999; Alvino 1996). This concept gained support in 1939 when Kirilian photography captured variations in colour and density from what appeared to be a luminous energy emanating from, and extending beyond, the physical body.

2.3 A multi-dimensional conceptualisation of disease

Within the Spiritual Healing paradigm, illness is conceptualised as the outcome of an imbalance in the (whole) body. The physical symptoms of illness draw attention to an imbalance that may be located within any of the 5 layers referred to above. According to the NFSH, Spiritual Healers are able to sense where energy levels are depleted in the body. While the concept of imbalance is congruent with many CAM philosophies (Mason et al. 2002), it is a very different way of conceptualising illness from that of contemporary medicine. Medical practitioners would agree that symptoms are the observable manifestations of a disease, but their explanations of disease are very different.

Evidence based medical practice relies on science to explain disease. Within that paradigm, the causes and treatment of disease are rooted in germ theory and genetic, nutritional, immunological, metabolic and cytological explanations (Thagard 1997). Medical practitioners seek to diagnose, distinguishing one disorder from others that may have similar signs and symptoms. Once the disease is diagnosed, they prescribe treatments that aim to eliminate or reduce the symptoms and course of the disease, often by affecting its perceived causes. Medical practitioners have a vast

array of treatment possibilities and judge treatment outcomes according to specified results. Spiritual healers, however do not diagnose or prescribe. They seek to restore whole body balance through the transfer of universal energy (National Federation of Spiritual Healers 2009) which flows to areas of need within the healee. Outcomes are judged at the level of the individual and Spiritual Healers do not attach importance to any particular outcome, nor do they claim any specific effects of healing (Tavares 2003).

2.4 Spiritual Healing

Spiritual Healing is often used as a generic term to include Reiki and Johrei Healing. The differences between these healing forms are primarily in their terminology and rituals. Although there are minor differences in the actual healing practice, the conceptual basis for the healing is the same, i.e. based on the premise that healing energy comes from a universal force, open to all, which can be channelled by healers to the benefit of patients (Brooks et al. 2006).

Spiritual Healing must be differentiated from faith healing where the recipient needs to believe in a deity who is the source of healing. Faith by the patient is not required for Spiritual Healing, which can be received by people regardless of their belief system (National Federation of Spiritual Healers 2009). While there is no requirement for any religious belief by the healee, it is necessary for the trained healers to believe in Spiritual Healing and the 2-year NFSH course for healers teaches the conceptual energy body framework and Spiritual Healing philosophy.

Spiritual Healing may be differentiated from therapeutic touch (TT), an energy therapy developed in the early 1970s and used within nursing. Unlike Spiritual Healers, TT therapists direct their own energy through their hands to modulate areas of perceived imbalance within the patient's energy field (Jonas and Crawford 2003a). A TT therapist will therefore diagnose areas within the patient's energy field that are in need of their attention. The TT therapist acts as a human energy support system until the patient's own immunological system is robust enough to take over (Krieger 1993). Thus TT claims to work through the integration of the therapist's and the patient's energy fields, allowing the patient to re-pattern their energy through a process of resonance (Sayre-Adams and Wright 2001; Krieger et

al. 1979) rather than through the undirected transfer of universal energy by Spiritual Healing.

2.5 The practice of Spiritual Healing

There are two distinct forms of Spiritual Healing, contact or proximate (also known as 'laying-on of hands') and absent healing. This study is concerned only with contact or proximate healing. Contact healing refers to the practice of touching the healee, whereas in proximate healing the healer's hands are held just above the healee's body. Proximate healing is used when the patient does not want to be touched; where the patient might feel discomfort - for example, over a tender wound or areas that are socially sensitive where it would be inappropriate to touch. Most healing sessions involve both proximate and contact healing. While the healer usually covers all the healee's body, the healing energy is deemed to flow to wherever it is needed by the healee.

All Spiritual Healers start a healing session by meditating and calming their mind; they then establish contact by touching the head of the patient. Contact or proximate healing down the length of the body follows this. Healees may experience a sensation of cold or intense cold, heat, or vibrations similar to a mild electrical current when the healer's hands are near them, or alternatively they may experience no sensations at all (Benor 1994). Healers report 'stickiness', unusual heat or other sensations when they pass their hands over a part of the body that is diseased (Benor 2002).

Spiritual Healing in modern Western societies is deemed to be a complementary therapy which is not considered part of mainstream medical care (House of Lords Select Committee on Science and Technology 2000). A small number of NHS Trusts do offer Spiritual Healing but it is more usual to receive Spiritual Healing outside of the state's medical provisions. There are 13,000 members of nine separate healing organisations in the UK (Abbot et al. 2001). Spiritual Healing can be accessed through the NFSH website or healing centres, UK Healers' website, through charitable establishments set up to provide Spiritual Healing, or from healers introduced through the personal recommendations of family or friends. Spiritual Healings can take place in a variety of settings including healing centres,

local community centres and individuals' homes. Healers may charge for their time or ask healees for a donation according to their means.

2.6 Researching Spiritual Healing

Spiritual Healing is a comparatively neglected area of research (Walach et al. 2002). In the 20th century the dominance of positivistic behavioural and health sciences has meant that the spiritual side of human existence was often considered to be 'immaterial and thus by definition, an improper topic for scientific investigation', (Miller and Thoresen 2003 p23); scientific investigation in this context being viewed as the study of the material world. Indeed, Spiritual Healing is believed by many to be premised on a conceptual philosophy that is not 'provable' using the positivist scientific methods favoured by evidence-based medicine. Although the mechanisms of Spiritual Healing are not currently understood, research into the effects of such healing is reviewed in the next section.

2.7 Literature review

Using the definition of Spiritual Healing given in 2.2 (the channelling of universal energy to alleviate the symptoms of disease, accelerate recovery and, engender well-being and acceptance in the healee), a review of published literature regarding the effects of Spiritual Healing available in 2009 is given in Table 2.1.1-2.1.7 (p28-34). This was obtained from the following databases: Cinahl, Cochrane Library, EBSCO, OVID and Science Direct using the key words: Complementary and Alternative Medicine; Complementary therapies; Alternative therapies; Spiritual Healing; Healing; Energy therapy and Reiki. Studies that did not adhere to this definition of Spiritual Healing were excluded from the literature review.

Most of the studies were quantitative, although a small number sought to use qualitative interviews to enhance the quantitative findings. A majority of the findings demonstrated positive outcomes although some were equivocal. Studies by Wirth or Wirth et al. (1987–2001) have not been included as they are subject to allegations of fraudulent research (Solfvin et al. 2007). The following matrices give details of the studies of Spiritual Healing. These are followed by a discussion of the challenges faced by researchers attempting to provide an evidence base for Spiritual

Healing interventions including variations in terminology, duration of intervention, the use of placebo and outcome measurement.

Table 2.1.1 Spiritual Healing research – pain

Outcome/author	Patient group	Study design/ intervention	Outcome measure	Findings
Pohl et al. 2007	80 advanced cancer patients	RCT Healer/sham	Questionnaires	Improvement in Healer and sham groups
Tsang et al. 2007	16 cancer patients	Healing + rest crossover	Questionnaires	Decreased pain in Healing group
Vaghela et al. 2007	15 cancer patients	Healing x 6	Questionnaires MYCAW + focus groups	Pain decreased with Healing
Gillespie et al. 2007	207 painful diabetic neuropathy patients	RCT Healing/sham/none	Questionnaires + walking test	Pain/walking improved in Healing and sham groups
Brooks et al. 2006	21 substance-abuse patients	RCT Healing/no Healing	Questionnaires	Decreased pain with Healing
Vitale and O'Connor. 2006	22 hysterectomy patients	RCT Healing/no Healing (pilot)	Questionnaires	Less pain with Healing
Olson et al. 2003	24 cancer patients	Healing/rest	Questionnaire + pain VAS/ opioid use	Decreased pain
Miles 2003	30 HIV level 1 practitioners	Pragmatic	Questionnaires	Decline in pain with Healing
Wilkinson et al. 2002	22 clients	RCT Healing/ Healing + control	Qualitative questionnaire	Relief of pain
Abbot et al. 2001	120 pain patients	RCT Healing/ sham distant/none	Questionnaires	No significant difference between groups
MacDermott and Epstein. 2001	32 child-abuse survivors	Time series x 3	Questionnaire + interview	Decreased body pain with Healing
Kennedy 2001	2 Sarajevo survivors	Case study	Healer notes	Pain alleviated with Healing
Sundbolm et al. 1994	24 idiopathic chronic pain patients	RCT Healing/no Healing	Questionnaires + medical interview	Minor decrease in pain/increased acceptance
Dressen and Singg. 1997	120 chronically ill patients	RCT Healing/sham/relax/control	Questionnaire	Decreased pain

Table 2.1.2 Spiritual Healing research – anxiety and stress

Outcome/author	Patient group	Study design	Outcome measure	Findings
Tsang et al. 2007	16 cancer patients	Healing + rest crossover	Questionnaires	Decreased anxiety in Healing group
Potter 2007	32 biopsy patients	RCT Healing/no Healing	Questionnaires	No significant difference between groups
Vitale and O'Connor. 2006	22 hysterectomy patients	RCT Healing/no Healing	Questionnaires	Less anxiety with Healing
Laidlaw et al. 2006	33 laboratory-stressed medical students	Healing/rest crossover	Questionnaire + biological measures	Decreased anxiety after Healing
Brooks et al. 2006	21 substance-abuse patients	RCT Healing/no Healing	Questionnaire	Decrease in stress
Shore 2004	46 depressed patients	RCT Healing contact/distant/sham	Questionnaires	Significant reduction in anxiety
Mitchell et al. 2004	4 patient/practitioner pairs	Convenience sample	Interviews	Decreased anxiety with Healing
Miles 2003	30 HIV level 1 practitioners	Pragmatic	Questionnaires	Decline in anxiety with Healing
Wilkinson et al. 2002	22 clients	RCT Healing/Healing/control	Qualitative questionnaire	Lowered perceptions of stress
Wardell and Engebretson. 2001	23 healthy subjects	Single group x 1	Biological markers	Anxiety significantly reduced
MacDermott and Epsein. 2001	32 child-abuse survivors	Time series x 3	Questionnaire + interview	Decreased anxiety with Healing
Kennedy 2001	2 Sarajevo survivors	Case study	Healer notes	Nightmares stopped
Dressin and Singg. 1998	120 chronically ill patients	RCT Healing/sham/relax/control	Questionnaire	Significant reduction in anxiety
Dixon 1998	57 chronically ill patients	RCT waiting list control	Questionnaires	Improved with Healing
Thornton 1996	42 female nursing students	Healing/sham	Mixed methods	Qualitative evidence of improvement unsupported

Table 2.1.3 Spiritual Healing research – depression, hopelessness and relaxation

Outcome/author	Patient group	Study design	Outcome measure	Findings
Depression				
Pohl et al. 2007	80 advanced cancer patients	RCT Healer/sham	Questionnaires	Improvement in Healer and sham groups
Vaghela et al. 2007	15 cancer patients	Healing x 6	Questionnaires MYCAW + focus groups	Decreased depression with Healing
Potter 2007	32 biopsy patients	RCT Healing/no Healing	Questionnaires	No significant difference between groups
Brooks et al. 2006	21 substance-abuse patients	RCT Healing/no Healing	Questionnaire	Decreased depression/increased positive emotion
Shore 2004	46 Depressed patients	RCT 2 x Healing/ no Healing	Questionnaires	Significant reduction in depression
Schmehr 2003	1 HIV/AIDS patient	Case study	Interview	Able to 'work through' depression
Shiflett et al. 2002	50 stroke patients	RCT 4 x crossover (sham)	Questionnaires	No significant overall effects
Dressin and Singg. 1998	120 chronically ill patients	RCT Healing/sham/relax/control	Questionnaire	Significant reduction in depression
Dixon 1998	57 chronically ill patients	RCT waiting list control	Questionnaires	Improved with Healing
Hopelessness				
Sundbolm et al. 1994	24 idiopathic chronic pain patients	RCT Healing/no Healing	Questionnaires	Decrease in feelings of hopelessness
Relaxation				
Pohl et al. 2007	80 advanced cancer patients	RCT Healer/sham	Questionnaires	Improvement in Healer and sham groups
Vaghela et al. 2007	15 cancer patients	Healing x 6	Questionnaires MYCAW + focus groups	Improved with Healing
Schmehr 2003	1 HIV patient	Healing	Case study	Extreme relaxation helping to maintain sobriety
Kennedy 2001	2 Sarajevo survivors	Case study	Healer notes	Able to relax
Witte et al. 2001	100 undergraduate students	Healing/placebo/tapes	Questionnaire + biological measures	No significant differences/methodological limitations

Table 2.1.4 Spiritual Healing research – sleep, fatigue, cognitive function, self-confidence, mood and inner peace

Outcome/author	Patient group	Study design	Outcome measure	Findings
Assist sleep				
Vaghela et al. 2007	15 cancer patients	Healing x 6	Questionnaires MYCAW + focus groups	Improved with Healing
Mitchell et al. 2004	4 patient/practitioner pairs	Convenience sample	Interviews	Increased ability to sleep with Healing
MacDermott and Epstein. 2001	32 child-abuse survivors	Time series x 3	Questionnaire + interview	Improved sleep with Healing
Kennedy 2001	2 Sarajevo survivors	Case study	Healer notes	Improved sleep – without sleeping tablets
Sundbolm et al. 1994	24 idiopathic chronic pain patients	RCT Healing/no Healing	Medical interview + questionnaires	Improved sleep patterns
Alleviate fatigue				
Tsang et al. 2007	16 cancer patients	Healing + rest crossover trial	Questionnaires	Decreased tiredness in Healing group
Cognitive function				
Crawford et al. 2003	24 Alzheimer's patients	Healing/control	Questionnaire	Increased mental function after Healing
Self-confidence				
Mitchell et al. 2004	4 patient/practitioner pairs	Convenience sample	Interviews	Increased self-confidence with Healing
Positive mood				
Laidlaw et al. 2006	33 laboratory-stressed medical students	Healing/rest crossover	Questionnaire + biological measures	More positive mood after Healing
Inner peace/calm				
Pohl et al. 2007	80 advanced cancer patients	RCT Healer/sham	Questionnaires	Improvement in Healer and sham groups

Table 2.1.5 Spiritual Healing research – quality of life, opioid use, placebo

Outcome/author	Patient group	Study design	Outcome measure	Findings
Quality of life				
Tsang et al. 2007	16 cancer patients	Healing + rest crossover trial	Questionnaires	Improvement in Healing group
Pohl et al. 2007	80 advanced cancer patients	RCT Healer/sham	Questionnaires	Improvement in Healer and sham groups
Vaghela et al. 2007	15 cancer patients	Healing x 6	Questionnaires MYCAW + focus groups	Improved with Healing
Brooks et al. 2006	21 substance-abuse patients	RCT Healing/no Healing	Questionnaires	Improved with Healing
Cleland et al. 2006	88 asthma patients	RCT (sham Healer) + control	Questionnaire + expiratory flow	No significant difference between groups
Olson et al. 2003	24 cancer patients	Healing/rest	Questionnaire + pain VAS	Significant improvement in psychological quality of life
MacDermott and Epstein. 2001	32 child-abuse survivors	Time series x 3	Questionnaire + interview	Improved overall feelings with Healing
Thornton 1996	42 female nursing students	Healing/sham	Mixed methods	Qualitative evidence of improvement unsupported
Opioid use				
Vitale and O'Connor. 2006	22 hysterectomy patients	RCT Healing/no Healing (pilot)	Questionnaires	Fewer requests for analgesics with Healing
Brooks et al. 2006	21 substance-abuse patients	RCT Healing/no Healing	Questionnaires	No difference in substance abuse between groups
Mitchell et al. 2004	4 patient/practitioner pairs	Convenience sample	Interviews	Decreased medication use with Healing
Olson et al. 2003	24 cancer patients	Healing/rest	Questionnaire + pain VAS/ opioid use	No significant change in opioid use.
Kennedy 2001	2 Sarajevo survivors	Case study	Healer notes	Decreased pain killers/stopped sleeping tablets
Sundbolm et al. 1994	24 idiopathic chronic pain patients	RCT Healing/no Healing	Questionnaires + medical interview	Minor decrease in analgesic drug use
Placebo development				
Mansour et al. 1999	12 students/4 cancer patient/4 observers	Healing/sham crossover trial	Questionnaire + interview	Sham suitable for future RCTs

Table 2.1.6 Spiritual Healing research – biological effects: heart rate, nervous system, blood, saliva

Outcome/author	Patient group	Study design	Outcome measure	Findings
Heart rate				
Mackay et al. 2004	45 healthy volunteers	RCT Healing/sham/rest	Autonomic nervous system function	Healing decreased heart rate
Olson et al. 2003	24 cancer patients	Healing/rest	Questionnaire + pain VAS	Blood pressure decreased with Healing
Witte et al. 2001	100 undergraduate students	Healing/placebo/tapes	Questionnaire + biological measures	No significant differences/ methodological limitations
Cell count				
Dixon 1998	57 chronically ill patients	RCT waiting list control	Percentage of CD16/CD56	No change in any group
Nervous system				
Brewitt et al. 1997	5 chronically ill subjects	Healing	Electrical skin resistance	Significant difference at 3 acupuncture points
Blood				
Mackay et al. 2004	45 healthy volunteers	RCT Healing/sham/rest	Autonomic nervous system function	Healing decreased diastolic blood pressure
Wardell et al. 2001	23 healthy subjects	Single group x 1	Biological markers	Significant drop in systolic blood pressure
Witte et al. 2001	100 undergraduate students	Healing/placebo/tapes	Questionnaire + biological measures	No significant differences/ methodological limitations
Wetzel 1989	48 Reiki trainees	Healing + control group	Haemoglobin/hematocrit levels	No change – further research needed
Beutler et al. 1988	115 hypertension patients	RCT Healing/distant/rest	Blood pressure	No significant difference between groups
Salivary IgA and salivary cortisol				
Laidlaw et al. 2006	33 laboratory-stressed medical students	Healing/rest crossover	Questionnaire + biological measures	IgA unchanged/cortisol not significantly changed
Wilkinson et al. 2002	22 clients	RCT Healing/Healing + control	Questionnaire + biological measures	Raised sIgA
Wardell and Engebretson. 2001	23 healthy subjects	Single group x 1	Biological markers	IgA levels rose/cortisol change not significant

Table 2.1.7 Spiritual Healing research – non-human research

Outcome/author	Experimental group	Study design	Outcome measure	Findings
Heart rate/Blood pressure				
Baldwin et al. 2007	Noise-stressed rats	Healing/sham	Implanted radio telemetric transducers	Heart rate reduced/blood pressure not affected
Cell growth				
Rubik et al. 2006	Cultured brain cells	Healing/no Healing	Cell count	Healing improved growth
Radin et al. 2004	In-vitro tumour cells	Healing/no Healing	Cell growth	Healing enhanced growth/increase in statistical order
Shah et al. 1999	In-vitro cell proliferation	Healing/sham	Cell proliferation	Data difficult to interpret
Tumour remission				
Bengston and Krinsley. 2000	Breast cancer mice	Healing/no Healing	Survival	Control mice died; Healed mice lived normal lifespan
Enzyme reaction				
Bunnell 1999	Egg albumen	Healing/sham	Pepsin enzyme activity	Reaction rate significantly increased with Healing

2.8 Variations in Spiritual Healing ‘dose’

Even where the Spiritual Healing intervention conforms to the conceptualisation used in this chapter, there is no evidence to confirm what an appropriate ‘dose’ of Spiritual Healing is, or the number of healing sessions that should be given. The length and frequency of healing sessions varies between trials:

- 1 session of 30 minutes’ Reiki healing (Wardell and Engebretson 2001)
- 5 sessions of 40 minutes’ Spiritual Healing over 5 weeks (Cleland et al. 2006)
- 8 sessions of 30 minutes’ Spiritual Healing over 8 weeks (Abbot et al. 2001)
- 10 sessions of 30 minutes’ Reiki healing over 2.5 weeks (Shiflett et al. 2002)
- 13 sessions of 25 minutes’ Reiki healing over 12 weeks (Gillespie et al. 2007)
- 6 sessions of 60 – 90 minutes’ Reiki healing over 6 weeks (Shore 2004)
- 2 sessions of 33 – 55 minutes’ Reiki healing – 7 days prior to biopsy/7 days post biopsy (Potter 2007)

My review of these studies indicates that any improvement in patient outcomes does not appear to be directly related to either the length or the frequency of healing sessions. The observational studies show either positive outcomes (Potter 2007; Shore 2004) or mixed responses (Cleland et al. 2006). Benefits included alleviation of pain, fatigue, anxiety and depression, and facilitation of improved sleep, inner peace and a general sense of well-being. However, it is noticeable that most studies that have included placebo control showed no difference (Gillespie et al. 2007; Cleland et al. 2006; Shiflett et al. 2002; Abbot et al. 2001; Beutler et al. 1988).

2.9 Seeking a healing ‘placebo’

In medical research, a treatment that demonstrates an outcome no better than placebo control is considered ineffective (Kaptchuk 1998). However, the use of a placebo for Spiritual Healing is problematic. The placebo (Latin for ‘I shall please’) has been conventionally conceptualised as an agent or procedure that replicates the appearance of the verum treatment, but is in fact inert. Mansour et al. (1999) sought to validate a placebo for Reiki healing using a four-arm crossover experimental design (Reiki + Reiki; Reiki + sham; sham + sham; sham + Reiki). The sham healers who provided the placebo healing were trained by the Reiki Master on the study but were not initiated as healers. The study failed to differentiate between the outcomes for Reiki healers and sham healers and concluded that sham healing was

an acceptable placebo. But this finding is based on the assumption that only practitioners who have been initiated are able give healing, and that initiation 'switches on' their ability to heal. Yet other Spiritual Healing organisations, including NFSH and UK Healers, do not have initiation rituals and subscribe to the view that everyone has the ability to heal and that healer training simply enhances this ability (Schwartz et al. 2004). Thus the sham healers in Mansour et al.'s study may have been giving healing unbeknownst to themselves or the researchers.

Also it is not possible to screen out the sham healers' intentions. Intentionality has been defined as 'the mechanism through which we perceive and create meaning and use our imaginations to alter behaviours' (Zahourek 2004, p47). Therapeutic Touch therapists use their intention and their energy field to facilitate healing, so it is possible that the sham healer's intention and energy field could impact on the recipients of sham healing and affect the research outcomes. The potential effects of sham healers may also include a 'meaning response' whereby the healee attaches meaning to the interaction and responds according to that meaning (Moerman and Jonas 2002).

The development of a placebo requires a thorough understanding of the attributes of the verum under investigation (Brinkhaus et al. 2008). Thus for complex interventions such as Spiritual Healing, where at present there is no such understanding, it may be impossible to develop an appropriate placebo. One way to eliminate the need for placebo from Spiritual Healing research is to test Spiritual Healing experimentally in non-human subjects. Here the results are once again mixed. Laboratory experiments have shown that Spiritual Healing significantly reduced the heart rate of noise-stressed rats (Baldwin et al. 2007) and remission of tumour growth in mice (Bengston and Krinsley 2000). The results of in-vitro cell growth vary; some studies show healing influence (Radin et al. 2004) while others show little or no influence (Yount 2004; Shah et al.1999). Indeed Shah et al. (1999) found that it is difficult to interpret the data and Yount (2004) suggested that in-vitro may not be the optimal setting to evaluate Spiritual Healing. Clearly, such experiments are unable to detect any multi-dimensional effects of healing that may occur in human beings.

2.10 Duration of healing effects

The duration of the effects of Spiritual Healing is unknown. Some researchers have found the effects to last at least until the end of their study, which has varied between 10 days (Pohl et al. 2007) and 1 year (Shore 2004). But there is no way of knowing how much longer the effects may have continued. As a consequence, crossover trials are problematic since they rely on a 'washout period' to ensure that the effects of Spiritual Healing have subsided prior to engagement in another aspect of the trial.

Tsang et al. (2007) sought to determine the washout time for the effects of Reiki healing on cancer-related fatigue, pain and anxiety. Using their clinical experience as a basis, they predicted 3 days to be sufficient washout time, but found that the beneficial effects on fatigue, pain and anxiety outlasted the 7-day period during which washout was monitored. Tsang et al. recommend that washout should in future be monitored for a longer period of time, although they do not specify how long this should be.

2.11 Determining outcome measurement

Tables 2.1.1-2.1.7 (p28-34) shows that many studies used questionnaires as outcome measures. Several of these studies administered the questionnaires many times, as exemplified by the following:

- Pohl et al. (2007) administered 1 (10-item Visual Analogue Scale) questionnaire 7 times in a 2-week period.
- Tsang et al. (2007) administered a Visual Analogue Scale and 2 questionnaires (13-item and 28-item) twice daily before and after Reiki healing, plus a symptom assessment scale (9-item) daily for 7 days during the crossover period.
- Brooks et al. (2006) administered 7 questionnaires (1 to 24 items), 5 were administered twice.

It is tempting for researchers to use several questionnaires to measure several different outcomes, particularly in the present climate where only validated outcome measures are publishable. But an excessive number of questionnaires for participants, especially those who are unwell and may be stressed by the experience, may call into question the validity of their responses. There are ethical concerns

regarding studies that burden patients/respondents with large amounts of paperwork; it also seems to be the antithesis of the holistic therapy they seek to measure.

The predetermined nature of questionnaires, chosen by a research team with preconceived views of what should be measured, may not capture unique healee responses to Spiritual Healing. For example, Shiflett et al. (2002) reported that Reiki did not have any useful clinical effects as measured by their questionnaires, although their own post hoc analysis indicated that Reiki had positive effects on mood and energy levels that were not measured by their questionnaires or addressed in their original study.

One study used MYCAW (Measure Yourself Concerns and Wellbeing) questionnaires (Paterson et al. 2007) which allowed respondents to nominate 1 or 2 concerns and score these concerns and their general well-being using a 7-point scale (Vaghela et al. 2007). The reported concerns of the 15 participants were amalgamated into super-categories and analysis focused on changes in the magnitude of these measurements. The most common was 'psychological and emotional' concerns, which included a wide range of concerns: fear and anxiety; stress and tension; sleep problems; and the future. Yet while this super-category is very broad it accounted for only 16 out of 40 expressed concerns, so in this instance it would appear that the creation of analytical categories failed to reflect fully all the experiences of the respondents.

In trying to capture the impact of Spiritual Healing, some studies have measured physiological changes. Beutler et al.'s (1988) study of hypertension used blood pressure as an outcome measure in their RCT of healing, distant healing or no healing and found there was no significant difference between the groups. Other studies using biological measures have found positive results (MacKay et al. 2004; Bunnell 1999; Wetzel 1989). But again by narrowing the outcome measures to biological effects, researchers may have missed additional multi-dimensional (mind and spirit) effects of Spiritual Healing. For example, Dixon. (1998) measured killer cell counts and found that although these remained the same throughout the trial,

patients reported their symptoms (general well-being, anxiety and depression) improved substantially.

2.12 Reviewing healing methodologies

Within the dominant paradigm of medical science, the randomised controlled trial (RCT) is considered the ‘gold standard’ for evaluating the effectiveness and safety of a medical intervention. The Jadad scoring system (Jadad et al. 1996) is widely used to determine whether or not RCT studies are methodologically reliable for inclusion into systematic reviews. Only a small proportion of healing studies met these criteria in the systematic reviews by Abbot (2000), Herron-Marx et al. (2008), and Lee et al. (2008). Each of these systematic reviews called for more well-designed RCTs into Spiritual Healing. Given the challenges identified above, it has to be questioned whether this positivist methodology has been applied appropriately to Spiritual Healing by researchers trained in Western science, whose research focus and outcome criteria have largely come from the biological science paradigms. Indeed it can be argued that to carry out an RCT on Spiritual Healing entails reducing the complexity of the intervention and potential outcomes to fit the standardised and reductionist nature of the RCT (Fonnebo et al. 2007; Barry 2005) to such an extent that it renders at best partial results and at worst misses important therapeutic responses.

Many researchers who subscribe to the conceptualisation of healing, described earlier in this chapter, reject positivist paradigmatic research altogether. Werbach (2004) has argued that the patient’s relationship with disease and Spiritual Healing is explained through their subjective world of difference, of feelings, of conflict and commitments that are important to human life patterns, but difficult to standardize for research purposes. Thus a narrow focus on physical or psychological outcomes, while potentially validating certain aspects of the Spiritual Healing response, cannot capture all the potential mind, body and spirit impacts of Spiritual Healing. To this extent, it would appear that qualitative studies have much to offer in terms of clarifying both the process and the outcome of Spiritual Healing. However, such studies are surprisingly rare. Some studies into Spiritual Healing have used mixed methods (Vaghela et al. 2007; MacDermott and Epstein 2001; Sundbolm et al. 1994). However, as observed by Tovey (1998), it seems the qualitative interviews

are used mainly further to validate the findings of an RCT and to ‘flesh out’ statistically significant findings and not to search for new information. The published qualitative studies available appear to be of poor quality. For example Mitchell et al.’s (2004) small qualitative study of 4 pairs of patient/Reiki healers sought to understand how both patients and therapists experienced Reiki. Each individual was interviewed several times and the results showed improved sleep, decreased anxiety, decreased medication and increased self-confidence. The research conclusions indicated that trust and communication were core elements of the patient/healer relationship and that the relationship was a key element of Reiki healing outcomes. Unfortunately the study looked only at patient/healer pairs that were already in existence, so the patients established a commitment to Reiki and their healers before the start of the study.

Patients who were already undergoing a course of therapy were likely to respond positively, reflecting their decision to seek and continue Reiki healing. It is also possible that patients felt ‘loyalty’ to their healer and this may have been reflected in their responses at interview. Healers’ responses to the research were likely to be positive as they were established healers. The results cannot show if effects claimed by the participants were due to Reiki or other elements within the decision-making process or the healing intervention.

2.13 Conclusion

In this chapter, I have shown that conceptualisations of Spiritual Healing sit uneasily with the paradigm of medical science. Observational research into the effects of Spiritual Healing has shown that it is potentially capable of easing pain, depression, anxiety and stress, encouraging relaxation, assisting sleep, alleviating fatigue and improving quality of life and general well-being. Controlled studies have shown that these effects are generally no better than placebo. However, erroneous methodological assumptions about what constitutes a healing placebo and an appropriate healing outcome may account for at least some of these results. Indeed, I have identified some good reasons why experimental methods may be inappropriate for studying Spiritual Healing at this time: the mechanisms of healing are unclear, its vital elements unknown, its dose and duration highly variable, the use of placebo suspect, and outcomes not clearly delineated. Such lack of

knowledge suggests the need for more exploratory and observational research into the nature and effects of healing.

In order to investigate the full range of potential outcomes of Spiritual Healing and to understand the experience of Spiritual Healing, it was necessary to find an appropriate group of patients who could be offered Spiritual Healing. Given the multi-dimensional nature of the body within the Spiritual Healing paradigm, it was essential to find a group of patients likely to manifest symptoms across each of physical, mental, emotional and spiritual domains. Breast cancer patients were selected because the effects of the disease and side-effects of treatment are well documented as including a range of physical, emotional and social effects, including pain, stress and anxiety, that Spiritual Healing has the potential to alleviate. The selection of this group of patients conferred many advantages. Breast cancer is a common disease in women. The highest rates are in the south of England (BBC News 17/06/2008) where the study was to be located. Women with breast cancer are likely to fit with a typical profile of the users of complementary medicine. They are more likely to be female (Ong and Banks 2003; Thomas et al. 2001), middle-aged (Ong and Banks 2003) and live in the south of England (Ernst and White 2000).

The next chapter looks at breast cancer from the medical perspective of treatments and treatment outcomes, and from the patients' perspective, as recipients of treatments.

Chapter 3.

Breast cancer

'Babies see food. Men see sex. Doctors see disease. Businessmen see dollar signs.'

M.Yalom. (1997). *A history of the breast.*

3.1 Introduction

A decision having been made to focus on the effects of Spiritual Healing for women undergoing treatment for breast cancer, this chapter summarizes key findings from a vast medical literature to reflect what is known of breast cancer patient's experiences of the disease and its treatments. Literature regarding the effects of breast cancer available in 2009 was obtained from the following databases: Cinahl, Cochrane Library, EBSCO, OVID and Science Direct, using the key words breast cancer; patient experiences; breast surgery; chemotherapy; radiotherapy and hormonal therapy. It is of note that while the academic literature gave very detailed medical analysis of the physicality of breast cancer, the chemical components of treatments and some potential physical and emotional side-effects, there was limited information regarding patients' experiences of living with the effects of treatments. Thus much of the information regarding living with breast cancer is drawn from patient information sites, that were found using the search engine Google. The terms breast cancer; cancer advice; cancer help; mastectomy; chemotherapy; radiotherapy and hormonal therapy were used in an effort to access information that might be found by breast cancer patients. This search accessed information provided by Cancer Research UK, Macmillan Cancer Support, Cancerbackup and Breast Cancer Care which give lay information and advice to patients regarding living day-to-day with breast cancer and treatment side-effects. An important purpose of the review is to highlight problems likely to make breast cancer a relevant focus for the study of the impacts of Spiritual Healing.

The idea that 'everybody knows somebody who has breast cancer' is an indication of lay perceptions of the prevalence of breast cancer. Indeed 1 in 9 women will develop breast cancer at some point in their lives. There were 38,048 new cases of women diagnosed with breast cancer in the UK in 2007, which is equal to 125 women diagnosed each day (Office for National Statistics 2009). The NHS provides screening every three years for women in the most-at-risk age group (50–70 years),

reflecting state concern regarding the prevalence of the disease and the desire to diagnose and treat as early as possible. Since the introduction of breast screening there has been an increase in the reported incidence of breast cancer, but without a reciprocal increase in mortality, indicating that early detection and treatment have improved survival rates. Breast cancer also occurs in men but is rare, with only 314 cases in 2006 (Cancer Research UK 2008b); however, as it was anticipated that breast cancer was likely to have a different holistic impact on men, they were not included in this study.

While statistics show increasing survival rates for women diagnosed with breast cancer, they represent a crude measure of outcome. There is a common misconception that survival rates are 'cure' rates, but statistics show that survival declines over time. The emphasis on improving survival rates appears to reflect the demand for measurable results in a state healthcare system. Yet, amid these successes, a detailed understanding of the personal cost of breast cancer, treatment and survival appears to have been overlooked.

In modern Western culture, self image and body image are inextricably intertwined and breasts are important to the image of 'woman' and femininity (Yalom 1997). There are images of 'perfect' female bodies everywhere, with women and their body parts used in advertising to sell everything from machinery and domestic goods to cars and hi-tech equipment. The American post-war motion picture industry promoted big-breasted actresses like Marilyn Monroe and Jayne Mansfield (Yalom 1997), and more recently actresses and pop stars with breast augmentation such as Pamela Anderson, Tara Reid and Victoria Beckham have been the focus of media attention. Women's breasts symbolize sexuality, nurturance and love and are at the heart of femininity, but sadly with breast cancer they also can represent disease and death (Yalom 1997). Women diagnosed with breast cancer must come to terms not only with the cancer as an illness, but also with the impact that treatment has on a part of the body that is rich in social meaning (Harmer 2006). Thus while breast cancer has the potential to impact on every aspect of a woman's existence, her life becomes sculpted by diagnosis and treatments. However, it is apparent that most contemporary medical literature on breast cancer fails to focus on the full range of impact on day-to-day living with breast cancer and its

treatments. It is these 'hidden' aspects of experience that this research into Spiritual Healing has exposed. The following sections give an overview of what is known about the effects on women at the various stages of the breast cancer journey.

3.2 Discovery and diagnosis

Payne et al. (1996) studied how it feels to discover a lump in the breast, or to be called back for further tests after a routine mammogram. Emotional reactions included terror, shock and panic, followed in minutes or days by emotional numbness, denial or disbelief. When presented with the diagnosis of breast cancer, women generally are shocked and upset (Iwamitsu et al. 2005), feeling a sense of sadness, despair and rage (Payne et al. 1996), followed by a growing realisation of the implications of the disease. Common early responses include overwhelming fear (Bertero and Wilmoth 2007; Gonzales and Lengacher 2007; Carleson et al. 2005), feeling vulnerable (McWilliam et al. 2000), an awareness of their own mortality and the possibility of death (Bertero and Wilmoth 2007; Kroenke et al. 2004; Ferrell et al. 1999), anger (Carleson et al. 2005), fear for their family (Gonzales and Lengacher 2007; Payne et al. 1996) and a desire to make meaning out of what is happening to them (Bertero and Wilmoth 2007).

3.3 Coping patterns

Life-threatening events such as breast cancer are known to prompt psychological distress (McBride et al. 2000), anxiety and/or depression (Burgess et al. 2008) and spiritual disequilibrium which triggers many to reach out for information, support from others and to faith resources (Coward and Kahn 2004). Fifty per cent of women with early breast cancer are known to experience depression and/or anxiety in the year after diagnosis, falling to 25 per cent in the subsequent 3 years (Burgess et al. 2008, p702). There is a strong association between the number and severity of patient concerns at diagnosis and the later development of anxiety and depression (Farrell et al. 2004). Women's psychological well-being was addressed by Gonzalez and Lengacher (2007), who showed that most women may be categorised according to one of three adaptive coping patterns: active, passive or emotional avoidance. Passive acceptance describes how women feel the cancer and its treatments are out of their control and decisions are deferred to the medical experts. Patients with whom treatment decisions are not shared are less satisfied with the consultation, the emotional support and the information about their treatment (Gattellari et al. 2001).

Emotional avoidance refers to women who do not reveal their fears or intense emotions because they are concerned about the reactions of their significant others – spouse, children, other family members (Gonzalez and Lengacher 2007). Active coping implies that women adopt a positive attitude and are actively involved in gaining knowledge about treatments and accessing support. Active involvement in treatment decision-making has been shown to improve outcomes and patients who are offered a choice of surgery suffer less anxiety and depression (Fallowfield et al.1990; Mickan and Askew 2006). It is generally accepted that active coping strategies are most adaptive in the longer term (Walker 2001). However, the literature contains little information about how women manage their lives following the discovery of breast cancer, nor about the impact it has on a woman’s family, work and domestic environment.

3.4 Medical responses to breast cancer

The medical treatment of breast cancer follows a predictable path: diagnosis is followed by surgery, possibly radiotherapy, chemotherapy and, for women with oestrogen-sensitive tumours, long-term hormonal therapy. After diagnosis, the preoperative wait can be one of the most stressful times (Saegrov and Halding 2004), particularly as women do not know the extent of their cancer spread until after surgery. It is at this time that women must confront their fears linked to cancer, linked to surgery and the fear of the unknown (Payne et al.1996).

3.4.1 Surgical treatment

There are two types of surgery to remove the cancer tumour – lumpectomy or mastectomy. A lumpectomy is a breast-conserving therapy that removes the least amount of breast tissue and leaves a small scar and sometimes a small dent in the breast. Studies indicate that women who have breast-conserving surgery have more positive feelings about their nude body (Schover 1991), but will still suffer from the psychological distress caused by the diagnosis of cancer (Harmer 2006; Fallowfield and Hall 1991; Fallowfield et al.1986). A mastectomy is the removal of the whole breast and is used when the breast lump is large in proportion to the rest of the breast, if the lump is located just behind the nipple or if there are several areas of cancer cells within the breast. A simple mastectomy removes only the breast tissue,

but it is sometimes necessary to remove underlying muscle tissue and lymph glands in the armpit.

For most women the fear of cancer is greater than the fear of losing a breast (Fallowfield et al.1990) and so some women who could have a lumpectomy elect to have a mastectomy. Although the risk of recurrence after a lumpectomy followed by radiotherapy is the same as for mastectomy (Cancerbackup 2008), fear motivates some women to have radical surgery, perceiving that the removal of the breast decreases their risk of recurrence of cancer (Fallowfield et al. 1986). At this point women are focused on survival (Harmer 2006).

Schover's (1991) review of 12 studies of mastectomy versus breast conservation found that in 8 studies patients who had breast-conservation surgery had better body image than mastectomy patients. Breast reconstruction is offered to most mastectomy patients either at the time of their mastectomy surgery or once the initial curative treatments are complete. It was hoped that breast-conservation surgery would prevent the psychological distress linked to mastectomy as many women who do not have reconstruction do not return to their pre-breast cancer comfort with nudity (Payne et al. 1996). Such concerns around body image can persist for more than 5 years (Arndt et al. 2005; Omne-Ponten et al. 1994). Although the evidence is contradictory, most studies show there are no major differences in psycho-social morbidity or sexual dysfunction between patients who have undergone different surgical treatment regimes (Arndt et al. 2005; Kroenke et al. 2004; Fallowfield et al. 1986). Yurek et al's (2000) study of women who had radical mastectomies with reconstruction showed they had poorer rates of sexual responsiveness and sexual activity. However, the Michigan Breast Reconstruction Outcome Study (Wilkins et al. 1997) found a significant increase post-operatively in general mental health, emotional well-being and functional well-being.

It might be anticipated that there would be a high uptake of reconstruction surgery but less than 20 per cent of patients eligible for reconstruction have the procedure (Alderman and Wei 2006). Reasons for fewer reconstructions include unrealistic perceptions of what a reconstructed breast may look like (Harmer 2006). However, the figure includes studies in America, where surgery is not always covered by

medical insurance (Alderman and Wei 2006). An alternative to reconstruction is the use of a prosthesis, but many women struggle to find brassieres, swimwear or nightwear that will hold the prosthesis (Engel et al. 2003; Rowland et al. 2000; Payne et al. 1996). African and Asian women also reported getting ‘white boobs’ rather than prostheses that match their skin tone (Bertero and Wilmoth 2007).

After surgery, women can experience chronic pain which is difficult to manage with orthodox medications (Bertero and Wilmoth 2007; Emery et al. 2001). Unlike acute pain that is self-limiting, there is no clear pattern of onset and resolution. Post-mastectomy pain syndrome (PMPS), which is commonly due to nerve damage during surgery, develops between 30 and 60 days after surgery and for 17 per cent of women has been reported as lasting up to 12 years (MacDonald et al. 2005). While PMPS and bone pain, the most common causes of cancer-induced pain (Emery et al. 2001), have been studied, these studies provide little no information regarding how women live with their pain, nor how they adapt their lives to accommodate such pain.

Lymphoedema, the painful swelling of the arm (caused by the removal or damage of lymph nodes), is common following surgery, but frequently therapeutically neglected (Engel et al. 2003; Tengrup et al. 2000) and dismissed as a common side-effect that will resolve (Williams 2006). Women often learn to manage their oedema using techniques such as self-massage (Jeffs 2006).

3.4.2 Radiotherapy

Radiotherapy can reduce the risk of cancer recurrence by 50-66 per cent (Breast Cancer Care 2008). Not all breast cancer patients will undergo radiotherapy, which can be a frightening experience. It takes place in a windowless room filled with imposing equipment and it is not unusual for patients to feel claustrophobic. Because of the nature of the treatment nursing staff are not present in the room and although they can talk to the patient, many women report feeling very alone and isolated (Payne et al. 1996). Women who undergo radiotherapy face a course of time-intensive treatment, sometimes consisting of 25 or 30 sessions administered 4 or 5 days a week for 5 or 6 weeks (Cancer Research UK 2008a; Cancerbackup 2008). It can cause burns and leaves the skin in the treated area with a tanned or

slightly pinkish look to it for up to 6 months after the last session of radiation. Some women may continue to have a slightly pinkish or tan hue for years after treatment (Payne et al. 1996).

One in three women undergoing radiation therapy finds that fatigue is a persistent side-effect of treatment (Bower 2006; Mock et al. 2005; Wratten et al. 2003; Bower et al. 2000) lasting up to 10 years (Bower et al. 2003). The fatigue felt with radiation therapy is not the kind of tiredness that comes from working too hard and does not go away with a good night's sleep. Radiation treatment-related fatigue is an overall, deeply felt lack of energy and exhaustion (Breast Cancer Care 2008).

3.4.3 Chemotherapy

Most breast cancer patients will undergo chemotherapy, a systematic treatment with drugs to kill any cancer cells that remain in the body after surgery. The course of chemotherapy generally lasts 3–6 months and is given in cycles in which a treatment period is followed by a rest period of 2–3 weeks. Patients feel at their worst during the first few days after treatment, with side-effects including nausea, vomiting, lack of energy and feeling emotionally low (Cancer Research UK 2008a; Cancerbackup 2008). Over the subsequent days, as they start to feel better, the next chemotherapy session is due and women begin to feel anxious and apprehensive. Initially women may feel they can cope with the side-effects, but the relentlessness of the cycles and the increasing intensity of the side-effects mean that many women start to dread their chemotherapy sessions (Payne et al. 1996).

While chemotherapy is effective against cancer cells it also affects other cells that divide rapidly (bone marrow; hair follicles; mouth lining; intestine lining). Probably one of the most well-known and visible side-effects of chemotherapy is loss of hair, which has become widely recognised as an outward sign of cancer. Chemotherapy, like radiotherapy, causes fatigue. The fatigue of chemotherapy is associated with significantly higher levels of depression, pain and sleep disturbance, which can last for several years (Bower et al. 2000). Many women find they have a decreased mental function, including short-term memory loss, an inability to concentrate, difficulty retrieving words, trouble multi-tasking and a sense that they have lost their mental edge. Known as 'chemobrain', in 15 per cent of patients this problem

can persist for years after treatment (Gross 2007). The strategies women adopt to cope with 'chemobrain' are not addressed in the literature. Yet for a woman running a busy family and work life, it must be problematic. While many of the side-effects are short-term or subside over time, others are permanent. Premature menopause and infertility are potentially permanent complications (Cancer Research UK 2008a; Cancerbackup 2008). Research has also linked certain drugs used in chemotherapy to rheumatism, which develops between 1 and 3 months after completion of the therapy (Loprinzi et al. 1993). Older women who become menopausal can have rapid bone loss leading to possible osteoporosis (American Cancer Society 2007). And while the end of chemotherapy is a welcome relief, it is frequently accompanied by feelings of vulnerability and anxiety around whether the treatment has 'worked' (Payne et al. 1996). These fears are reinforced by the need for follow-up treatment and regular medical checks where the emphasis is on 5-year and 10-year survival rates.

3.4.4 Long-term hormonal treatments

Once the initial treatments are completed, a majority of women are prescribed hormonal therapies that they take for 5 years. Hormonal therapy comes in tablet form and has to be taken at the same time each day. Many women choose to take it with food as it can make them feel sick and leave an unpleasant metallic taste in the mouth. All hormonal drugs have common side-effects, but it can be difficult to distinguish these symptoms from those caused by chemotherapy, induced menopause, or the withdrawal of hormone replacement therapy (Ganz 2001). The combination of chemotherapy and hormonal treatments creates menopausal symptoms in younger women and exacerbates the symptoms of menopausal women (Gross 2007). For some women the side-effects may be few and brief, mild and manageable, while for others they may be serious. Common side-effects include hot flashes, joint pain, fatigue, early menopause, mood swings, depression, bloating, weight gain, hair loss, vaginal dryness and diminished sexual functioning (Breast Cancer Care 2008; Ganz 2001). An estimated 50 per cent of women experience menopausal symptoms and 25 per cent experience hot flashes, nausea and vomiting (DeMarco 1997). Women who experience severe fatigue are 'more bothered' by menopausal symptoms (Bower et al. 2000).

Other known side-effects of hormonal therapy include tiredness, dizziness, headaches, visual problems, voice changes, hair and nail thinning, abnormal growth of uterine tissue, increased risk of uterine cancer, blood clots and stroke, cataracts and fertility problems (Cancer Research UK 2008a; Cancerbackup 2008). Side-effects of aromatase inhibitors, given to post-menopausal women, include sore muscles, joint pain/stiffness and arthritis, hair thinning, headaches, vaginal bleeding, weakened bones with the risk of osteoporosis, possible increase in blood cholesterol levels and an increased risk of blood clots, and some products cause upset stomach, nausea, vomiting, diarrhoea and sweating (Cancer Research UK 2008a; Cancerbackup 2008).

The side-effects of long-term hormonal medications can become very wearing and, while some may subside over time, 33 per cent of women still experience hot flushes after two years of treatment and 13 per cent of women admit to seeking a respite from the side-effects of Tamoxifen by intentionally missing tablets in the form of a 'drug holiday' (Fallowfield 2005). The figure for intentionally missed tablets may in fact be greater than 13 per cent, as almost 50 per cent of women admitted to 'forgetting' to take Tamoxifen from time to time, according to information obtained through face-to-face interviews (Fallowfield et al. 2005). Non-adherence to hormonal therapy may start as early as 1 year (Ziller et al. 2009). Research on the discontinuation rate for Tamoxifen found it to be 22 per cent after 1 year rising to 35 per cent after 3.5 years. Women who stopped Tamoxifen and started another drug were not included in these figures (Thomas et al. 2007). Clinical observations suggest that adherence to aromatase inhibitors may be even lower than to Tamoxifen, with only 69 per cent of women adhering to their hormonal therapy based on prescription control data. The information from prescription control was different from the patients, self-reported adherence which gave an adherence rate of up to 85 per cent, indicating that patient reports regarding adherence may not always reflect reality (Ziller et al. 2009). The effects of the discontinuance of adjuvant hormonal therapy are not known, but potentially could be very serious (Smith and Chua 2006). Yet anecdotal evidence shows that some oncologists deny the existence of side-effects and refuse to recognise the impact side-effects have on the lives of their breast cancer patients.

3.5 Implications for this study

It is apparent that the medical literature focuses predominantly on the physicality of breast cancer and responses to medical treatment. Orthodox medicine has had much success in treating the physical aspects of cancer. But while psychological distress associated with breast cancer has been well documented, it is apparent that little attention has been given to the ways in which women manage their daily lives while dealing with all its long-lasting physical, emotional and social effects. Spiritual Healing is a complementary therapy that sets out to address the mind (alleviation of fear, stress, anxiety and depression), body (alleviation of pain, fatigue and sleep problems) and spiritual dimensions of being. It was therefore predicted that Spiritual Healing, offered as a complementary therapy, might assist women to cope with the full impact of their breast cancer. This research provided the opportunity to study both the impacts of living with breast cancer and the effects, if any, of Spiritual Healing on these. The next task was to identify a methodology that would enable me to capture these multi-dimensional experiences and allow the fullest understanding of dynamic and changing human experiences. The next chapter outlines my chosen methodology and details the reasons for choosing it.

Chapter 4.

Methodology

'Truth is entirely a matter of style'

Oscar Wilde (1889). *The decay of lying*.

4.1 Introduction

It became apparent from the literature for both breast cancer and Spiritual Healing that there remain many gaps in our current understanding. Within Spiritual Healing there is limited knowledge about the lived experience of receiving Spiritual Healing as well as the impact of such healing in the short and longer term. The breast cancer literature has focused predominantly on the physicality of breast cancer, and to a lesser extent on psychological distress and sexual dysfunction, but there is little reference to the day-to-day experience of 'living with' the disease. Not all women experience their breast cancer and its treatments in exactly the same way, as individual experiences vary according to life patterns, priorities and constraints.

This study was originally conceived as an observational study of Spiritual Healing that was to form the initial stage of a larger-scale study of the outcomes of Spiritual Healing. I sought a qualitative methodology that would capture a diverse range of experiences and selected Unitary Appreciative Inquiry (UAI) as the most appropriate. This methodology was developed by Richard Cowling, based on a desire to create a methodology that could explore the fullness and richness of human life (Cowling 2001; 2000).

UAI was derived from Rogers' (1992; 1970) model of nursing. This was based on a universal energy system which originated as a 'synthesis (not a summation) of facts and ideas' (Lutjens 1991, p3) from subjects as diverse as anthropology, astronomy, mathematics, Einsteinian physics, post-Einsteinian quantum physics and philosophy (Biley 2002; Lutjens, 1991). The conceptual framework and the language used to explain it are complex. Rogers rejected philosophical or theoretical labels that sought to pigeonhole her concepts, insisting that the Science of Unitary Human Beings (SUHB) was a novel abstract conceptual framework. Contrary to the medical model that places cells as the fundamental unit of life, Rogers draws on post-Einsteinian quantum physics to place the energy field as the fundamental unit

of life, whereby individuals are differentiated by their unique energy pattern or life pattern. Within this conceptual framework individuals are irreducible, whole energy fields that are more than the sum of their parts (Wright 2007; Lutjens 1991) and extend beyond the boundaries of their visible mass (Biley 2002). The environment is also viewed as a complex energy field that acts on, and reacts with, other energies including human energy systems. Thus SUHB acknowledges a multi-dimensional complexity both to human existence and to the impact of the environment and human energy upon individual being.

4.2 SUHB and Spiritual Healing

There are clear parallels between the conceptual framework of SUHB and the conceptual framework of Spiritual Healing outlined in Chapter 2. Although the philosophical roots are very different, viewing individuals as unique and whole underpins both SUHB and Spiritual Healing. Rogers' view of human beings as units of energy can be seen as similar to Spiritual Healers' view of the 5 energy layers of the human body. Both are based on the idea of visible and invisible energies that shape human beings and the world they inhabit. The concept of energy provides an alternative way of viewing health and healthcare to the purely biological model that currently dominates evidence-based orthodox medicine. Applying an energy-based conceptual framework to understand disease would mean that breast cancer could be viewed as a disruption within the individual's energy fields (Spiritual Healing) or a change in their individual energy pattern (SUHB).

Rogers proposed a model of nursing which incorporates both art and a science (Wright 2007) and developed SUHB to inform nursing care, recognising that the interactions between individual and group energy fields could inform therapeutic nursing interactions that would act contemporaneously and in the future. Rogers highlighted the importance of non-invasive care, including the use of touch, humour, guided imagery, light and colour therapies, music and meditation (Lutjens1991), all of which would work energetically on the patient. Therapeutic touch was developed from Rogers' energy framework (Krieger et al. 1979). Although conceptually different from therapeutic touch (see Chapter 2), Spiritual Healing fits well with the concept of energetic healing as a non-invasive therapy that complements and supports orthodox medical responses to disease.

4.3 Choosing the methodology – Unitary Appreciative Inquiry (UAI)

An understanding of the art of healing needs to be reflected in a research methodology that is sympathetic to the holistic and person-centred approach (Tonelli and Callahan, 2001). UAI provides a qualitative methodology that seeks an understanding of ‘the wholeness, uniqueness and essence of human life as a context for understanding phenomena and conditions’ (Cowling 2001, p32). It thus appeared to represent an appropriate methodology to study the multi-dimensional needs of breast cancer patients and their responses to Spiritual Healing.

4.3.1 UAI and feminism

My other priority was to find a methodology that would ‘fit’ with my feminist sociological roots and the feminist critiques of positivistic ‘malestream’ research. The traditional medical focus on clinical outcomes, noted in Chapter 3, may be paralleled with the andro-centric bias of science noted by early feminists (Reinharz 1992; Harding 1991; Oakley 1981; Millet 1971; Firestone 1970), which led a major element of society, namely women, to be neglected in the belief that the male view was universal. This was not an overt intentional disregard for women’s views and it is likely that medical research does not intentionally neglect the ‘whole’ patient. But if research reflects the inherent beliefs of the researcher, then medical research reflects the belief that the physical is of prime concern.

In contrast, I sought a qualitative methodology that would allow the voices of the women participants to be heard throughout, and would therefore allow for some sculpting of the focus of the study as data collection progressed. I have been influenced by Oakley’s (1981) belief in non-hierarchical collaborative research and the concept of ‘women’s talk’, the intimate talk between women (as opposed to the talk between a researcher and a respondent). Women’s talk allows women’s intimate experiences of breast cancer and healing to be shared and understood. My method had to be able to capture the many dimensions of women’s lives as expressed in women’s talk. UAI methodology is specifically designed to address the metaphysical concerns of human life and actualizes the ontological and epistemological assumptions of a unitary worldview. It redresses the neglect of the whole person within scientific analysis of health and healthcare. It responds to the

call of research in complementary medicine, and this research in particular, to address the multiple levels in the healing process and the essence of what is valued by the patients (Mason et al. 2002). Indeed, UAI was created by Cowling to avoid the neglect of important facets of human life that may not be recognised within other methodologies.

UAI is similar in its conception to early feminist standpoint epistemology that recognised that the unique experiences of individuals within society are contextually located. The power of feminist methodologies, and now UAI methodology, is that they connect with everyday life, valuing personal experiences, which are accessed not only intellectually but also through all the senses (Cowling 2000; Hartssock 1998). UAI methodology advocates the holistic valuing of the participant and their experiential reality while rejecting the dualism and mechanical abstraction of a Cartesian worldview that has led to the tendency to focus on ‘empirical, conceptual and theoretical approaches that yield sometimes erroneous accounts that miss the wholeness, unity and uniqueness of human existence’ (Cowling 2000, p16). So while UAI creates a group portrait of the patient participants, it acknowledges that the group is dynamic and changing (again paralleling standpoint feminism), and does not seek to create a universal definition of breast cancer and Spiritual Healing.

4.3.2 UAI and holism

The UAI methodology seeks to capture the ‘more than’ element of human beings by denying the analytical confines of individual academic disciplines. Thus a woman with breast cancer can be viewed holistically; she is ‘more than’ her physical disease, ‘more than’ her psychological distress, ‘more than’ her work or social status; she has a life that can incorporate all these elements and more. This all-encompassing view of a woman within SUHB would be deemed her life pattern or energy pattern. It is seen as being unique, different from every other life pattern, because it is the energy of an individual, sculpted by all aspects of life experiences and by interactions with other energy fields (human and environmental). Spiritual Healing as an energy therapy may impact on many aspects of a breast cancer patient’s life and UAI methodology has the flexibility and capacity to capture holistic experiences.

UAI is a form of participatory or co-operative inquiry (Reason and Bradbury 2001; Heron and Reason 1997; Reason 1994) in which everyone involved in the research (researcher, healer, patient) is considered a participant. All participants can influence the study format and the study outcomes, thereby ensuring the outcomes reflect the group's experiences. Co-operative methodologies parallel the feminist traditions of non-hierarchical research methods and seek to move the patients from 'researched on' to 'researched with', equalling out the power between the researcher and the researched and empowering the patients.

4.4 The UAI process

The process of UAI research is fluid and allows the researcher to adopt and adapt data collection and analysis to suit the research topic. Thus data collection can involve a variety of different methods to suit the needs of the participants and the study; for example, immediate responses may be collected by direct observation and patient journals, while a retrospective 'gestalt' overview of experiences may be captured later in one-to-one interviews. Data collection and analysis demand a focus on life patterns and human wholeness, and, according to Cowling (2000), have four essential components – appreciative knowing, participation, synopsis and transformation. These are explained below.

4.4.1 Appreciative knowing

Appreciative knowing refers to the knowledge generated by all participants through mutual engagement in the research process, unrestricted by prior judgements of what is to be investigated that can screen out aspects of experience. Appreciative knowing goes beyond diagnosis and epistemology, positing that human life is a miracle of extraordinary variety. It provides a way of understanding human conditions that goes beyond disciplinary fragmentations and superficial knowing (Cowling 2000; Cooperrider and Srivastva 2000; Kolb 1984). Appreciation is a process of affirmation based on trust, belief and conviction that allows comprehension to develop. From a counselling perspective, appreciative knowing can be viewed as the same as non-judgemental counselling, where a counsellor offers unconditional positive regard even though what the client describes may not be within a personal frame of experiences. Thus within this methodology the researcher participant, in focusing non-judgementally on the participant

(patient/healer) in every encounter, seeks to understand their experiences of breast cancer and Spiritual Healing in a way that reflects their wholeness, uniqueness and essence.

4.4.2 Participation

Participation is the cornerstone of UAI methodology (Cowling 2001; 2000) and relies on the willingness of all those involved to join in the exploration freely and without fear of judgement. Recognising the concept that human beings have the capacity to participate knowingly in a process, the participatory nature of the relationship is a critical feature of the research process. Using UAI methodology requires openness to discovery by all participants, an acceptance of the unpredictability of outcomes and the potential for negotiation that is dynamic and can challenge any preconceived ideas. From the start of this study, it was essential for me as the researcher participant to empower the other participants to participate as fully as they wanted in the research process. This links to the non-judgemental, appreciative nature of the research process, and recognises the potential for mutual discovery that informs the shape and focus of the research project. It is acknowledged that this research process may have therapeutic potential in its own right.

4.4.3 Synopsis

Through synopsis the researcher uses the patient's own words to produce an all-inclusive view of their experiences, perceptions and expressions regardless of category (physical, mental, emotional, social and spiritual). The synoptic process acknowledges environmental processes and contextual influences, so everything is viewed as information that reflects pattern and wholeness. The multiple strands of living with breast cancer and receiving Spiritual Healing, which may initially seem unrelated or unconnected, are drawn together in a tapestry that expresses the whole experience. Thus, in the synoptic process, connections and relationships within the data of 'experiences, perceptions and expressions associated with living [with breast cancer and receiving Spiritual Healing] are viewed in an inclusive way, to reveal the fullest picture of the inherent wholeness' (Cowling 2001, p35). The synoptic process gives a life-pattern profile of a woman with breast cancer experiencing

Spiritual Healing. It is created by the researcher and approved or modified by the participants.

4.4.4 Transformation

The potential for transformation is at the heart of the endeavour; UAI methodology can potentially be transformative in 3 ways:

1. UAI seeks to understand a condition of existence. Within this study UAI seeks to understand breast cancer and Spiritual Healing, appreciating the wholeness of patient experiences. Thus understandings of breast cancer and Spiritual Healing may be transformed and seen in a new context.
2. It is also recognised within the methodology that all participants may be changed by their experiences on the study. Without doubt, participating in the study changed my knowledge and understanding of academic process, breast cancer and Spiritual Healing.
3. Engagement with UAI methodology encourages the recognition that the self is 'more than' the limits of the physical body. The concept of interacting energy fields that extend beyond the visible (SUHB) or aura (Spiritual Healing) encourages a view of individuals and their environments that moves beyond the physical to a more complex understanding of being, that can incorporate mind, body and spirit.

4.5 UAI knowledge

Based on the principles outlined above, 'the overarching intent of UAI methodology is to generate knowledge that is both informative and transformative' (Cowling 2006, p124). Four forms of knowledge – experiential, presentational, propositional and practical – are created through the UAI research process. For each participant, **experiential knowledge** is a deep, inner knowing that encompasses every aspect of their life experiences; including the experiences of having breast cancer and its treatments, and receiving Spiritual Healing, much of which may be difficult to put into words. For the researcher, experiential knowledge is the inner, personal knowing that results from engagement with the research process, the participants and the research environments.

Presentation knowledge is the expression of experiential knowledge. Each participant can present their experiences through various means, including interviews and daily logs. The extent to which these truly reflect their priorities and the meanings they attach to the experiences will depend to a great extent on the environment of participation and sharing that is created by the researcher. Thus it must be recognised that a non-judgemental environment is essential to allow participants accurately to reflect their experiential knowledge, without the fear of being judged by the researcher or healer participants.

Data from an individual's presentation of their experiences is reviewed and presented in the form of a profile of the participant and the group. This profile can take a variety of different forms. In his research into the life patterns of people living with spinal cord injuries, Alligood (2006) used well-known songs to reflect each participant's life patterns and to capture for the reader a sense of who each participant was. Rushing (2005) asked her participants if there was any particular artefact, poem, song, movie or picture that was significant to them during their recovery from addiction, but only 2 had anything they shared. In his study of despair, for each individual participant Cowling (2004) created presentation knowledge in story form, using metaphors and images derived from the individual transcripts. This presentation knowledge gave the reader a sense or feeling of the experience of despair and was 'more than' the details of the participant's life with despair. Thus UAI opens up opportunities for data presentation not normally recognised within other research methodologies.

Propositional knowledge emerges from a synthesis of data derived from shared presentation knowledge and includes observations of environmental processes and contextual influences. Synthesis brings together all the data to form an integrated pattern of experience which is greater than the sum of its parts (Barnett-Page and Thomas 2009). The form of propositional knowledge evolves during the study and, while the researcher creates it, the other participants check to ensure it accurately represents their experiences. In contrast to theoretical propositions developed using scientific observations, the presentation of propositional knowledge can take different forms. For example, although it always includes a descriptive narrative, Rushing (2005) created a propositional group profile in the form of a poem.

Practical knowledge involves the identification by the researcher of information that may be useful in developing skills or developing new strategies to enhance the quality of care for future similar patient groups. Practical knowledge addresses gaps in what was previously known through published work and reflects presentational and propositional knowledge. This final stage of the research is not participatory as it is the researcher's analysis of the other forms of knowledge that creates this fourth form of knowledge.

The next chapter describes the actual method of collecting data. It highlights the challenges and the creative elements of UAI and acknowledges where this study has created new expressions of outcome, while adhering to the UAI philosophy of acknowledging and valuing all aspects of the patient participant's experiences.

Chapter 5.

Method

5.1 Introduction and study design

The purpose of this chapter is to explain how the methodology of Unitary Appreciative Inquiry (UAI) (Cowling 2004; 2001; 2000) was applied in this study in order to understand the experiences of Spiritual Healing in the overall context of women's experiences of breast cancer. The study was designed to capture the multi-dimensional impacts of both breast cancer and Spiritual Healing. A series of individual Spiritual Healing sessions, given free of charge by experienced healers, were offered to women suffering from adverse consequences of long-term hormonal treatment for breast cancer. Data collection focussed on the experiences of both breast cancer and Spiritual Healing using a variety of data collection methods to capture reflections on the cancer journey as well as the immediate and the sustained effects of healing. Although the term 'patient' fits uneasily with a feminist study, I refer on occasions to breast cancer participants as 'patients' or 'patient participants' as a means of distinguishing them from the healers who participated in the study and whose data is also reported.

5.2 Ethical and governance considerations

The research focused on intimate aspects of personal experience, both during healing and during subsequent interviews. Therefore it was essential to ensure that the study addressed important ethical concerns, particularly those involving the safety and well-being of all participants – healers, healees and the researcher.

The Harry Edwards Healing Sanctuary (HEHS), which provided the healers, has its own ethical code that includes the use of either chaperones or a web-cam to exclude any possibility of impropriety during healing sessions. In order to minimise bias that might be introduced by the presence of a third person, I planned to record all Spiritual Healing sessions using a video-camera. Although the original intention had been to use these recordings for the purposes of research observation, this was rejected by the reviewing committees and the recordings were retained with other study data, for the legal protection of healers and patients only. I and all the healers

had Criminal Records Bureau (CRB) checks and were given honorary contracts by the NHS trust prior to commencement of the study.

It was recognised that those receiving treatment for breast cancer were dealing with difficult or distressing issues that needed to be addressed in a sensitive way. Immediate and on-going support systems were put in place and detailed in the patient information pack. As a trained counsellor, I am qualified to deal with situations arising during the course of the study and was able to ensure that participants were fully supported should they express any signs of distress. Throughout the study I carried details of relevant support organisations should the participant need these. I also provided a list of local NFSH healers for patient participants who wished to continue Spiritual Healing after completing their 10 study healing sessions. I also recognised that the healers might hear distressing information from their healees and I made myself available to deal with any such situation, should it arise. Healers were also able to contact the Head of Healing at HEHS for support if they so required. In terms of dealing with my own feelings, I had available clinical supervision as part of my professional counselling role, as well as regular academic supervision.

While informed consent was gained from all participants prior to inclusion in the study, consent to all aspects of data collection was reconfirmed verbally at each contact, in line with good practice in qualitative research. I reinforced the information in the participant information sheet (PIS) that nobody should expect a cure and might not receive any benefits at all. Participants were aware of all forms of data collection (session reports, daily logs, field notes, audio recordings) and that they could see the data pertaining to them at any time. Although nobody chose to withdraw from the study, they were made aware that they could withdraw at any time and all information pertaining to them would be destroyed if they so requested. The healers were also made aware that, should they choose to withdraw from the study, their working relationship with the HEHS would not be jeopardised.

Healers chose to be known by their first names and preferred to be referred to in this way throughout the study. Patient participant anonymity is protected by the use of a self-selected pseudonym (a flower name), used by them during all conversations

and interviews, for appointment bookings, on all study paperwork, video and audio recordings, field notes, during any discussion with my supervisors and in any quotes used in this document, conference presentations or future publications. The code that links the flower name to the participant's actual name and address is held in a locked filing cabinet and will be securely stored at the end of the study at the University of Southampton. Any references to medical staff by name were changed or removed.

The study proposal was peer reviewed and approved by the National Cancer Research Institute Clinical Studies Group for Complementary Medicine. It was subsequently approved by the local Cancer Sciences Division Protocol Review Committee to enable recruitment to take place within that directorate (Appendix 1). It was approved for the purposes of research governance after consideration by the local NHS Trust Research and Development Unit (Appendix 2). The study was approved by the research committee in charge of the specialist clinical research facilities, enabling the research to take place in their unit. The study was approved by the Isle of Wight, Portsmouth and South East Hampshire Research Ethics Committee (Appendix 3).

With informed consent, each patient's medical consultant (Appendix 8) and GP (Appendix 9) were advised of their participation in the study. All paperwork from the study (interview transcripts, patient daily logs, session reports, filed notes, personal reflections), videos and CDs of interview audio recordings were held securely in a locked filing cabinet at the university. An Investigator Site File containing all documentation related to the study was maintained and is available for audit in accordance with the requirements of NHS R&D. In addition to the paperwork referred to above, this includes risk assessment, financial management, professional indemnity insurance and all correspondence with the breast cancer clinic.

5.3 Study location

All Spiritual Healing sessions took place in a specialist clinical research facility (SCRF) located within a large district general hospital. Usually used for clinical trials, this provided an environment removed from the hustle and bustle of the

general hospital. The unit has its own ‘meet and greet’ facilities, together with a comfortable waiting area with water machine and hot drinks facilities. Although the study did not require nursing assistance, all studies using the SCRF are allocated a nursing team. The nursing team maintained SCRF and hospital research records and helped with the setting-up of the healing room.

5.4 Study participants

While the breast cancer patient participants’ experiences are the focus of the study, other participants in this study included myself as researcher participant, and healer participants. The role of the healer participants was crucial in providing Spiritual Healing that replicated usual practice and in collecting data for the session reports (Appendix 5).

5.4.1 Recruitment of Spiritual Healer participants

The Spiritual Healer participants were trained to at least practitioner standard as defined by the National Occupations Standard, drafted by UK healers under the guidance of Skill for Health, with a minimum of 2 years’ practice. Suitably qualified Spiritual Healers who worked with the Harry Edwards Healing Sanctuary (HEHS) were eligible to volunteer to take part in the study. All healers who were interested in participating were given a Healer Information Pack that contained a Healers’ Information Sheet (Appendix 10), a copy of a PIS (Appendix 6), the inclusion/exclusion criteria chart (Table 5.1), the Spiritual Healing intervention flowchart that was developed in collaboration with HEHS as a guide for all study healers (Figure 5.2), a copy of the session report for use in the Spiritual Healing consultation (Appendix 5) and healers’ consent form (Appendix 11). Interested healers were invited to attend an introduction meeting at the research unit where they were given a tour of the facilities. They were able to see the rooms that were available to the study and to decide on their suitability for healing. At this time they were also able to meet me and the SCRF team, and ask any questions they might have regarding the study.

Healers who decided they would like to take part in the study completed the consent form (Appendix 11). They also completed the honorary contract request form and a CRB application form, both of which are necessary to work in the hospital. Once

satisfactory CRB check results were received by the Human Resources Department, an honorary contract was issued to each healer and they were able to work within an NHS facility and give Spiritual Healing to patient participants. HEHS paid the volunteers travelling expenses to attend the research unit. Although none of the healers left the study once it commenced, healers were made aware that should they want to stop taking part, their relationship and working arrangements with HEHS would be unaffected.

Although 5 Spiritual healers were recruited and, having successfully completed the CRB checks, were in receipt of a hospital honorary contract, delays during the recruitment of patients meant that only 4 healers were able to take part in the study. All the healers who took part were women.

5.4.2 Recruitment of patient participants

In accordance with the protocol that had been nationally and locally approved (see above), I arranged to recruit patients through the local breast cancer clinic. It was agreed at the review and ethical approval stages that staff would make information packs available to patients who met with the inclusion and exclusion criteria. The pack contained the letter of invitation (Appendix 13), a PIS (Appendix 6) and a patient response letter (Appendix 12). There was a pre-paid return envelope so patients could reply direct to me if they wanted to participate in the study or required further information. It was agreed that I would also attend the breast cancer clinic to be available to answer any immediate questions such patients might have.

Nursing staff working in the breast cancer clinic were initially enthusiastic and agreed to hand out the PIS. However, one member of the medical staff subsequently declined to allow any of the patients in his care to receive the PIS. My own direct observations, made while sitting unobtrusively in the clinic and on other occasions when talking with members of the medical and nursing teams, revealed both overt and covert hostility towards the study and a refusal to inform patients about the study. On one occasion, I saw a team member deliberately remove information packs from patients' notes (including those of the patients of other team members). After only a few weeks I was asked to leave the clinic. As a result, only two patient participants were recruited through the breast cancer clinic and I was left with no

choice but to find alternative ways of letting potential participants know about the study. I contacted the local newspaper, local radio stations and BBC television, all of whom reported on the study. Anyone hearing about the study who was interested in taking part was invited to contact the Complementary and Integrated Medicine Research Unit (CIMRU) and was sent an information pack with an attached pre-paid return envelope.

Recruitment was slow and I wrote articles for the HEHS in-house magazine *The Healer* (Appendices 21 and 25), and the NFSH magazine, *Healing Today* (Appendix 22), to try to inform people about the study and to reach potential patients. The *Psychic News* also ran a front-page article about the study (Appendix 24) and I was able to arrange two full-page stories in the local newspaper (Appendices 23 and 26).

5.4.2 (i) Inclusion criteria for patient participants

The criteria for patient inclusion in the study are shown in Table 5.1. This table was developed originally to inform the nurses and oncologists of the breast cancer clinic. However, as much of my recruitment occurred away from the clinic, the criteria were sent to patients who expressed an interest in participating in the study and verbally checked by me when I telephoned patients to make arrangements for joining the study. Potential participants were not excluded on the grounds of ethnicity or religious affiliation and translation facilities were available for any non-English speakers (though this was not required).

Table 5.1 Inclusion/exclusion criteria

Women breast cancer patients must be able to answer YES to all statements to be eligible to join the study.

Criteria	Include if Yes to all	Exclude if No to any
Initial treatment completed at least 6 months ago	Yes	No
Patient receiving long-term hormonal therapy for breast cancer	Yes	No
Patient reports at least one unpleasant/unwanted side-effect of hormone therapy	Yes	No
Patient has no pre-existing medical condition (prior to their cancer) for which they are currently receiving treatment	Yes	No
Patient has no major mental health problem	Yes	No
No known metastases or recurrence of the cancer	Yes	No
Patient has not received Spiritual Healing for their breast cancer	Yes	No
Patient is not a Spiritual Healer	Yes	No

Patients were excluded if they had a pre-existing medical condition, prior to their cancer, or were currently receiving treatment for a major mental health problem, or had known metastases or had recently been diagnosed with a recurrence of their cancer. Women who had previously received Spiritual Healing for their breast cancer and those who were Spiritual Healers themselves were also excluded.

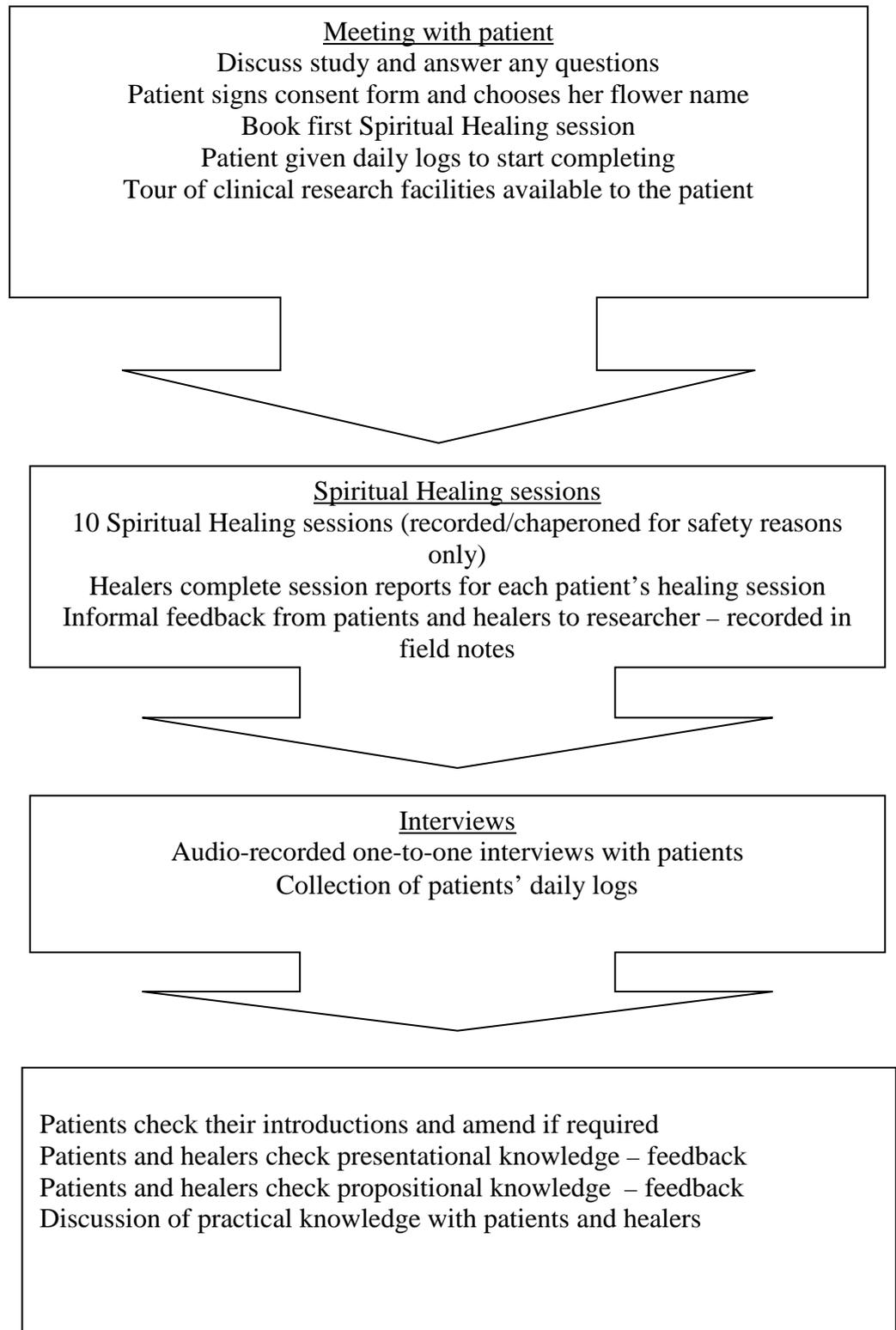
Accordingly, 12 breast cancer patients were recruited into the study. Patient participants received *no* financial reimbursement for any costs they incurred participating in this study, including transport and parking. All the women were 50+ years old, white, able-bodied and English-speaking. Their individual profiles are presented in Chapter 6.

5.5 Study procedure

The study process flowchart (Figure 5.1, p68) provides an overview of the patient participant journey through the study from recruitment to the generation of presentational, propositional and practical knowledge.

Figure 5.1

Study process flowchart



5.5.1 Meeting with the patient

I contacted breast cancer patients who had expressed, in writing, their interest in participating in the study and, after checking their eligibility using Table 5.1, invited them to an induction interview at the research unit. I outlined the structure of the study and was able to answer any questions they might have. If the patient wanted to continue and participate in the study, they were asked to sign the consent form (Appendix 7). After completion of the consent form, the patient participant chose a flower name by which they would be known throughout the study. In addition to protecting patient confidentiality, the individual flower name highlighted the patient participant's uniqueness within the study. It also emphasised the UAI concept of participation in a way that the allocation of a meaningless study reference code could not have done. The women soon came to identify quite naturally with their chosen flower name which was used in every aspect of the study including this thesis.

At the end of the induction interview the patient participants were given a tour of the research unit, including the volunteers' kitchen where they could help themselves to refreshments free of charge and the volunteers' lounge which offered an alternative waiting area to the reception foyer. They also booked their first Spiritual Healing session.

Patient participants were given a batch of daily logs (Appendix 4) which they were asked to start completing immediately and to continue until the end of their Spiritual Healing sessions. Guidance on completing the daily logs was limited to an explanation of how to name and date the logs and permission to write 'anything you like' about daily life experiences, feelings and thoughts. This allowed the log entries to reflect the priorities of the patient participant. Each patient participant completed between 12 and 15 weeks of daily logs. There was a variety of formats adopted by the patient participants from cryptic notes to detailed commentary and one chose to use symbols (☺ ☹) with additional information if she felt it was appropriate to explain the symbol.

5.5.2 Spiritual Healing intervention

The Spiritual Healing sessions were held weekly on Fridays. Where a patient participant had prior engagements, or where the research unit was closed for a Bank Holiday, participants were able to complete their 10 Spiritual Healing sessions over an 11 – 13-week period. At all times the appointments were made to suit the patient participant and they were not penalised for missing a healing session. The ability of the patient participant to control their appointments reflected normal Spiritual Healing practice, giving patient participants ownership of their healing journey and reflecting the UAI philosophy of collaborative participation. There was no charge for the healing sessions but patients were expected to get to the hospital at their own expense.

I was present at the research unit every week, and although never directly involved in the Spiritual Healing consultation or Spiritual Healing, I was able to chat to each participant every week. When a participant arrived at the unit she was greeted by the receptionist using her chosen flower name and asked to sign the visitor book. I then escorted the patient participant to the healing room where the healer would be waiting.

The Spiritual Healings took place in a single consulting room. In order to try to replicate a usual healing room, as much of the clinical equipment as possible was removed. For the consultation at the start of the healing session, 2 armchairs were placed at one end of the room facing each other. The bed was moved to the centre of the room to allow the healer easy access all around it. The healers brought pastel-coloured bed coverings and pillowcases for the bed, removing the hospital white bedclothes. Healers also brought a selection of tranquil music that was played at a low volume on the compact disc player at the side of the room once the actual Spiritual Healing started. In lieu of a chaperone, video-camera equipment was set up in the corner of the room facing the end of the bed, to ensure as much as possible of the consultation and healing was captured.

5.5.3 The Spiritual Healing session

One HEHS healer attended the research unit each week to provide Spiritual Healing. Because of holidays and prior commitments this was not always the same

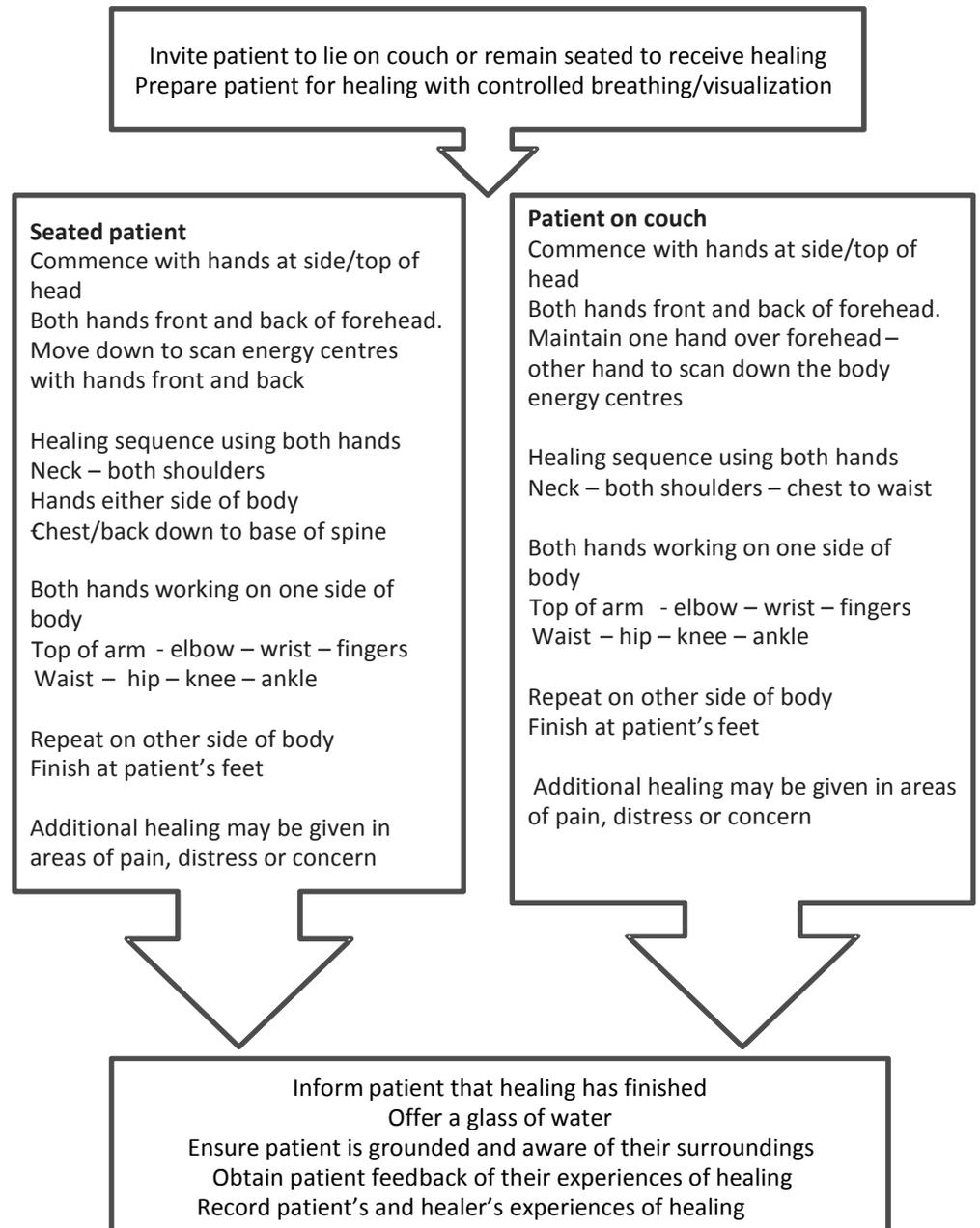
healer and most patient participants saw more than one healer during their time on the study.

Ten Spiritual Healing sessions, held at weekly intervals, were offered and all of the participants took up all 10 sessions. The Spiritual Healing sessions reflected the normal practices of Spiritual Healing available to the general population. When the patient participant arrived in the healing room, the healer sought their permission to switch on the video recording equipment. None objected to the use of video for security purposes, but on one occasion there was a fault with the equipment and a member of the nursing team acted as chaperone until the fault could be rectified. I decided to use a nurse who had no active part in the research, rather than sit in on the healing session myself, because I felt my presence in the healing room might prove disruptive of the usual flow of the healing session for the patient, or the healer, or both.

Prior to giving Spiritual Healing, the healer noted any issues the participant brought to their healing session. This usually included what had happened since their previous Spiritual Healing session and their on-going side-effects of treatment for breast cancer. These issues were written on the session report (Appendix 5). Next the participant received approximately 40 minutes' Spiritual Healing following the agreed Spiritual Healing intervention flowchart (Figure 5.2, p72). During the healing session the patient remained fully clothed.

Figure 5.2

Spiritual Healing intervention flowchart



All the patient participants elected to have Spiritual Healing on the bed and removed their shoes before lying down. Patients were first instructed in controlled breathing and visualisation. The healer then proceeded to give Spiritual Healing either as contact healing (healer's hands touching the patient) or proximate healing (healer's hands above the patient's body). Spiritual Healing started at the crown of

the patient's head and the healer worked their way down the length of the patient's body, finishing at their feet. Most healing sessions involved a combination of contact and proximate healing, as healers avoided touching socially sensitive areas. If the patient participant had any special concerns, these were addressed either after the initial whole-body healing or prior to starting the whole-body healing, as requested by the patient.

At the end of the Spiritual Healing the patient was gently roused and 'in their own time' invited to sit up and take a glass of water. The healer ensured that the patient felt 'grounded' (a term for awareness after deep relaxation) and able to return to the reception area. In line with usual practice, healers completed session reports that included notes made at the beginning and following each session (Appendix 5). These reports captured information of life experiences (presentational knowledge) that the patient participants told the healers during their healing session and were included as research data for this study. The focus of the session report was primarily the lived experiences of the patient participants. This is reflected in the space allocation of the form. The healers also noted their experiences and observations of the healing session in the 'notes' section of the session report.

Once the Spiritual Healing session was completed, I escorted the patient to the reception area and booked her next appointment. During this time we chatted informally about the patient participant's life pattern and her Spiritual Healing experiences. Notes from these conversations were kept in my field journal and were included as data of presentational knowledge. I also talked to the healers about their experience of giving Spiritual Healing to a particular patient participant and these notes were recorded on the reverse of the session report or in my field journal and were included in the research data for this study.

5.5.4 Interviews

On completion of the ten Spiritual Healing sessions, each patient participant agreed to take part in a one-to-one interview with me (interview consent form, Appendix 14). The interviews took place either at their home or at the research unit, whichever was more convenient for them. For my own protection, home interviews were conducted in accordance with university policy for lone interviewing which

included ensuring that my location was known to a responsible person at all times. If the interviews were held at the unit, they were conducted in a small consulting room with as much of the clinical equipment as possible removed or hidden behind screens. Nine interviews took place in the home and 3 took place in the research unit.

The interviews lasted between 1 and 1.5 hours and were audio-recorded. The participants were aware when the recording equipment was switched on and also that they could switch it off at any time. None asked to switch off the audio recording despite the sensitive and emotional content of some interviews. Indeed, some asked for it to be switched on again at the end of the interview if they had thought of something else they wanted recorded. It can be viewed as a measure of their ownership of their input into the study and their comfort with me and the interview, that they felt able to take control of what was recorded.

I wanted to understand each individual's situation from their perspective, so the technique I adopted for the interviews was very similar to the style I use at an initial counselling consultation, which is a non-judgemental stance of unconditional positive regard. This form of consultation always starts with an open question, followed by focused questions later when particular issues need clarifying. Thus I started each interview with an open question regarding the participant's cancer journey prior to joining the study: 'Please can you tell me about your cancer journey.' Apart from using verbal and non-verbal encouragers, such as gestures of interest (facial expressions, hand gestures) or vocal gestures ('mmm' or 'oh'), I did not interrupt, allowing each woman to express her life pattern in her own way and reflecting her own priorities. Once she had completed the narrative of her breast cancer journey, I asked focused questions to clarify any aspects where I was unclear or to ensure my understanding was correct. The next open question was regarding their experiences of Spiritual Healing: 'Please can you tell me about your experiences of Spiritual Healing.' This topic was approached in the same way as breast cancer with verbal and non-verbal encouragers, followed by focused clarifying questions where necessary.

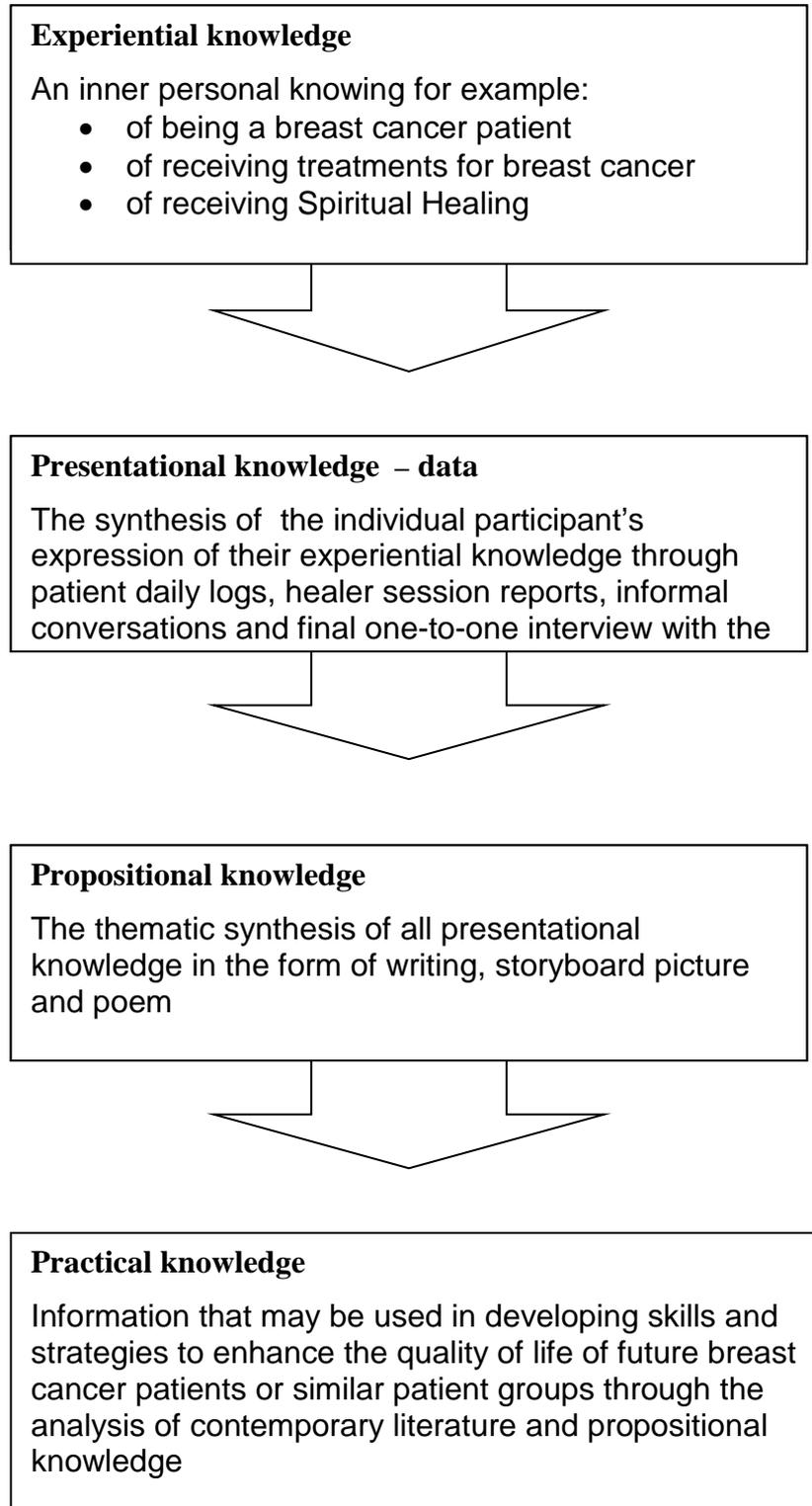
Each of the interviews was transcribed verbatim and is the presentational knowledge of the individual patient participant's experiential knowledge of their lived experiences of breast cancer and Spiritual Healing. Each interview was stored on my password-protected laptop in the form of a digital voice file and a transcribed Word document. A separate CD was made of the interview, which was labelled and stored with other patient participant documentation in a locked filing cabinet. Interviews were deleted from the audio recording device after transcription so that it could be used for subsequent interviews. Because the flower pseudonym was used throughout each interview, the individual's anonymity was preserved. Where other names and locations were referred to, these were anonymised during transcription to protect identities.

5.6 Data analysis

Data for each of the 12 patient participants included 10 healer's session reports; 12 to 15 weeks of daily logs (depending on their actual time on the study); and an audio file and transcription for each one-to-one interview. Data also included my field notes which recorded additional information from my informal conversations with patients and healers, and contextual notes such as events that were outside the study but which might affect the participants or indeed others peripherally connected to the study. An example of this is press or TV coverage of topics related to either breast cancer or Spiritual Healing that could affect the oncologists, the nursing team, the family of participants or any of the participants (healers, patients or researcher).

UAI creates 4 forms of knowledge and Figure 5.3, (p76) shows each form of knowledge and how it was acquired in this study.

Figure 5.3
UAI knowledge of breast cancer and Spiritual Healing



5.6.1 Experiential knowledge

This knowledge form is an inner knowing that is accessible only to the individual concerned, through direct experience and reflection. It is available to others as

presentational knowledge in the form of words, gestures and actions. However, it is recognised that experiential knowing may be modified through processes of learning, reflection and sharing with others. It is possible that an individual may share experiential knowledge in different ways with different people and in different contexts and at different times. Thus, it cannot be assumed that individual presentational knowledge represents ‘the truth’. However, where several individuals report on the sharing of similar experiences, it can be assumed that these serve to cross-validate each other and have stronger ‘truth value’.

5.6.2 Analysis of presentational knowledge

Presentational knowledge is derived from summarised versions of the raw interview, documentary and observational data, first at the level of the individual and second at the level of shared and differentiated experiences within the group. The first stage of analysis consisted of the construction of individual patient participant pattern profiles at the point of joining the study, crafted from their reports of their cancer journey before joining the study. Patient participants were sent a copy of their pattern profile introduction prior to its inclusion in this thesis, together with a pre-paid return envelope, and invited to comment. Thus the pattern profiles were approved or amended by the individual participant and represent how they wish to be seen by the reader. These introductions appear in Chapter 6, providing an insight into the life patterns of the breast cancer patients. They allow the reader to get to know the women and thus aid an understanding of the impact of breast cancer on their life patterns.

The second stage of analysis focused on the construction of profiles of breast cancer and Spiritual Healing, crafted using words and concepts taken directly from individual interviews, daily logs, session reports and field notes. As is the nature of multiple sources of data, patient participant life patterns were not presented in a sequential form but had to be restructured to present experiences of breast cancer and Spiritual Healing in linear time order. In keeping with the tradition of qualitative research, I have, in Chapters 7 and 8, ensured that presentational knowledge is seen to emerge from the data by making extensive use of quotations and rich description to illustrate the patient participant’s experiences. Many of the quotations are taken from the one-to-one interviews, but references to all other

forms of data are included to give as full a picture as possible of individual experiences of breast cancer and Spiritual Healing.

5.6.3 Propositional knowledge

At the next stage of analysis, individual patient participant's life patterns were synthesised to create categories that represent common experiences of breast cancer treatment that had emerged as salient during the cancer journey. The development of categories may seem contrary to the holistic philosophy of UAI methodology but I needed to balance the non-categorical nature of UAI against the requirement to demonstrate shared experiences of breast cancer and Spiritual Healing in a way that would yield meaningful research findings. The strength of the methodology is that it allows the method to be adapted to fit the study and I felt that by forming presentational knowledge of breast cancer and Spiritual Healing into categories of response, I might more easily generate meaningful information for a wide audience within both orthodox and complementary medicine.

Analysis of the presentational data through a process of thematic synthesis produced propositional knowledge. The data was organised into descriptive themes that captured common presentations of patient participant's experiences of Spiritual Healing in the context of the experience of breast cancer. The propositional pattern profiles within the themes are presented in a narrative form through which the patient participants' experiences are woven together to produce an overview of what it is to have breast cancer and Spiritual Healing. The propositional themes were discussed with participants to ensure validity and are presented in Chapter 9.

Propositional knowledge is also represented as a picture, in the form of a storyboard that illustrates a journey through breast cancer and the impact of Spiritual Healing on that journey. The aim of the picture is to give propositional knowledge in a different format, which may be accessible to arenas other than the purely academic. The contents of the storyboard were taken directly from the pattern profiles of the patient participants. It is made up from my artwork, magazine cuttings, internet pictures and words that represent the life patterns of the patient participants before breast cancer, through breast cancer and its treatments, to the experience and impact of Spiritual Healing and their new emerging life patterns. Patient participants were

sent a copy of the poster with a pre-paid return envelope and invited to comment (anonymously if they so wished). Their comments are shown below the picture in Chapter 9.

I created an additional knowledge profile in the form of a poem, to witness the experience of disempowerment I felt, and which I imagined might be felt by family and friends, when confronted with the immensity of breast cancer's impact on the life patterns of the women. The poem was shared with patient participants, healers and non-study associates to verify that it conveyed a message that was accessible. This final profile acknowledges a transformation in my own life pattern as a consequence of participating in the study and immersing myself in data that details, often poignantly, the lived experiences of the patient participants. As with the storyboard, patient healer participants were invited to comment. Patients were sent the poem, with a pre-paid return envelope and invited to comment (anonymously if they so wished) and these are shown below the poem in Chapter 9.

5.6.4 Practical knowledge

Practical knowledge is the final form of knowledge and reflects the conclusions of the study along with recommendations for future research and practice. This knowledge was created by collecting and synthesising the findings with patient participants' expressions of what was good and what was not, during their breast cancer journey and journey through Spiritual Healing. This practical knowledge includes recommendations for possible strategies that could benefit future breast cancer patients and potentially patients in general.

5.7 Methodological rigour

Qualitative research relies heavily on the ability of the researcher to capture and retain the reality of participants' experiences during the process of data collection and analysis. This is particularly important in a study such as this, which is based on a topic that is highly emotive and sensitive to the context in which it is shared. The debate concerning methodological rigour within qualitative research is confounded by its diversity and a lack of consensus (Sandelowski 1993). However, rigour includes the avoidance of selective interpretation of the data and the inclusion of all aspects of the phenomena researched. Pursuing a rigorous approach within this

UAI study required continual reflection on the form of the study and regular communications between myself, the patient participants and the healer participants. I have tried throughout to ensure that the study has not deviated from its aims and that the results reflect the wholeness, uniqueness and essence of the individual and the group. I received monthly academic supervision sessions throughout to ensure I engaged in on-going reflection and the maintenance of research focus. These sessions were challenging since supervisors did not share my background in Reiki and counselling and did not always subscribe to my interpretation of the data. They helped to ensure that the data and participants were always the final arbiters of presentational and propositional knowledge.

Trustworthiness refers to the extent to which the data collection process addresses the intended topic of the research and the analytic and presentation techniques ensure that the findings faithfully represent the data collected. In this study I have endeavoured to demonstrate trustworthiness through the extensive use of quotations from interview transcripts, patient participants' daily logs, healers' session reports and field notes, which captured experiences throughout each stage of the study and enabled me to reflect on the process of the study and participant transformation. Analysis of field notes throughout the study allowed me to see how the study was shaped and re-shaped by the data.

The fact that I was a Reiki Master may have provided a source of bias, both in the way that I interacted with participants and the way that I interpreted the data. In fact none of the participants (patients or healers) was aware that I was a Reiki Master. I withheld this information from patients to avoid any 'researcher pleasing' that might occur from their desire to have healing results that I, as a healer, might want to see. Simply being Fiona, the researcher, allowed the patient participants to feed back any negative experiences of Spiritual Healing or the healer. I withheld the information about my Reiki background from the healers so they would not assume any prior knowledge of Spiritual Healing process and outcomes. Thus the healers explained their healing experiences and the patient participants' responses in detail and in lay terms, assuming I had no prior knowledge.

I attempted to enhance the trustworthiness of the study data through the participatory design in which the participants were continually involved in a reflective process, thus ensuring the focus of the study reflects their lived experiences of breast cancer and Spiritual Healing. The patient introductions, presentational knowledge and propositional knowledge were all subjected to 'member check' on completion, whereby participants validated the results and ensured I had interpreted their data accurately. All patient participants were sent copies of their introduction, the storyboard and the poem together with pre-paid return envelopes and invited to comment. They were able to return their comments anonymously if they so wished.

Chapter 6 is the first of the findings chapters. It presents each of the participants, including myself and the healers, and gives insights into the life patterns of participants at the time of joining the study.

Chapter 6.

Participant pattern profiles

*You know me not...
But entered into being
Like invisible thread
Sown together into the fabric
of my life...
Words that shared a common bond...
Of depths that only few will see.
Yet so profound a mark was left...
To sweeten the life of one...
Who sought to share a part.
Of living in words that tell...
Vickie Yannuzzi (2004). 'Strangers'.*

6.1 Introduction

The purpose of this chapter is to introduce each of the study participants to the reader. Using the concept of life patterns, where each participant is uniquely sculpted by their life experiences, these introductions have been crafted to express each participant's life pattern and experiences in a way that is acceptable to them. This allows them to decide what elements of themselves they wish to share with the reader.

Participation is the cornerstone of UAI (Cowling 2001; 2000) and the following introductions to the patient and healer participants reflect the participatory nature of this UAI study. They also reflect feminist research traditions that allow the voices of women to be heard and not lost in the 'gaze' of scientific research or the academic language of specific disciplines. For me it has been essential throughout the study that the voices of the patient participants are heard and honoured for their unique insights into the life experience of having breast cancer and receiving Spiritual Healing. In accordance with the participatory principles of UAI, each patient introduction was agreed with the individual concerned, while the healer participants and I wrote our own introductions.

I include myself as a participant in a bid to deny a hierarchical status within this study. I debated in what order I should present the individual participants and decided to start with my own introduction because, in a sense, I am the common thread throughout the thesis. I have followed my introduction with the healer

introductions, giving an insight into them as people and also a glimpse of their motivations for becoming healers. The patient participants who are the focus of the study follow. I hope the reader will start to engage with these women and that this will enhance an understanding of the impact of breast cancer and Spiritual Healing on individual life patterns, as described in the forthcoming chapters.

6.2 Researcher participant

Pattern profile for Fiona

In providing my profile it is necessary to recognise that I come to the study with a life pattern which potentially could influence, and be influenced by, the human and environmental energies I encountered throughout the study.

I have a personal interest in breast cancer, which has touched my family on two occasions. My mother died of breast cancer when I was 13 years old, and later my sister-in-law also died of the disease. Despite these two losses, at the start of the study I had little knowledge of breast cancer and its treatments. When I was a child in the 1960s, adults sought to hide such knowledge from me, and later as a sister-in-law I was geographically too far away to be aware of all the day-to-day effects of breast cancer and its treatments.

In the introductory chapter (Chapter 1) I indicated my background as a Reiki Master. I am also a social scientist. Indeed it was during my academic studies in sociology at undergraduate and master's level that I encountered the feminist philosophies that influence my work and my personal tenet. I am an accredited counsellor/psychotherapist working within the Assagiolian paradigm, which has a strong spiritual component.

Although far from naïve regarding the many issues encountered through my work and life experiences, I entered this study with my mind as open as possible to the new experiences and knowledge I would encounter and with a desire to honour all those who took part. I anticipated that my skills as a counsellor to listen and approach other participants with unconditional positive regard would be useful in seeking to understand their life patterns, but this did not prepare me for the personal

transformations that occurred from the start of the study to this moment as I write my introduction.

From the beginning of the study, a member of medical staff in the oncology unit had been involved as a member of the steering group and was supportive throughout the process of gaining approval from the oncology department. At the meeting at which our application was considered, it was clear that one particular doctor had little sympathy with complementary therapies, referring to Spiritual Healing as 'hocus pocus'. But others were more supportive and, having gained the approval of cancer research authorities at national as well as local level, I had not anticipated any significant opposition during recruitment. In the event, I was shocked by the overt opposition I encountered from the doctor concerned. Worse still was the realisation that the support I had initially received from other medical and nursing staff quickly had evaporated in the wake of this hostility. I was totally unprepared for the overt and covert patriarchal and patronising attitudes I was encountering in this first decade of the 21st century. It felt as though a tremendous boulder (of prejudice, professional arrogance and close-mindedness) had been placed on my recruitment road and recruitment unexpectedly became one of the biggest challenges of the study. These attitudes also led me to wonder about the manner in which women patients were treated and I became even more determined to give breast cancer women a place to be heard.

The alternative recruitment strategies I was forced to embrace led me into unknown territories. My encounters with the press, radio and television were new and exciting experiences and I was encouraged by their interest and willingness to cover 'the story'. The Head of Healing at HEHS (Toni) was enthusiastic about the study and always very supportive of me, and that prevented any additional worries regarding slow recruitment and study funding. Indeed Toni agreed to take part in the press and television interviews and they became shared adventures.

The fact that people with breast cancer were willing to self-refer into the study highlighted to me how incredibly giving these women were, prepared to take time to fulfil the requirements of my study with no guarantee that it would help them in any way. I feel a deep desire to ensure they are heard and honoured and that future breast cancer patients' care should benefit from the experiences of these brave

participants. The women whose introductions follow have shared their personal lives and their cancer journey with me, with a trust and affection that have at times left me speechless.

6.3 Healer participants

The healer introductions have been written by the healer participants themselves for inclusion in this document. They include information that each individual healer participant wanted to share as relevant to their participation in this study. The two main healers on the study were Toni and Stephanie, while Tina and Elizabeth covered days when Toni or Stephanie were unable to attend the research unit for the weekly healing sessions.

6.3.1 Pattern profile for Toni

Working in the caring professions is something I consider myself born into. Both my parents worked as psychiatric nurses for over 40 years and the awareness of the needs of others was part my everyday life from an early age. I had my first experience of observing Spiritual Healing at the age of 14 and I was told by the healer that I ‘would be good for this work’. I did not understand and was very sceptical of his words.

I followed in my parents’ footsteps and became a qualified nurse; my field was caring for people with learning disabilities. Over the course of my 26-year nursing career, the subject of healing kept emerging and I found myself fascinated and wanting to know more. I became more aware when caring for people who had limited ability in communication that my colleagues and I were working on an intuitive level. Spiritual Healing appeared to have some explanation for this.

I trained with the National Federation of Spiritual Healing (NFSH) while I was still nursing and many of my colleagues were willing guinea pigs, especially when they gained relief from the common complaints of shoulder and back pain, so prevalent among the nursing profession. This new dimension to my understanding helped me to grow as a person and enhanced my skills in caring for others. In 2003 the opportunity to work as a volunteer healer at the Harry Edwards Healing Sanctuary

came my way and in 2005 this grew into an offer to work full-time in a combined administration and healing role.

I consider myself fortunate and privileged that I have been able to work in occupations that I love. Working as a Spiritual healer has given me the opportunity to expand the way in which I am able to help people of all ages, both in person and from afar. I never cease to be amazed at the effect Spiritual Healing has on people, their families and close relationships, as well as the support and strength they have gained through some of the most difficult periods of their lives.

There is great satisfaction in seeing someone leave the healing room after a session, looking more relaxed, uplifted and sounding more positive in their outlook than when they came in.

6.3.2 Pattern profile for Stephanie

I always felt that growing up as the eldest of a large family in Ireland gave me a modicum of common sense and kept my feet on the ground.

I trained as a Registered Nurse in London in the 1970s, a thoroughly enjoyable period of my young life. Having married a dentist and been active in the dental practice kept me up to date with the world of medicine at some level. Being a dedicated mum to 3 daughters was very rewarding and gratifying. It was also a big part of my identity.

A new world opened to me when I took Reiki courses in 2000. I was intrigued by this new way of being, having come across Reiki through my sister. I opened my eyes and mind to a more rewarding way of life when I started healer training with the NFSH (National Federation of Spiritual Healing).

I now help to run a local NFSH healing centre. I'm also a voluntary healer at a local hospice and at the Harry Edwards Healing Sanctuary in Shere. I continue to feel privileged at the honour bestowed on me by those seeking my services. The time and dedication large numbers of voluntary healers give to the general public is very humbling in this day and age.

I'm always thrilled and delighted to see how well patients respond to healing. It's a pleasure to see how people blossom and improve their quality of life. By extension their families benefit too. The feeling of calm afterwards seems to be universal. In fact, I can honestly say that I've never seen anyone who hasn't benefited from healing in some way, however small. Being aware of that is very satisfying indeed! This role brings a lot of job satisfaction.

6.3.3 Pattern profile for Tina

I have always been interested in alternative treatments. I somehow had a 'knowing' that there must be an alternative treatment in a lot of cases to the conventional route of medication. However, I do accept that alternative treatments work alongside the conventional medical system. My role in this study is that of healer from the Harry Edwards Healing Sanctuary. I have enjoyed being part of this study and I am grateful to Fiona for allowing me the opportunity.

My healing training started back in the middle eighties (1985ish) and I have enjoyed every experience of healing. In 1995 I trained and graduated as a homeopath, which complements my role as healer very nicely. This in turn gave me the ability to treat my clients holistically, but always respecting the medical profession, explaining to my clients that we can work alongside, in harmony, which ultimately creates a perfect healing environment for clients/patients.

6.3.4 Pattern profile for Elizabeth

I am a retired nurse, having trained at Southampton General Hospital. During my nursing career I was privileged to have been asked to help with healthcare in some remote villages in Uganda, which I found very interesting and enjoyable. I first became interested in Spiritual Healing many years ago after my husband had two very unsuccessful knee operations, from which he continued to suffer such severe pain, that he was taking pain killers like a child would eat Smarties. After being referred to the pain clinic and prescribed strong epilepsy medication, he became scared and decided against taking the tablets. So as a last resort he visited a Spiritual Healer and has never looked back since. I was so amazed and realised the power of healing can be beneficial in conjunction with orthodox medicine; therefore I then began my Spiritual Healing journey.

6.4 Patient participants

Here then are the patient participants, based on information that reflects how they wish to be known and introduced in words which they approved. I crafted these introductions from the various data given by the individual women. These profiles reflect the way they chose to present themselves. The narrative is not necessarily linear or coherent, which in some cases serves to illustrate the disruption that breast cancer caused to their life patterns. Each participant was able to change any aspect of their introduction prior to its inclusion in this document and agreed it was an accurate portrayal of their life pattern at the point of joining the study.

6.4.1 Pattern profile for Camellia

I was a sales consultant selling retirement homes. There was a lot of paperwork and follow-up calls as well as showing people around, so I was sitting down for much of the time, which was great. I loved meeting people. I wanted to carry on but I was very, very tired after my radiotherapy, and although I was working only 3 days a week I decided to give up work.

I am a widow; my husband died 12 years ago and I have lived on my own since then. My Dad and brother lived in the ground floor flat of the house. I looked after my father, who was a widower, until he died 2 years ago. I also look after my brother, who has a learning disability.

I have 2 adult daughters and, although they live some distance away, they have been really supportive. They came down to attend important hospital appointments and while I was having the treatments they made sure I had groceries for the week, because I didn't really like going out. They also paid for me to have a colour and style consultation, which really made me feel good after all the cancer treatments. The style consultants tell you what colours and styles are best for you, so I know how to make the best of myself and feel more confident, even though I put on a lot of weight with the chemo!

It has been very busy over the last 2 years and I have had to pace myself. I have been selling my house and getting my brother into a sheltered apartment and finding myself a new home. My new home is called Camellia House, which is why I chose my name for the study. It is a new beginning for me.

I love to visit National Trust properties and gardens and go on coach trips where it is all organised for you, either as days out or even a week away.

(Camellia was aged 63 on joining the study.)

6.4.2 Pattern profile for Daffodil

I am married and have 3 adult children (2 sons and a daughter). I live with my husband, who has been very supportive. I am a care worker for people with mental disabilities and dementia, which is very demanding physically and mentally. Having cancer meant I had to take 9 months off work.

I had breast cancer 18 months before the start of the study. My daughter was with me when I received the diagnosis, which I wish had not happened. I was quite upset before the operation, but I dealt with it all then, so it hasn't bothered me since; I was more afraid of the actual operation than the outcome and now I am just grateful to be alive! I had a mastectomy, chemotherapy and radiotherapy. Some of the treatments were painful and made me feel unwell, but they served a purpose and there is no point in complaining. You just have to get on with it. I am taking hormonal therapies to prevent a recurrence of the cancer.

I wish I had more energy. I used to be fairly active, but since the chemo and radiotherapy I do feel a bit lethargic; most things seem to be an effort and sometimes I feel I can't be bothered. Also since the chemotherapy I have found that chocolate tastes salty; I can still eat sweets and chocolate cake, but I really don't like bars of chocolate any more.

Cancer has made me more aware of my own mortality, especially when I was first diagnosed, and it is still in the background, because there is always a chance that the cancer might come back. Cancer has made me focus on 'living' life, doing things I want to do.

I did not know much about healing before I joined the study, so I had no real expectations.

(Daffodil was aged 56 on joining the study.)

6.4.3 Pattern profile for Foxglove

I worked in chemical engineering for a major oil company. Before my breast cancer I was a bit of a workaholic, but since I have had my treatments for breast cancer I have been off work. I have returned intermittently, but I am struggling with joint pains, so any activity, even holding a book to read, is extremely painful. I also have bad hot flushes, up to 30 a day, so there are times when I am just dripping, which is very unpleasant and embarrassing.

I discovered I had cancer and had the surgery just before my 50th birthday. I'd had a big party planned for ages and I decided to go and enjoy myself; I wore a strappy dress I had already bought for the occasion.

When I was diagnosed I just dealt with it on my own. I nursed my father for 10 years with cancer, so I was used to the subject and it was something in my life. I'd worked in the local hospice as a volunteer, so it was a subject that didn't frighten me. I was a bit blasé about it, but breast cancer has changed my attitude to life and now I am more concerned with the fact I don't have a good quality of life, rather than that I can't quite do my job or my career.

I decided a few years before I was 50 to take up hobbies I had always wanted to do, so I learnt aerobatic flying and was training to perform at air shows all over the place. I also took up surfing, which was great fun. Unfortunately the side-effects of cancer treatments and now Tamoxifen have meant that I cannot fly any more, but I hope one day to get back out on the surf board, even if I have to body-board for a while. I miss my hobbies and the social life of the village where I live.

I take several herbal remedies to help with the side-effects, I don't think it does much good, but I will try anything to get my life back.

(Foxglove was aged 52 on joining the study.)

6.4.4 Pattern profile for Fuchsia

I used to work for a consultant psychologist. It was very interesting work. When I first came out of hospital after surgery I worked from home, but I thought there is more to life than work and I didn't want the pressure of meeting deadlines, so I retired and I think that helped my recovery. This was my second breast cancer. The first was 11 years ago.

I have 3 adult daughters and 1 is living at home for a while, before she goes of to Canada to visit my eldest daughter and her husband. When she goes it will be the first time it is just me and my husband. My husband works from home and has been able to support me through the cancer this time. With my first breast cancer, he worked away and I had the girls, all young then, and it was much harder as I had to keep going and being Mum while he was away; and I didn't want to worry him, so it was tough at times.

When I found out I had breast cancer again it was a shock. I was not as worried about the surgery and treatments the second time because my experiences the first time round were very positive. I was lucky both times that I didn't have to have chemo or radiotherapy, but went straight on to hormonal therapy. I have had several side-effects from the medication and put on nearly 2 stone, which is hard to lose.

Even though I am retired I am still busy running the home and arranging family events; being chief cook and bottle washer! I believe if you don't get on with life, you might as well dig your own grave, so I try to be cheerful and happy.

(Fuchsia was aged 61 on joining the study.)

6.4.5 Pattern profile for Jasmin

I was a bank nurse before I had breast cancer. I used to work nights in intensive care and I loved it, but I had to stop work while I was having the cancer treatments, because I felt so unwell and had no energy. I hope one day to go back to work. It has been a very busy year as I have been selling a flat in London and moving down to Dorset. All the upheavals and traumas of selling, packing up and moving have taken a lot of my energy, physical and mental.

I live with my husband, who has been supportive throughout. It has been difficult for him because he could see how ill I was, especially with the chemo, but he couldn't do anything to make it better.

The diagnosis of breast cancer was a huge shock, and I underestimated the effects of the treatments. It has taken a long time for me to recover from it all. I coped by turning in on myself and concentrating on one day at a time. Cancer has rubbed my nose in my own mortality and I am very aware that time is limited. I used to be busy, busy, busy and always putting things off; now I slow down and 'smell the roses'. I make time for family and friends, and to do things I want to do, now rather than leave it for another day.

Since I had my cancer I have become very involved in working with oncologists and patient forums, to try to improve healthcare provisions for women dealing with cancer. I feel I have a lot to offer, having been through the whole thing myself, and I would like to help others.

(Jasmin was aged 66 on joining the study.)

6.4.6 Pattern profile for Orchid

I am a retired retail worker and I live with my husband who is also retired. We have an adult daughter and grandchildren. My husband has suffered with ill health for the last few years, so I tend to put myself on the back burner. When they discovered I had breast cancer I viewed it a bit like a broken leg: they set a broken leg in plaster. I had a lump inside me that shouldn't be there, so they would take it out and then I would be fine. I tried to carry on exactly as before, looking after everyone, but I found I couldn't, which made me very sad. I can't pick up the grandchildren any more.

I am a very 'tight' person, so nobody really knows what is going on with me, but I worry a bit about my daughter now that cancer is in the family. I have suffered from depression since I was in my 20s and the GP has put me on anti-depressants. It has been a very stressful time recently, which has made me bad-tempered and tearful. My husband has had several operations and we recently moved to our new home.

There have been quite a few things to sort out at home such as the shower, the telephone, new kitchen, etc., so a very stressful time.

(Orchid was aged 62 on joining the study.)

6.4.7 Pattern profile for Paintbrush

I am qualified psychiatric nurse but recently I have been working on a big contract for the national programme for IT for the NHS in London. It is stressful work but I think I cope with it well; I trained how to cope with stress and not internalise it when I was doing my nursing.

When I discovered I had breast cancer my manager was brilliant, very supportive. I just needed some space and work suddenly meant nothing because it just hits you what your priorities are – to survive and deal with your closest relationships. I am back at work now, but some days I work from home.

My husband was a solid rock; he said we'll just get through this. We have 2 adult sons and telling them was really hard, because they had lost their paternal grandmother to cancer. One of our sons is a bit of a rebel; he was doing his PhD and said he wasn't going to the graduation ceremony, but when he heard I had cancer he said he would graduate. So I went to his graduation, all dressed up with my wig, which was hot and itchy; but I looked pretty good and it was a lovely day.

I have read a great deal about cancer and possible causes and I have changed my diet to cut out all the potentially carcinogenic foods as much as possible. So I have cut out all dairy, red meat, even sweet potatoes which I used to love.

I am a member of the United Reform Church and my faith has helped me through all this. My minister was very supportive throughout and gave me a book of prayers when I was in hospital. Every time I had a chemo treatment I used to say a little prayer to help it work and kill the cancer cells.

I am very keen on sport and keep fit, and although I had to stop for a while when the chemo kicked in, I am getting back into running and the gym now. However, the days when I commute to London are very tiring.

I chose the name Paintbrush as it is an American Rocky Mountain flower which is bright and bold red or orange and looks like the bristles of a brush.

(Paintbrush was aged 53 on joining the study.)

6.4.8 Pattern profile for Poppy

I work at a local police station on the front desk, so I am the first person the public sees when they come into the station. It is shift work, which can be tiring. I always wanted to be a policewoman, but my dad didn't approve.

I have 2 adult children. My son lives with his family in Ireland and my daughter lives at home with me. She has been stressed by my breast cancer and was unable to help with my cancer treatments. Luckily I found support from a life-long friend who lives locally and she came on hospital visits, helped with meals and was someone to talk things through with. I do not think I could have managed without my friend. I couldn't believe it when I heard the diagnosis of breast cancer – it was totally unexpected. When I went to the doctor with a lump I thought it was a 'breast mouse', but when the hospital confirmed breast cancer, I needed persuading to stay for all the treatments. At first it seemed like it was happening to someone else. I didn't want all the information they gave me – lump size, etc.

I had a lumpectomy followed by chemotherapy and radiotherapy. The chemotherapy was very hard because I felt so 'horrible'; the drugs 'messed with my brains' and made me feel sick all the time. The radiotherapy burnt me badly.

I cope taking one day at a time; cancer is always in the background now and I know it may return. It has robbed me of my dreams. I retire next summer and I wanted to move away to a bungalow by the coast, but now I can't move too far away from the cancer unit. I am not happy to travel abroad on holiday in case the cancer returns and I need to get to the cancer unit quickly. Every day I am reminded I have had breast cancer. I get bad hot flushes where I am absolutely dripping, which is so

embarrassing, especially at work when I am dealing with the public. I am not sleeping well and have very disturbed nights.

I have had Spiritual Healing before for a joint problem and it helped, but I was not sure it could help with my breast cancer.

(Poppy was aged 63 on joining the study.)

6.4.9 Pattern profile for Rose

I am married with 2 adult children. I live with my husband and worked in the same company as him, doing clerical work. Half way through the study I lost my job and we were worried about my husband's job, so it was a very stressful time.

Fortunately my husband's job was secure and I now work from home as a freelance clerical worker, which I enjoy. I have recently bought a puppy as I can look after him now I am home all the time. He keeps me company and is great fun.

I was on holiday with my husband when I noticed a lump on my breast. I was not particularly concerned as I am prone to lumps, but saw the GP when I got back. There were several visits to the hospital and nearly a month of waiting before the diagnosis of breast cancer was confirmed. This was a difficult period as one minute I was telling the family I was OK, the next I had to tell them I had cancer.

I was given the choice between mastectomy and lumpectomy and chose lumpectomy. After surgery I was offered 6 months' chemotherapy and radiotherapy, but as there was only a 4 per cent benefit from chemo, I decided to have only radiotherapy, which burnt me and made me feel tired.

There is now numbness under my arm, which aches. I am often tired and my sleep pattern changes frequently. I started taking Tamoxifen immediately after surgery and I have up to 20 hot flushes in a day, which gets me down, as each time it reminds me I am taking Tamoxifen for breast cancer. I wish I did not have to take Tamoxifen and could have a break from the menopausal side-effects, but I would never intentionally miss a tablet for fear of cancer returning. I have had several infections since my surgery and have breast oedema, which is uncomfortable but which I am learning to deal with myself.

Cancer has changed me, mentally and physically. It has spoilt my future because I can't plan too far ahead in case the cancer returns. The distress of cancer is like a bereavement – I have lost the certainty of health I had before. Initially cancer was on my mind all the time, the first thing I thought about when I woke up and the last thing I thought of before sleep, but that has lessened over time.

Life goes on and I try to make the best of it. Physically I feel less attractive to my husband; I have put on weight and I am scarred by the usual surgery. I had counselling after surgery to help me cope and I had aromatherapy and reflexology, offered at a local centre, which also helped.

My husband also wants to move forward and not dwell on the past, but there are times when I feel the need to talk and focus on myself. My daughter still finds it difficult to talk about my cancer. I think she is afraid of losing her Mum, so prefers not to think about it. My daughter-in-law has had ovarian cancer, so she and my son were very understanding and supportive as they understood more what I am going through.

(Rose aged was 55 years on joining the study.)

6.4.10 Pattern profile for Snowdrop

I am a PE teacher and I specialise in the trampoline. I train youngsters but I have had to stop work since I had my breast cancer because at school I have to get all my equipment out and I am not strong enough to move the trampoline. Also I am not strong enough to support a gymnast in a harness on the trampoline. I wish I could go back to work because I loved it, but maybe in the future something can be sorted out and I can have some help.

Breast cancer has made me change my priorities. I used to be really house proud, but now if I get the chance to go out with friends I leave the housework, which I would never have done before.

My husband has been affected by my breast cancer. We used to be very close but now he can't come to terms with the cancer and he won't talk about it. He is

working extra hours at work to make up for my wages, so we don't have so much time together. I have 3 adult daughters and 5 grandchildren, 3 of whom are girls. I don't know how they would all cope if I wasn't here because everybody's always leaned on me a bit.

I have joined 2 support groups and my new social circle is very large. I've made some wonderful friends. And because everyone has done it, been there, they are all happy to sit and talk about cancer; there are no taboo subjects, which is great because I don't talk about it at home.

I am doing more than I used to, because there are so many things I want to do – silly things like visiting certain places; going on a hovercraft; going through the Channel Tunnel.

I used to be quite religious but not so much now. I have a lovely relationship with the vicar, who always seemed to know when I was having treatment and would be the first person to phone when I got back from hospital to see how I was. (Snowdrop was aged 53 on joining the study.)

6.4.11 Pattern profile for Sweetpea

I am married and have 2 adult children. I live with my husband and our disabled daughter. My husband retired a few years ago and has been very supportive through both my cancers. I have been a housewife and carer all my married life. I enjoy outings to go shopping, or visiting places and going to the races, but since my second cancer I haven't really felt like doing it.

My breast cancer was discovered at a regular mammogram 4 years ago. Because of the position of the tumour I had to have a mastectomy, followed by Tamoxifen. I decided not to have reconstruction, having seen other women suffer with the surgery. Then a year ago, when I was only 1 year off completing my course of Tamoxifen, I discovered another lump. After several investigations, I was told the breast cancer had spread to my rib and it was inoperable. The news was shattering for me and my husband. It felt like a death sentence. The consultant recommended

extensive radiotherapy, but I had to wait 3 months, which was very stressful. The radiotherapy burnt me to a 'frazzle' and I had to take morphine for the pain. The consultant also prescribed Arimidex, which has given me hot flushes, fatigue, nausea, difficulty sleeping and depression. I have also lost a lot of weight. I am worried in case the cancer recurs and, although my body is healing, it is hard to get it out of my head. When I heard I'd got cancer again I went through all the bank accounts and premium bonds and sorted everything out, so if I died it would be easier for my husband. Since this second diagnosis, cancer has taken over my life; I think about it every day. Every time I get a pain or lump I worry that the cancer has come back.

Spiritual Healing was not something I had considered but I was happy to join the study. I chose my flower name because I had sweetpeas in my wedding bouquet and I have always loved them.

(Sweetpea was aged 64 on joining the study.)

6.4.12 Pattern profile for Violet

I am retired and live with my husband and my elderly mother. I used to run a very busy pub with my husband, but I enjoy being retired. I have an adult daughter and a 5-year-old granddaughter. I have always helped look after my granddaughter and I think if it weren't for her, I might not have had treatment for my breast cancer. I always said if I had cancer I would not have any treatment, having seen friends suffer badly with cancer treatments.

I discovered my breast cancer lump quite by accident. I didn't feel any panic. I didn't tell my husband until late the following day and booked a GP appointment for the day after. The consultant was very nice and not at all pessimistic, which made me feel good. The scan found another lump, which meant that a mastectomy was advised. I wanted a mastectomy anyway to feel that it had all gone. I was not so worried about the loss of a breast as I was about the possible spread of the cancer.

My husband was an absolute brick, not over-emotional but very supportive. My poor mother found it very difficult to cope with; she has always been one who would wish it happened to her rather than me.

I had a course of chemotherapy and I insisted on using the cold cap because I would have been devastated if I had lost my hair through the chemo. It made me feel tired, but I was lucky because I did not feel really ill with it. I was able to do basic everyday things but didn't have the energy for anything else. I used to 'treat' myself to chocolate, etc., while I was having treatment and I put on 2 stones in weight! At the end of the treatments I felt depressed with my weight gain and now I am working at losing it.

The treatments meant I had little contact with my granddaughter for a year, which was a great sadness for me. That year upset me more than anything and left me feeling useless.

I was initially put on Tamoxifen, but later changed to an aromatase inhibitor. I have hot flushes, joint aches and tiredness as side-effects, but it is better to put up with side-effects than in a few years' time have cancer return and have to live with regret.

(Violet was aged 55 joining the study.)

6.4.13 Overview of the patient participants and their treatments

Table 6.1 (p100) shows each patient participant and the treatments they underwent for breast cancer. The treatments were not always described in their introduction, reflecting how they wished to be introduced. However it is necessary to note their treatments as in subsequent chapters the patient participants refer to their experiences of treatment.

Table 6.1**Patient participant treatments**

Name	Surgery – lumpectomy	Surgery – mastectomy	Chemo- therapy	Radio- therapy	Hormonal therapy
<i>Camellia</i>		✓	✓	✓	✓
<i>Daffodil</i>		✓	✓	✓	✓
<i>Foxglove</i>	✓		✓	✓	✓
<i>Fuchsia</i>		✓			✓
<i>Jasmin</i>		✓	✓		✓
<i>Orchid</i>	✓			✓	✓
<i>Paintbrush</i>		✓	✓		✓
<i>Poppy</i>	✓		✓	✓	✓
<i>Rose</i>	✓			✓	✓
<i>Snowdrop</i>		✓*	✓		✓
<i>Sweetpea</i>		✓		✓	✓
<i>Violet</i>		✓	✓		✓
12 women	4	8	8	7	12

* Snowdrop initially had a lumpectomy, but later had to have a mastectomy.

6.5 Summary

This chapter has introduced each of the participants in the study: 1 researcher; 4 healers and 12 patients. Each introduction has been written to allow the reader to ‘get to know’ the participants’ unique life patterns and to contextualise the information given in the subsequent chapters. Introducing the patient participants here enables the reader to see for themselves how the experiences of breast cancer have impacted in their individual life patterns. Chapter 7 is a presentation of patient participants’ experiences of their breast cancer journeys, while Chapter 8 presents the experience of Spiritual Healing.

Chapter 7.

Presentational knowledge 1.

Pattern manifestations: breast cancer diagnosis and treatments

'It stops you realising your dreams.'

Poppy.

7.1 Introduction

This chapter gives presentational knowledge of breast cancer, constructed from patient interview data, as described in Chapter 5 and shown in Figure 5.3. The patient participants all experienced breast cancer and its treatments in a personal and intimate way. They presented intimate, experiential knowing in the form of interview narratives, thus their experiential knowledge was translated, through reflection, into presentational knowledge; the external expression of an intimate, internal knowing.

What follows are the pattern manifestations that allow the reader to accompany participants on a breast cancer journey. Details of each individual journey are set within the context of each individual life story and were not always presented in time order at interview. However, for the sake of coherence, I have chosen to present the cancer journey in a linear form, following the diagnosis and treatments for breast cancer in the chronological order in which they actually occur. The emergent data are compared to contemporary literature and quotations are used throughout to exemplify each step of the journey.

Although the participants in this study included myself and the healers as well as the healees, this chapter refers specifically to the cancer journey. Therefore, the terms 'participants' and 'women' are used throughout to refer to the patient participants.

7.2 Pattern profiles: discovery and diagnosis

Diagnosis is the moment of forced life-pattern change, when a woman must change from the usual pattern of her life to address potentially life-threatening breast cancer. This moment of pattern change is not a gradual or selected life change; it is

a dramatic, unexpected change, forced upon women by their disease and the medical responses to it, and from which there is no return. As the women talked of discovering a lump either at a regular mammogram or through self-examination, they all remembered the exact day and date when they were told they had breast cancer. The date of the diagnosis marked a change point, at which the previous life pattern was lost and the women became 'breast cancer patients', as Fuchsia explains:

I sort of went from one day being fit and healthy to the next day being a wreck. Um, well, withering wreck, because I'd been told I had cancer.

Iwamitsu et al. (2005) noted that when presented with the diagnosis many women are shocked and upset and this was true for all the patient participants, although the terror and panic noted by Payne et al. (1996) was not apparent. Diagnosis was a 'huge shock' and there was no time to prepare or adjust to the diagnosis, as Jasmin explains:

I was there at 1.30 and I think by 5 o'clock I knew that I had cancer, which came as a huge kind of shock, and I suppose one's first reaction is, well, shock and disbelief, um, and really it's something you've got to think about, it's not something that you've actually kind of catered for.

Breast cancer is a well-known disease and the women in this study had a preconceived profile of the risk factors for developing breast cancer. These align with the government statistics regarding breast cancer risk factors that show links to a woman's reproductive history; the use of oral contraceptives and/or hormone replacement therapy; obesity and drinking alcohol (Office for National Statistics 2009). Most participants also looked for possible inherited or genetic causes, searching back through their close female family members to see if any had previously had breast cancer. None of the patient participants felt they fitted their profile of a breast cancer patient and they could not understand how they had 'got' breast cancer. Paintbrush and Camellia exemplify these feelings:

How could this happen to me (!) and people who knew me, who know me, and friends, they say I can't believe of all people, you! You know, why you... shouldn't happen to you, as if there's, you know, a sort of criterion. And if you look at the risk factors of people for breast cancer, I haven't got any of them. You know, my children are a decent age, I breast fed, there's no family history, you know, genetic thing going on, um, I just don't fit the picture. So, you know, trying to come to terms with it was... was really quite something, plus I'd never ever had any real physical ...serious physical problem, you know, before – medical sort of problem I just never had. Paintbrush

We've never had breast cancer in the family; that's why I was so surprised to get it. If you've got it in the family you sometimes think, 'Oh well, it is my turn' sort of thing, but I think that's why I was very surprised' cos we're not, sort of, what I call a cancer family, you know. It's not known in our family to have cancer so that was a surprise. Camellia

To Jasmin it never occurred that she could have breast cancer, based on her knowledge of the profile of a breast cancer patient, so her discovery of a lump had not been a priority when she visited her GP:

I discovered a lump, quite by accident, and went to see my GP for a totally different reason. Really I didn't consider the fact that I had cancer or could have cancer, I didn't think it could be me: a) I haven't got enough breast and b) you know, no, not me and I feel perfectly okay, absolutely fine. So I happened to mention it as a kind of 'Oh by the way' and before I knew where I was, I was in [hospital] and was rushed through this diagnostic interview and I was told that I had cancer...which came a huge shock.

For Fuchsia and Sweetpea this was their second breast cancer diagnosis, but this in no way made the diagnosis more 'understandable', as they explain:

I was fit and well – there was no reason for it, as there was no real reason for the second time round. Fuchsia

Because I didn't really go into any of the factors, when they say 'Oh, you're obese' or all this sort of thing, is, er, all things for breast cancer, um, I didn't sort of have any of them, except the stress. I don't know if the stress was sort of, you know...and I do tend to, I didn't smoke, I mean I've never drunk in my life, we're completely teetotal in this family...I've never ever had a cigarette so I mean you couldn't say anything like that was done...it was out of the blue, you know, completely unexpected. Sweetpea

This lack of understanding about why the individual should have breast cancer reflects a desire to make meaning of their diagnosis, concurring with McGrath (2004). While hearing the actual diagnosis was a shock, many also expressed a sense of 'knowing' once the diagnostic process had started. This was accompanied by a sense of dread, as Foxglove exemplifies:

I was called in for just a routine scan because it was a breast scan; proper title is, 'cos I was coming up to 50. And, um, they found a problem...I knew...I have a second sense. I know I have a sixth sense or something and there's often things I know and absolutely the evening before I was talking to a friend and just...I just knew what it was. I just knew that I'd got breast cancer.

Several women on the study had previously found benign cysts and did not expect 'this lump' to be anything more. Yet the process of diagnostic testing and the

language and non-verbal communications of the nursing staff made them think it would be a positive diagnosis of breast cancer this time, as Paintbrush exemplifies:

When they did the biopsy they actually did 2, which I thought, 'Whoa!' You know, they were really concerned about this one. Um, and it was...the person who did the biopsy said, 'How long will it be before you see Mr M [consultant oncologist]?' And that was the comment that really made me, you know, think, 'Ah! This isn't just a benign cyst; this is...the real thing.'

In line with contemporary research findings (Bertero and Wilmoth 2007; Kroenke et al. 2004; McGrath 2004; Ferrell et al.1999) it was apparent that, following the diagnosis of breast cancer, life's certainties are lost and existential issues come to the fore. After the initial shock, participants reflected on their mortality and there was a fearful new awareness of how uncertain life can be. Many had not thought about their death before this point, but the diagnosis and possibly fatal outcome of cancer brought this into their immediate consciousness, as Paintbrush expresses:

It's, it's a death sentence. You immediately think, you know, 'Wow, just like that!'

For others there was a growing awareness of breast cancer's threat to their lives.

Daffodil and Jasmin speak of their own mortality:

Suppose it just made me more aware of my own mortality. I mean, we all know we're going to die, but when you first know that you've got cancer, you think, 'Oh well, I might die, you know, kill me!' Daffodil

I think it's certainly rubbed my nose in my own mortality. Well, quite frankly you wonder whether you're going to be around next year or not, you really have no idea. Jasmin

Most were accompanied to the diagnostic interview by their husbands, daughters or a long-standing friend. All the participants found it difficult and emotionally taxing to tell their close family of their diagnosis. Daffodil exemplifies:

They [adult children] were very upset obviously. But, um, they were fine and I just said, 'Well, just 'cos I've got cancer doesn't mean I'm going to die. It's hopefully small and they'll get rid of it and then I'll be all right again.' But, um, my husband was really, he said, 'I wish it was me that had it, not you,' which was nice.

Some of the women knew of family or friends who had previously suffered or died from cancer and this made imparting the news of their diagnosis more difficult, as

Paintbrush explains:

I found it really hard to tell my boys. They lost their paternal grandmother to breast cancer and, you know, and they were quite young at the time, but they, you know, it's still a memory of, so that was really hard; it was really hard to tell my mother; those three were the hardest. Meanwhile, my husband was like a solid rock,

he has been from day one, just, you know' We'll get through this, you'll be all right.'

Current evidence indicates that 33 per cent of breast cancer patients reported little or no disclosure to some of their social network (Payne et al. 1996). Of women who choose not to disclose, 33 per cent wanted to keep their disease a secret and 33 per cent found it difficult to talk about their cancer (Henderson et al. 2002). Indeed, many of the women in this study reflected this desire to choose whom to tell, and most did not want to tell anyone except close family as they were unsure of how such information would be received or how they would handle the responses. Violet and Jasmin explain:

He's [husband] very considerate, you know, he doesn't sort of brush over it as though nothing's happening but he doesn't make a fuss, you know – I didn't want a fuss. So she [mother] was really, it really did knock her, I think. Well, in fact, when I'd told her we went to a barbecue and she just cracked while we were there and started crying out, 'My daughter's got cancer,' and there's all these people that I didn't know that were stood around. What do we say now? Oops!! Violet

The only reason I have not told some people about it is because I don't think they would have coped with it very well. And, um, you know, why upset them unnecessarily? Because I think there was a certain amount of guilt, um, getting cancer in the first place. You know, I'm doing this to other people. It was a big thing actually, it's something, it upsets so many people and it was me doing it. Um, you know, I just felt very sorry for them. I think I...yes...I think that was also something I...I...one tried to, you know, console them. Say, 'Look it's going to be okay.' Jasmin

The overarching responses to diagnosis of breast cancer were shock and fear, and these were expressed by all the participants. A review of literature regarding breast cancer diagnosis reveals that fear (Bertero and Wilmoth 2007; Gonzalez and Lengacher 2007; Carlsson et al. 2005) and shock are common responses (Iwamitsu et al. 2005). However, other emotions such as sadness, despair, rage, terror, panic (Payne et al. 1996) and vulnerability (McWilliam et al. 2000) were less common responses at diagnosis in this study. All the participants expressed sadness at having breast cancer, though this was not apparent at the diagnosis stage. None expressed anger or rage at their diagnosis; there was more an attitude of 'getting on with it' and deference to the medical experts who started to take control.

Despair at diagnosis was described only by Sweetpea, for whom this was a second diagnosis of cancer. She recalls that it was almost *unbearable* and she suffered from depression as a result:

The second time it really, it really got to me and now I think it's harder in my head than what it is in my body.

In summary, the discovery and diagnosis of breast cancer is unexpected and life-changing. Women are changed in an instant from healthy woman to breast cancer patient, with no warning and no time to prepare. Fear (fear of cancer; fear of the unknown; fear of death), which is to become a constant companion, is born the day of diagnosis and seems to permeate every aspect of daily life thereafter.

7.3 Pattern profiles: surgery

The first medical response to their breast cancer was to instigate surgery to remove the tumour and possibly selected lymph nodes. Surgery is a first step on a 'conveyor belt' of medical interventions that follow a cancer diagnosis. While contemporary literature indicated that the gap between diagnosis and treatment could be several stress-filled weeks (Seagrov and Halding 2004), all the participants commented on the speed with which their surgery was arranged (often within a fortnight of diagnosis). For Paintbrush it was even faster:

I had private insurance. Mr D[consultant] could do the surgery 4 days later.

Participants remembered the exact date of their surgery, which was the date when they physically became a breast cancer patient. Eight women had mastectomies and 4 had lumpectomies. There did not appear to be any differences in their view of the surgery based on the surgery type and all of the women had to confront their fears linked to the surgery itself and the physical mutilation resulting from it.

Research evidence indicates that fear of cancer is greater than the fear of losing a breast (Fallowfield et al. 1990) and for some in this study this was true. The desire to 'get rid of it' (Jasmin) meant that in their view there was really only one surgery choice and that was a mastectomy. For others the desire for minimal surgical intervention meant they chose to have a lumpectomy, as Rose exemplifies:

I had a lumpectomy; I was, I was able to have either a mastectomy with reconstruction straight away, or I could have a lumpectomy. And it was my choice. And, um, I'd thought if ever I was to live with that diagnosis I'd immediately plump for mastectomy, but if I didn't have to have it, I decided I didn't want it. I'd go for the lumpectomy with radiotherapy afterwards. So, that's what happened...

While some research indicates that patients involved in decision-making suffer less anxiety and depression (Mickan and Askew 2006; Fallowfield et al. 1990), other

research found that the choice of lumpectomy or mastectomy added another layer of anxiety (Gattellari et al. 2001; Payne et al. 1996). Participants who chose a lumpectomy did question whether they had made the right long-term choice. The implications of a poor surgical choice are at worst life-threatening or at best will require rectification by further surgery. For some the surgical decision (mastectomy or lumpectomy) was influenced by family and friends, as Snowdrop exemplifies:

They [the family] weren't prepared. They said that it was up to me, it was my cancer and I should decide what I thought was best. But I knew that they wanted me to do that, just from what they were saying, so that's what I done [lumpectomy].

Others simply agreed to whatever the oncologist recommended. As Paintbrush explains, consent to her mastectomy was a formality:

You're really at the mercy of the hospital; you know, you don't, yes, you, you want to be informed and make decisions, but frankly, hey, whatever you want to do to me, just do it. You know, just do whatever to help me survive. You know, you didn't think there was a lot of choice involved there.

Fuchsia, when discussing her second mastectomy, joked that she would be 'more balanced' and 'smaller-breasted':

The second time round I thought, 'Oh great, I'm going to be balanced. I'll have two equally weighted boobs. I can choose my size!' I'd been a D/E cup, so I was quite heavy-breasted and suddenly I thought i could go to a B, you know. Felt quite excited about it.

Yet underneath the joking and bravado there was a deep sense of loss, which at interview brought Fuschia to tears: 'Loosing your breast is like a bereavement...and its you.'

Commonly participants were discharged from hospital 24 hours after surgery, still connected to draining tubes, and this left them feeling anxious and very alone. The diagnosis and surgery move so fast that the implications of the change to previous life patterns are not fully comprehended, but returning home to the familiar in a changed state appears to register the new status of 'breast cancer patient'. It seems to highlight the fragility of their body and their subjugation to the potentially life-saving medical processes. Violet and Poppy exemplify this:

I had my op, um, last day of July last year and stayed in just overnight, which I thought was a bit panicky, but it was just an overnight stop and you come out with the drain and everything for 5 days; and you've got the drain – they tell you to take a belt in and they put, they give you this sort of hessian sort of bag that your drain goes into. So you come home, walk home with that. Violet

When I first came out of hospital and I came through the door, I was still connected to the tubes; I wanted to run and hide all the time, I didn't feel able to sort of join in. I...but that was me, I just didn't want to; I just wanted to run and hide. Poppy
It is during this period that the extent of surgery is actually apparent. While the removal of a breast is discussed during the diagnosis phase, once a woman returns home, the full impact of living scarred or without a breast forces new unwelcome life patterns. Violet exemplifies:

I did tell her [granddaughter]; I was totally open with her. 'Cos when she stays here she always likes to have a bath with me, so of course she saw the bruising from the biopsies. So, because I'd been there at least 5 days a week, sometimes 7 days a week, I didn't want her to think that someone was sort of running out on her. So, um, oh dear [tearful pause]. So I thought it was better to be open with her, so I told her, you know, I said, 'Nanny's got this bruised booby', and I said, 'Well, it's poorly and I'm going to have it removed.' 'Well, when will you get a new one?' So I said, 'Well, I don't know. I might not.' So, but of course now, and she was very good and she was, when she'd come and visit she'd say, 'I'll sit this side [non surgical side], then I won't hurt you,' you know. Bless her, she is lovely. I mean, I know I'm biased but, but she says, 'I do wish you would have a bath with me.' But I won't because I think she might be fine at the time but it might play on her mind afterwards. Yeah, terrific sadness.

7.3.1 Reconstructive surgery

Participants who had mastectomies were offered reconstruction either at the time of their initial surgery or once the initial treatments have been completed. None of the women decided to have reconstruction at the time of initial surgery. It appears to be difficult to make a decision regarding future body shape, when the main focus for patients is getting rid of the cancer. Paintbrush expresses this:

All you want to do is, you know, rip the cancer out of your body. You know, you start having images: 'I think I'll just go and get a sharp knife, get rid of it now.' You know, you just can't stand knowing that that's in there, you know, growing, and, you know, they describe the cancer – um, it was a grade 3, aggressive, um, at that point, so it's probably in your lymph nodes, so be prepared for that...so an awful lot of potential in there bubbling away and, you know, you just feel like you've got this horrible hot thing, you know, growing like mad inside you.

Previous research indicated that less than 20 per cent of patients eligible for reconstruction have the procedure (Harmer 2006). None of our participants had reconstruction at the time of their initial surgery, but all re-addressed reconstruction once their initial treatments were complete. Only Snowdrop decided to undergo further surgical procedures for reconstruction and breast matching. Most made the decision not to pursue reconstruction; frequently the decision was based on their age, as Fuchsia and Sweetpea exemplify:

No, I decided not to. I mean, I thought about it, but then I thought, 'Look, I'm 50.' We both said, 'Do I really want to go through another operation, and Mr M [consultant] explained it to me and I thought, 'Mm, no, no, it's not worth it, you know, it's not necessary.' Um, and so I didn't bother. Fuschia

I could have had, well, I mean he did say at one time reconstruction, but I thought, 'No.' 'Cos I'm not, I mean, I'm 63, I don't really worry about that sort of thing and I'm not that well-endowed anyway, so it didn't really worry me, you know [Laughter]. Sweetpea

Another factor which influenced the decision not to have reconstructive surgery was minimising the number of medical interventions as Paintbrush and Camellia exemplify:

Frankly my view of reconstruction is that it's, um, mutilation: why take muscle out of your back and plonk it on your front.? Um, I, I think back muscles have enough to contend with without messing with them. Um, and the other thing is that, I, I don't know, it's not like I've ever been real proud of my breasts – they've always been small, you know; I remember as a teenager thinking, 'When are they going to grow?' [laughter]. Never happened! And I, you know, so, it's not like I've got this one huge one, its, um, needs a mate, a matching mate. I don't know, I, and I guess I'm one for doing, you know, do as little as necessary in terms of interven...you know, intervening from a medical point of view, even though my other, my breasts have never been that big, so the one I still have is somewhat small; you do have a sense of it's, it's missing its partner, you do have that sense of loss. But to me it's one I can cope with. I...I...I wouldn't, would never put myself for reconstruction. Paintbrush

I have thought about it but it's quite a long operation, about 4 hours, and at my age – I think if I was younger I would have opted for it, but, um, I don't think it's really worth it at my age, you know. I've had so many other ops and I've got lots of other problems and, um, I don't really see the sense in putting yourself through it really. There's one part of me says, 'Yes, I'd like it' and another half says, 'No you don't' [laughter]. Camellia

The decision not to have reconstruction seems to have been revisited several times in the period since initial surgery. This study observation concurs with contemporary research which indicated that the loss of a part of the body that is rich in social meaning, both sexual and nurturing (Harmer 2006), has an impact on a woman's perception of her sexual desirability (Bertero and Wilmoth 2007) and on intimate relationships (Huber et al. 2006; Engel et al. 2003; Hartz et al. 2003). Thus the views of a participant's husband or partner appear to influence the on-going decision-making regarding reconstruction, as Violet exemplifies when she explains her decision not to pursue reconstruction:

I think someone sort of telling you that, you know, you're no different because you've had this done. I, in fact I asked my husband last week, you know, would he

prefer me to have a reconstruction, and he said you know, it's entirely up to me. And I've heard different stories about that and I don't think it's for me. I'm quite happy as I am. If I was younger, then fair enough, but I'm not going to be lying on a beach in a bikini any more. So it's not important, but then it's down to the individual, isn't it?

7.3.2 Post-surgery intimate relationships

For some patients, and their partners the changes in their sexual and intimate relationships can be significant and life-altering (Engel et al. 2003; Kneece 2003; Rowland et al. 2000). Indeed, for Snowdrop dissatisfaction with her body and a loss of sexual intimacy informed her decision to pursue reconstructive surgery and other procedures to match her breasts:

The reconstruction was completely for me. And then we got to the state of the reduction, because the reduc...this side[reconstructed breast] wasn't as big as my side[natural breast] and I sort of said to my husband, 'What do you feel about this?' you know...

For Rose there was also a feeling of being less sexually attractive as a result of her lumpectomy, but she and her husband learnt to adjust to her different body shape:

I don't feel sexually attractive any more really. I just feel, with clothes on, yeah fine, and I've made more of an, made even more of an effort to try and look nice, um, and keep myself looking nice. I'm not saying I've been mutilated, but I just don't look, it doesn't look the same as the other one, let's put it that way. Um, felt a bit sorry for it actually! [laughter]. Um, I mean it's affected, obviously it's affected my sex life 'cos I can't bear my husband touch it; he's only allowed to touch one now and he knows. You know, and immediately that's a barrier, straight away. You know, but it's getting better, it's getting better and we'd laugh about it, try and laugh about it a bit. 'Oh, not allowed to touch that.' 'Well, no, not yet,' sort of thing.

7.3.3 Post-surgery oedema

Rose has also had to learn to manage her breast oedema resulting from the removal of lymph nodes during surgery. Only limited help was available through the NHS and private support is expensive. Rose's experience concurs with contemporary research that indicates most women have to learn to self-manage their oedema (Jeffs 2006).

7.3.4 Post-surgery shape

For some women just finding a comfortable bra was difficult because of the change in their physical shape, as Fuchsia explains:

Mind you, I didn't realise how long it was going to take me to find a bra that was comfortable. Oh, it's been a terrible problem because I had two different

consultants: Mr P did the first one and I'm not sure who did the second one – it was another doctor. And he, the second one, used a different technique. Um, oh yes, I mean, I'm completely odd; I've got all this fat, this, I think they call it like a dog tag or something, and consequently every bra I put on, it all rolls, they roll up. It's not so bad now I've lost weight. I must say, that has improved. Um, and I had a hell of a job – I went through 20 bras. I used to come home and say, 'I think I've got one...I think I've got one,' and then find, you know, that it wasn't any good or some such.

7.3.5 Post-surgery results

Initial surgery is followed by a period of waiting to hear if the surgeon has managed to get a clear margin around the tumour and if it has spread to the lymph nodes.

This was a time of great stress and uncertainty for all the participants, as exemplified by Jasmin and Violet:

I came in on the 9th of May and I had a right mastectomy. All went well; the usual kind of, you know, problems or discomfort and whatever but nothing too special. Um, I think the most difficult time of my life was the time between the mastectomy and the interview, um, with the surgeon when he gave me the result and told me what cancer I'd got, what type and all that, so I knew at that stage, um, where I was and what was going on. Jasmin

I was obviously anxious because it's fear of the unknown and...the actual breast didn't worry me but it was if it had spread. I was more anxious about any of the lymph nodes results of that biopsy than those in the breast. Violet

The outcome of surgery may reveal the need for further surgery, which can be distressing and stressful, particularly with limited information or support. Snowdrop had to undergo a mastectomy, after her initial choice of a lumpectomy.

It was all 'if this, if that', but after the lumpectomy in the safe area they took the tumour and the safe area, there were little multiple tumours, and immediately, I mean, we'd never, the consultant never talked about mastectomy – it was always, 'After this we might have to take a few more lymph nodes but that will be it.' And then radiotherapy. And then it just all changed after that. It's like, you know, you don't need radiotherapy now but you do need chemotherapy and you do need mastectomy. You know, you just...and they don't tell you anything. They really don't tell anything more than you need to know, which I found really hard 'cos once I got diagnosed my brain just wanted as much information as I could get.

7.4 Pattern profiles: radiotherapy

Eight of the women had radiotherapy. In an era when there is growing awareness and fear of carcinogenic exposure to radiation, participants had to expose themselves to repeated concentrated doses of radiation. The side-effects are less well-known than those of chemotherapy and in some cases not fully explained to

the patients. The side-effect of burning caused patients extreme pain and distress, as Sweetpea exemplifies:

I had the extensive radiotherapy in which I was totally burnt like a frazzle. I had never been so burnt in all my life. I spent Easter crying my eyes out and I had to go up the hospital every day for dressings because it just, and it was just like a, well it was like a piece of raw meat, it was terrible. I mean, people had told me that it would be and Mr Q [consultant] said, 'Well, if I'd have told you before what I intended to do, you might never have gone through with it [radiotherapy].'

During treatment the burns caused great pain and discomfort and for Camellia waiting for them to heal meant that she stayed at home. She could not wear anything that would touch the burnt area as she was advised by the nurses 'to let the air get to the burns' to help them heal:

I just lost all my skin. Went down to the nurses at the surgery and they dressed it with burns dressing but, um, because it had got so bad the only thing that they said really it's got to, you know, got to leave it open for the air to get to it, so I sat for about 3 days at home with nothing on it and, but every, it started to dry over, every time you moved it cracked, so it was horrible. But after that, after about 3 days, it wasn't so bad but it, as I say, it was difficult because it sort of cracked quite a bit.

For some, the discomfort from radiotherapy burns continues to this day. Paintbrush explains, 'the radiotherapy made my chest wall so sore and I'm still dealing with that soreness.' All the women who had radiotherapy must be careful when exposing their skin to sun, which means that on holiday they have to cover up more than before they had cancer. Rose exemplifies:

I no longer feel at ease sunbathing and have to be so careful now. This makes me sad, anxious all the time. Feel fat and unattractive a lot of time (Log: Week 1. Saturday 04/08/07).

Throughout the immediate treatment phase of breast cancer, the participants spoke of living a day at a time, moving from one hospital appointment to the next, coping with the side-effects of treatments moment by moment. Poppy and Foxglove exemplify:

Definitely a day at a time. I mean, specially when, because of the chemo, I then had a haematoma in my leg. Oh dear! Of all the things to happen. Poppy

During the radiotherapy I think, with having to go to the hospital every day, everything got worse and I really started to struggle. Foxglove

7.5 Pattern profiles: chemotherapy

For most of our participants, a course of chemotherapy followed surgery, although for some there was a choice whether to have chemotherapy or not (based on their

tumour size and the surgical outcome). For women who have no evidence of cancer spread, chemotherapy can be an adjuvant therapy. Jasmin and Rose were given the choice. Jasmin chose to have chemotherapy to ‘cover all the options’ in her fight against breast cancer:

I decided to go for the chemotherapy, and as I'd had a mastectomy I didn't need radiotherapy, so that was a bonus. And that's when I started on my 6 months of, um, chemotherapy. It was a grade 2 cancer and it hadn't actually gone into the nodes as far as they could see, so I was actually given the option, did I want to have chemotherapy. Um, they never forced me, they didn't say, 'You don't have to have it' but they said, 'Do you want to have it' and if I had decided no, um, I was perfectly happy, I think they would have said, 'Well, it's up to you entirely.' But my feeling was, once I'd come to terms with it, that I didn't want to end up in a position where I would say later on, 'If only I had done this or if only I had done that.' And so I just wanted to cover all my options, so I wanted to have the chemotherapy. Not knowing what it would feel like and, ha ha, I might actually have thought twice about it if I, if I realised just how tough the whole process was and it was very tough physically as well.

For Rose the statistics showed little benefit, and with her fear of the side-effects she decided not to have chemotherapy:

They told me that he'd managed to get clear margins round the tumour, got all of it out. But then he said to me, the next course of action was, because it was a grade 3 tumour, normally ladies like myself then had 6 months' chemotherapy and I absolutely freaked out. I was really upset about that 'cos nobody had even mentioned that. I had to wait and see the oncologist. He spoke to me about all the statistics that he'd actually put into the computer and all the data had come out, um, and I would only benefit 4 per cent over the next 10 years if I had chemotherapy and he basically said that anything over 10 per cent then he would, he couldn't recommend, he couldn't tell me what to do, he couldn't recommend, it's my choice, but anything over 10 per cent yeah, go for it, normally. It was up to you, um, you've got to outweigh the benefits with nasty side-effects, i.e. losing your hair, being sick and any sort of like internal sort of long-term damage – liver or whatever. Um, and then I thought to myself, well, if I haven't got to have it, I don't want it.

Concurring with Gattellari et al. (2001), the choice of whether to have chemotherapy or not adds another layer of anxiety for women as they take responsibility for making the ‘right’ decision, knowing the potentially negative long-term implications of a wrong decision (the recurrence of cancer). Most participants followed a recommended course of chemotherapy. The chemotherapy treatment programme can last several months. It has many unpleasant side-effects most commonly nausea; hair loss; joint aches; tiredness and ‘chemobrain’. Side-effects were dreaded and dealing with them became the focus of daily life, exemplified by Paintbrush:

Um, it's poison. You know?, I can remember the very first treatment I had, I was just scared witless. They give you all the literature on all the side-effects and it's, it's a carcinogen. So we're going to treat your cancer with a carcinogen! Okay?! [laughter]. And these are the things we really need to watch for because it's, you know, it can put you physically in quite a dangerous state very quickly and, you know, you need to keep a thermometer handy and, you know, all these things you have to watch and do. And so I was petrified really. And you don't, you know, you don't know how you're going to react, you know, they give you this pile of pills to take for nausea, so you imagine being like really, really nauseous and sick with it and, oh, and, so you take all the pills they give you, you know, you have the treatment. It's cold and it burns and I got back to the car and I had to come home and go to bed. And that, you know, that's when it was really starting to hit, 'cos the first, the day they give it to you, it's not, you don't feel that bad. Doesn't hit you till the day after all of a sudden and the worst day is 2 days after having received the treatment...almost flu-like but you just...you just start to lose your energy and just start to feel like you're going to collapse; flu-ish is the best way I know how to describe it. You don't want to eat, um, and interestingly enough, I mean I...I really, I really struggled to eat, I just didn't want to eat.

7.5.1 Side-effects of chemotherapy

Coping with the side-effects of treatment was, for many, a personal battle that husbands and friends could only stand by and watch, unable to assist, as Jasmin exemplifies:

I think I might have actually been quite selfish during the time of my treatment because I really think that I did concentrate very much on myself and I think I was trying to hold it together, because when you're not feeling well, when you're feeling awful, you know, you...you haven't really got that much more to give to other people. You turn in. And I think it's a natural defence maybe that, you know, and I'll think about it when it's all over or I'll cope with it when it's, when it's all over, but yes, you do need to concentrate on yourself. I think in many ways I've felt incredibly sorry for my husband because he was helpless and all he could see was what was going on and say, 'What can I do to help?' and there's nothing you can do, nothing. You know. 'Why are you crying'? Because I feel so awful. 'Well, what can I do?' Nothing. And, you know, that in itself is hurtful, if you say, well nothing, you know, they want to help and they can't.

7.5.2 Hair loss

Loss of hair is a common side-effect of chemotherapy (Ferrell et al. 1999). All but one of the participants who had chemotherapy lost their hair; for some it was a dreaded side-effect, for others there was a pragmatic acceptance. Several prepared for the loss by cutting their hair very short prior to chemotherapy and many talked of the distress of finding clumps of hair on their pillow. Few were aware of using the cold cap as a way possibly to save their hair; indeed, use of the cold cap was not encouraged by the oncologists, as Paintbrush exemplifies:

Dr B [oncologist] said you could wear the caps if you wanted and he said, 'Well, even if you wear a cap there's no guarantee you're going to keep your hair and what happens a lot of times is that people who use the caps end up with bald spots.' I'm thinking, well, a cap's going to look worse than being bald completely and also he explained, you've got to...you spend a lot longer in the hospital: you've got to go in and put this thing on, it's got to chill down, it takes an hour to chill down and then you've got to leave it on for hours after the treatment, so you're in there for, like, I don't know how many hours. Every time you have a treatment.

The set-up of the cold-cap equipment not only adds to the appointment time for a patient receiving chemotherapy but also adds to the work of the nurses. The use of the cold cap is not encouraged by the nurses, possibly for that reason. Snowdrop illustrates how her concerns about losing her hair were not acknowledged by nursing staff:

I wanted to use the cold cap so I could save my hair and the nurse said to me, 'Your hair is quite fine and thin; it won't save it.' She said, 'It'll put 3.5 hours on your chemo and it won't save it [hair].' She said, 'I can tell you now, she said, with this chemo your hair will fall out on day so-and-so and so-and-so,' and it did.

While the use of the cold cap adds considerably to the hospital appointment time, Violet insisted on using the cold cap. She and her husband would take flasks of coffee and sandwiches to the hospital when she had her chemotherapy. Violet reflects:

I was also fortunate with my chemo because I didn't lose my hair. I used the cold cap. They don't push it, they don't really recommend it. They tell you about it but they don't really sell it to you. But I thought it was worth a go because, to me, to lose my hair would have been very devastating and I'd lost a bit, it thinned and this is starting to grow. I lost it sort of round the hair line, but I really – when they say damp it down, I really soaked it and it was dripping, and when they took it off after the 4 hours it was solid ice. But I felt I didn't care, as long as, you know, if it worked. My husband came with me and he'd bring a flask of coffee; although there's coffee making there, he used to bring a flask and sandwiches, 'cos it's, you wear like, you know, like when jockeys go out training, they wear like a leather, it's like that...and it's inside, it's just a mass of, like, a network of water tubes and it's fixed to a cooling thing which takes it down to minus 6, so it is cold!

While the loss of head hair is a well-known side-effect of chemotherapy, the loss of all body hair, brittle nails and in some cases tooth and gum problems were not expected, as Snowdrop exemplifies:

It took 3 days and it was the worst 3 days of my life. It was horrible and it's not just your hair, it's your eyebrows, your eyelashes, everything. I mean, it was wonderful I didn't have to shave my legs or under my arms or anything like that (!), but everything and then even in your nose, and then because there's no hair there's nothing to keep the snot there or anything, so your nose is constantly dripping and

dripping and, and it's silly little things. And my fingernails were hell, my teeth. Oh, my teeth were hell, yeah.

7.5.3 'Chemobrain'

Most of those who had chemotherapy described how they suffered from a loss of mental agility (termed 'chemobrain'), a side-effect that for 15 per cent of breast cancer patients can continue for several years after treatment (Gross 2007). While they acknowledged forgetfulness and loss of a mental edge, only Poppy talked of a coping strategy. At work Poppy frequently asked associates for information that she simply could not recall.

The chemo was horrible. And the drugs they give you to go with it, to stop the sickness, messed with my brains and I couldn't remember a thing. I...it was silly things I couldn't remember. And I was tired and it was all these other things it kept doing and then I felt sick and, oh dear, it was awful.

7.5.4 Daily life with chemotherapy

Chemotherapy lasts between 3 and 6 months as an adjuvant therapy but may be longer for more advanced cancer. Managing their health and managing hospital appointments, consultations and treatments was a full-time occupation which impacted on patients as much as their physical well-being. Participants described the seemingly unending and repetitive nature of the chemotherapy as wearing and dominating daily life. Jasmin exemplifies:

It's tough, um, because it, one feels so awful and it's the repetitiveness of, um, you go for treatment and you start this downhill and then you finally come up for air and you are starting to feel better and you go for your next [chemotherapy].

7.6 Pattern profiles: hormonal therapy

Once the initial tranche of treatments is complete, patients with oestrogen-sensitive tumours (i.e. 75 per cent of post-menopausal patients and 50 – 60 per cent pre-menopausal patients; Breast Cancer Care 2003) are prescribed adjuvant hormonal therapy. Adjuvant hormonal therapies are taken for 5 years and have been shown to reduce the annual breast cancer death rate by 31 per cent (Moore 2007; Smith and Chua 2006). An inclusion criterion for this study was that patients must be taking hormonal therapy to prevent a recurrence of their breast cancer, which means that all of our participants had oestrogen-sensitive breast cancer and were taking either Tamoxifen or Arimidex.

7.6.1 Breast cancer clinic appointments

Once prescribed hormonal therapy, participants had to attend a breast cancer clinic only once every 6 months initially, and then annually after that. Moving from a routine of regular daily or weekly hospital contact to a 6-monthly and then yearly consultations caused feelings of aloneness and anxiety, as Paintbrush exemplifies:

After all the treatments are all done and they're basically saying 'goodbye', you know, I was told at my 6-month check up in October, 'We don't want to see you for a year' and you do feel like you're really out there on your own. I mean, that's great news, its fantastic news, they don't want to see you, but it's a long time.

Jasmin also expressed the 'on your own' feeling after the initial treatment regimes:

I think there is a bit of a gap after the intensity of treatment and a period of time and then you are very much on your own.

7.6.2 Side-effects

Tamoxifen and Arimidex have several unpleasant side-effects. The combination of chemotherapy and hormonal treatments are known to create menopausal symptoms in younger women and exasperate the symptoms of menopausal women (Gross 2007). The physical impact of hormonal therapy commonly includes hot flushes, joint aches, tiredness, nausea and night sweats. For some women these side-effects are manageable (Breast Cancer Care 2008; Ganz 2001) and decline over time, but for 33 per cent of women distressing side-effects are still present 2 years after treatment (Fallowfield 2005; Ganz 2001). Inclusion criteria for this study stated that patients would have been taking hormonal therapy for at least 6 months (thus allowing for any possible natural decline in side-effects) and currently be suffering from at least one unwanted side-effect. All the women suffered more than one unpleasant side-effect.

None was prepared for the side-effects of their hormonal therapy. Indeed, they had not been informed of all the potential side-effects of hormonal therapies, as Fuchsia and Jasmin exemplify:

No, I had no inkling whatsoever, nobody has ever said to me, either with Tamoxifen or Anastrozole, that you could have these side-effects, or this could happen. And the only time I've ever seen side-effects was on the list that you get on the print-out with your pills, with your medication. Fuchsia

I wasn't prepared for the side-effects of Arimidex, um, and it certainly took my body a long time to get used to it. And I wouldn't say that I'm now symptom-free

anyway, but certainly to start off with I...I'd, it was pretty horrific. Um, I could barely get out of bed, I, my joints ached, it really was very, very uncomfortable. Apart from the joint pain I think the other side-effect that really was very unpleasant was the hot flushes. Jasmin

It is apparent that over time the side-effects become physically, mentally and spiritually wearing and the 5-year minimum treatment period can seem to be almost unending. Most were counting how much longer they had to take their hormonal therapy. Jasmin exemplifies;

I think things like that do wear you down; um, however strong you are or you know it's for your own good, um, it's still pretty tough because you get very tired of it all. So it's been, yah, it's been quite a time getting used to it, but I think I'm there and I've got to take it for another 3½ years, I think, now, so...

7.6.3 Hot flushes

While 33 per cent of women are reported to experience hot flushes after 2 years on hormonal therapies (Fallowfield 2005), all of our participants complained of having hot flushes. Poppy described a hot-flush experience as '*lobster red, sweating hot flushes, water pouring down my face*' (Session report 2. 27/07/07). She explained that such hot flushes were both uncomfortable and very embarrassing if noticed by friends or work colleagues (Field notes 27/07/07). For many of the women in this study the hot flushes were very frequent throughout the day:

It wasn't just one or two [hot flushes] but it was continuous, um, all day through, all night through. Um, as many as 20, 30 a day easily, so that really was also unpleasant. Jasmin

These were frequently accompanied by night sweats, causing disturbed sleep and tiredness the following day. Snowdrop exemplifies:

I was waking up. I mean, to start off with on the Tamoxifen, we would change the bed. I'd have to get up and change the bed, it would be that wet!

7.6.4 Joint aches

All participants experienced joint aches, a well-documented side-effect of hormonal therapy (Burnstein and Winer 2007) that prevented them from doing many of their usual everyday activities, re-enforcing their new status as a breast cancer patient.

7.6.5 Nausea

The side-effect of nausea was not as common as joint aches or hot flushes, but several women found it difficult to cope with, as Camellia exemplifies:

Yeah, I did try Tamoxifen for a month or so, but it made me feel sick all the time, just had this nausea feeling all the time. I just couldn't get my head round it all the time; it was just making me feel horrible.

Camellia was able to change from Tamoxifen to Arimidex and the nausea subsided.

7.6.6 Weight gain

After the effects of surgery, chemotherapy and radiotherapy there was another unwanted body change as several participants put on weight, which they found difficult to lose. Rose exemplifies:

I mean, I think Tamoxifen has made me put on weight, although not on the scales necessarily but clothes are tighter and this round here [midriff], and also the same when I'm sort of like with no clothes on...

For some the weight gain was a reaction to their medication and also, not knowing how much longer they would live, some gave themselves 'treats', as Fuchsia explains:

I know I put on, ooh. Nearly 2 stone when I went on to the Tamoxifen but was it because I thought, 'Oh, I'm not going to be here next year – oh, I'll have another drink; oh, I might eat chocolate, I might, you know, oh I'll have some more chocolate.' I, you know, whether it was that, so it's psychological or whether it was the Tamoxifen, I don't know, but having spoken to women since who have also put on weight, I think maybe it was the Tamoxifen but of course once you've put it on you don't lose it!... When I went on the Anastrozol I didn't have that problem. I seem to have stabilised and, um, although I, I never lost the weight, um.

7.6.7 Living with hormonal therapies

Results from this study concur with the finding of Payne et al. (1996) that the regular taking of Tamoxifen or Arimidex acts as a constant reminder of the threat of cancer's return, as Rose exemplifies:

Hot flushes remind me of having had cancer as they were due to me taking Tamoxifen and not just the menopause as it would normally be. And then immediately you think, 'Why am I taking Tamoxifen? Because I've had cancer,' and so it was a knock-on effect. I mean, my sister's having hot flushes as well – she's 5 years older than me. And she is, it's really getting her down, she's gone back on HRT and I think, 'Ooh, lucky for you,' you know – I can't even take that if I wanted to. And I'm having to deal, and the thought of not being over that period, you know, and not having so many hot flushes or night sweats or mood swings and this sort of thing, um, you know, would normally be over probably by now, but I know they're

not going to be because I'm going to be taking drugs for the next 4 years and that's sort of, like, that cheeses me off a bit.

Foxglove suffered from many side-effects including severe joint aches, hot flushes, night sweats, exhaustion and weight gain and finding them difficult to cope with she asked her consultant how long the side-effects would last. She was told between 5 and 7 years by a consultant who suggested she should 'get used to it' (Consenting interview 16/03/07). Foxglove expanded her experiences of trying to talk to medical staff at our final interview. She explained how she would select the member of the oncology team she would see for her appointment at the breast cancer clinic:

Dr Y and Dr Z, they weren't interested. But there were 3 doctors that I could [talk to]. The Registrar didn't really care; in the end I used to wait until the end of the thing or rang to make sure I got certain doctors. Or I'd refuse and say 'If it's Doctor Y I don't want to see her.' Some were a little more helpful but some aren't; some will just tell you, 'You'll get better in 1 – 10 years. I just can't tell you when it will be and there's nothing else we can do.'

The lack of support from hospital doctors regarding the side-effects of treatment was expressed by several participants, as Violet exemplifies:

You don't like to complain. When you say you have this or that side-effect they look at you as if to say, 'You don't have cancer any more,' and you feel as though you are being ungrateful mentioning it. It's like you don't like to bother the oncologist with 'trivia' – they are busy people. (Consenting interview 28/08/07)

As Foxglove and Violet's experiences exemplify, this study's findings concur with contemporary research that highlights patient concerns about hurried, limited or insensitive consultations (Gross 2007; Shukla and Pal 2004; Wyatt et al. 1999) and the focus of allopathic medicine on the disease, ignoring the mental, emotional and spiritual realities of the patient (McIllmurray et al. 2001; Geffen 2000). Indeed, many participants turned to the breast cancer help line, the clinic nurses or fellow patients for help and advice.

Yet for Sweetpea there was a reassurance in the side-effects; it meant that the medication was 'working':

I do get hot flushes, not terrible ones, but in a way I'm quite pleased, because when I had the Tamoxifen I didn't have any effects at all. When my friend – you make friends when you have it done – she lives quite near me, she had the same thing and she had Taxoxifen and she was suffering terribly with it. And I kept thinking, 'Well, I wonder if it's working for me?' because I didn't have any of the effects. I kept thinking, 'Well, I hope it's working, you know, I hope it's working.' And now I've got some side-effects with Arimidex in one way I think, 'Well, yeah, it is working.'

Despite the unpleasant side-effects none admitted taking a drug 'holiday', which is contrary to research that found the discontinuance rate for Tamoxifen is 2 per cent after 1 year rising to 35 per cent after 3.5 years (Thomas et al. 2007). Previous research has reported that 13 per cent of patients admit to taking a drug holiday and 50 per cent admit to 'forgetting' to take their tablets (Fallowfield et al. 2005); the figures for non-compliance are even higher for Arimidex, with only 69 per cent of women adhering to their treatment regime (Ziller et al. 2009). In this study, fear of the recurrence of their cancer tended to over-ride everything else and adherence to their hormonal therapy drug regime was claimed, as Violet exemplifies:

I could do without the side-effects!! But, yes, if it does, stops it coming back, then I should be more than pleased. I don't think you can mess about like that. I'd sooner put up with what I've got than go through that again 'cos, I mean, it could be worse next time. I feel very lucky that, you know, it hasn't spread and, you know, not worth it, is it? It's no good living to regret not taking it... Violet

However, Rose did recall one time when she forgot to take her Tamoxifen. The tablet was 'lost' in her dressing-gown pocket and she discovered it the next day. It was not intentionally missed.

I'd be frightened to stop taking them. I would be frightened to death. In fact I freaked out the other day: I didn't take one, I found it the next morning, I didn't take it and it was in my pocket and that worried me, it did worry. So, no, I would not be tempted to stop taking them. Rose

Although several wished they could have a break from the side-effects, only one, Snowdrop, had seriously considered taking a drug holiday:

Yeah, I have thought about it [drug holiday] lots of times. And then it's just like, yeah, I've got this far, I've got to keep going. Another 3½ I think. Yeah, it is 3½ years.

Many described a daily ritual they have to ensure they take their tablets every day. Sweetpea and Paintbrush exemplify:

I wouldn't dream of missing it. I mean, it's in my, I take it every dinner time and, you know, they all say to me, 'One o'clock Mum.' I say, 'Yes, I know, I've done it.' I wouldn't dream of missing it. Because to my mind that's what, you know, that's my lifeline. Sweetpea

I have a little ritual to make sure I don't forget to take it and also I then know that I have taken it. Because the cancer was an aggressive grade 3 oestrogen-positive, to me it's very important to take them to knock out any oestrogen in my system.
Paintbrush

The fear of recurrence causes many women to conceptualise themselves as ‘still at risk’ and not as survivors (Bertero and Wilmoth 2007; Saegrov and Halding 2004). Indeed, the idea that the hormonal therapy will stop and it would be necessary to continue living without its ‘protection’ can be a cause for concern, as Camellia exemplifies:

I think I'm going to feel quite frightened at the end of 5 years with not having anything. I suppose that's my shield against it [breast cancer] at the moment, that's how I feel about it, you know, so I'm going to feel a bit strange when 5 years comes and they'll say, you know, 'We're stopping it now.'

7.7 Long-term pattern profiles of breast cancer and its treatments

While many patients achieve long-term survival, there is an awareness of their vulnerability and a fear of cancer's recurrence (Saegrov and Halding 2004; Fredette 1995). Cancer is a constant companion; it is part of everyday life and sculpts new life patterns for all the participants. Rose explains:

I say, it's a big, big impact on my life, let's put it that way. And I don't think that will ever go away now. Oh yeah, I said even though the cancer has gone, people still speak and treat you like you still have it. Um, you'll always be a cancer patient to the medical profession, I think – well, it doesn't help you trying to move on really, does it? It's a, it's a weird, it's weird...

Patient participants lived with uncertainty regarding the quality or quantity of future life, and the physical effects of treatment act as a continual reminder that they have had breast cancer. Snowdrop and Fuchsia exemplify:

I don't know how these people can walk away from hospital and just have their treatment, go back and just carry on as normal, because it does affect your whole life. I think, yes, I think it does go through your mind every day, you know. I think I'm always grateful when I wake up and I think, 'Ooh, I'm alive again today. I'll enjoy today and worry about tomorrow, tomorrow.' So, yeah, it must go through my head every day. Snowdrop

It's there all the time. You know, at the back of your mind. It's, it's, you never really sort of completely forget it. And obviously I know that I haven't got any breasts [Crying]. That does bother me a bit but, um, but, um, so you know, you are aware of it all the time. Fuchsia

There is a sense of loss, as old life patterns have been forcibly replaced by new, cancer-sculpted life patterns. Rose exemplifies:

It's a mental thing to come to terms with and I think, sort of, like, it's affected me like that and I'm very preoccupied still about it. But I mean, I have, I've been told, you know, that will lessen. But, um, it's like, it is like a bereavement, that's the only way I can describe it to somebody who doesn't know – when they say that, and they're right, it is like a bereavement. Um, 'cos it is, um, you've lost what you had

before and it's coming to terms with that and trying to sort of, like, get on like you do when you've lost somebody.

Contemporary research shows that having cancer makes women aware of the many things in their lives they are not ready to give up and things they have not done (Bertero and Wilmoth 2007; Saegrov and Halting 2004) and this new awareness is exemplified by Snowdrop:

I think now I tend to do more than I did before because there's so many little things that I've never done that I want to do. Silly little things like visiting places. I mean, I've never been on the hovercraft, just silly little things that, yeah, we're going to go over to, I want to do the Tunnel, so that's on my list this year. No...um...I think my leisure time is more important; I used to worry about housework and things like that and I don't any more. It's more important to go out and enjoy the children and all those things...And it's just like, you know, some...like yesterday, M and B[riends] came round and said, 'Shall we go down the owl sanctuary?' Yeah, why not? You know, does it matter that I haven't hovered? No, it doesn't. You see, before I would have said, 'No, I can't, because I haven't done the hoovering yet.' So from that point of view I can leave the unim...what I think now are unimportant things.

This reprioritising, caused by a revaluing of time as precious and limited, means that many participants no longer have the patience to deal with 'trivia' and are more aware of 'spending' time, as Jasmin and Foxglove exemplify:

I think before I was diagnosed with cancer I was always busy, busy, busy, and I'll have time for this tomorrow and I'll come and see you next...next week or, no, maybe next year; I just haven't got time just now. Now, I am much more relaxed from that point of view and I say, 'Well, you know, I haven't got eternal life. Let's get on with it and do it.' So I think, yes, I have changed, um, in that respect. I think I, I'm, I'm more aware of, of my own mortality. Not that it bothers me in any kind of way, but, um, I think I appreciate that one's time here is limited, not necessarily because of cancer, but I'll make the most of it. So, yeah, yeah, I think it has had an effect on me and I think maybe for the better because it's actually managed to slow me down and, and smell the roses. Jasmin

It has changed my attitude to life. Completely changed me. I'm not the same person at all. Even if I got all my energy back I would never be the same person. I'd be spending all my time or energy on quality of life, I'm sure. I'd probably be surfing and too tired to go to work! [laughter]. So, yes, I've got a very different view. Foxglove

Some participants made diet and lifestyle changes, avoiding foods or substances that are deemed carcinogenic and increasing foods that are claimed to help prevent breast cancer, as Sweetpea and Paintbrush exemplify:

I'm a little bit, if I read of anything that they say is good for breast cancer, like, you know, eating broccoli and all that, I'm a little bit like that, I do try to tend to take it up. Because I didn't really go into any of the factors [preconceived risk factors],

when they say, 'Oh, you're obese,' or all this sort of thing, is, er, all things for breast cancer. Sweetpea

[Oestrogen], one of the main reasons for not ever having dairy products again, I also limit. I don't use soya products – they're a phyto-oestrogen. I know some of my favourite foods such as sweet potatoes have a high level, so I don't have them very often. So, you know, even though your body will produce them naturally anyway, the only other thing would maybe be other lifestyle changes. I mentioned the diet; the other thing I think is important is trying to reduce your exposure to toxins in chemicals, so I, you know, use friendlier types of detergents for cleaning, and eat organic as much as possible. Paintbrush

All of the women lost the desire to plan too far ahead or to realise previous plans, as Rose and Poppy exemplify:

Well, it changed me. It's changed me, yeah. I don't feel, I don't feel the same person as I was. Um, it's difficult to put into words, um, but, um, I feel it's spoilt my future. I can't think about, um – when I think of the future I can't think too far ahead because I don't know if it's going to re-occur. Um, so therefore, I think that's a shame 'cos, I mean, everybody likes to sort of plan ahead and I will say to...you know, I can't sort of; like, think that far ahead, I don't like, it's scary to think too far ahead. Also, um, I don't know, um, it's difficult to put into words. Rose

Poppy planned to retire to a bungalow in Weston-Super-Mare, but for her the possible return of cancer has prevented her from moving away from the town where the breast cancer unit is located. It has also affected her holidaying.

I've always wanted to go to a beach somewhere but now I have to think in terms of: have they got a cancer unit near there? Just in case it comes back. I've always been able to get up and travel at a minute's notice. I mean, that again, you can't get up and travel now. I mean, I won't pay, I can't see paying extra-high insurance premiums, so therefore I'm curtailed in where I can go 'cos I've got to be home at sort of more or less a minute's notice or be able to get home within 2 to 3 hours just in case. So, well, in case it comes back. Say I notice it's come back when I'm abroad: I've got to be able to get on a flight and get home. And get help fairly quickly. Whereas I couldn't do that if I did a long-distance haul and I wouldn't want to pay the higher insurance premiums. Poppy

For single women, the physical scarring can mean they no longer feel complete, perceiving themselves as damaged goods. According to Payne et al. (1996) this saps confidence, limits horizons and may prevent the establishment of new relationships. There were only two single women in this study. Poppy did not discuss any desire to form a new relationship whereas Camellia expressed concerns about her ability to do so.

I think because I've lost my right breast and everything I don't feel – that's upset me a lot actually. Um, sometimes I think I'd like to go out and meet somebody but I

don't feel I can because I don't think I'm right, if you know what I mean. Yeah, I just don't feel as if I'm a whole person if you know what I mean. Um, that has upset me a lot actually but, um, I try to put it at the back of my mind a lot, um, because otherwise I think I would get upset about it.

The time taken by cancer and its treatments meant many normal activities were suspended and opportunities missed, and participants expressed their regrets for such losses. Violet's inability to support her daughter and spend time with her granddaughter was one of the greatest sadnesses of her breast cancer:

I didn't look after [granddaughter] for a whole year. She went to a full-time nursery, which did her a lot of good, but I did miss her. I am the sort of person who – I like to be needed. So although sometimes it gets too much, I felt useless for that year. That would upset me more than anything that I couldn't see her [granddaughter] so much, but I wasn't physically able to get in the car and go over and do [daughter's] ironing or whatever, you know, whereas I like to do that 'cos I like to surprise people with, you know, like her coming in on a cold wet night and thinking, 'Oh God, I've got to do the ironing' and she comes home and I've done it. Something like that: I get a lot of pleasure out of that. Although she tells, she will sometimes tell me off, sort of say, 'Oh, I would have done that when I got home.' Well, now you can have some quality time with [granddaughter] because, I know all mums work today, but I think they dip out.

The joint aches experienced by many of the women had a great impact on their life pattern. Many were unable to continue paid employment and work around the home had to be left or given to others. Previously enjoyed hobbies were all set aside.

Despite good intentions to resume old life-pattern activities, the cancer treatments and the side-effects of treatment often prevented it. Sweetpea and Foxglove exemplify:

I'd get up in the morning and I'd think, 'Oh yeah, we'll do so and so today; we'd do so and so today,' and by about this time I'd be, you know, I'd sort of be, like this, and they'd say, 'Well, are we going out or not, and I just couldn't, you know, I could not go out. I never went out in the evening. We never went out for – I had it done about last October; we never went out all summer. Sweetpea

I went back to work intermittently, I was off work, at work, off work, at work, and during that time I was really crippled with joint pain; walking, anything, sitting, lying down was painful. Reading a book, I had to – I couldn't hold the book; I could hardly write or use the computer. It was very painful, so everything I did was extremely painful. Um, I had quite severe hot flushes and tiredness and I was starting to feel like giving up actually [laughter]. And I was very desperate.
Foxglove

There is often a longing for the old life pattern. This does not necessarily mean old activities but can mean simply an old way of being that is familiar and comfortable, as Sweetpea explains:

I used to think to myself, you know, when you're all right you think, 'Oh, what we going[to do]?' – you know, bit boring, not doing anything. And when I was ill I thought, 'Oh, I'd love to go back to those times where I used to think, "Oh, what are we going to do?"' you know, boring. Just to know that you're all right because – that's what I, that really is what I look forward to being, just normal, you know, just, just normal again... 'cos my life compared to a lot is boring, compared to people that flit off here and there and can do that, 'cos obviously we've got to consider. But I love that, you know, I just loved it and I thought, 'Oh, wish I could go back...'

Many want to talk to their family about their on-going life as a breast cancer patient, yet such discussions are often discouraged because the family wants to forget their loved one's life-threatening cancer. A resulting sadness was reflected by Rose:

My daughter, doesn't like to keep talking about it, doesn't like to keep thinking about it. I think it's sort of like, um, 'Well, you're okay now and we don't want to keep talking about that, do we?' because she thought she was going to lose her Mum so, you know, initially, so she doesn't want to. I'm not going to [die], as far as she knows; she thinks everything's all right now. Um, you know, we don't want to keep dwelling on that, do we? So, no, I don't, I try not to talk to her or sort of refer to it with her. My husband, either way, sometimes, I did feel that he didn't want to, um, talk about it, keep talking about it 'cos at some point you've got to move on, as far as they're all concerned, it's all gone, you know, and it's sorted and so we leave that behind and we get on. It isn't quite as easy as that for me; I do still need support. My husband definitely obviously realises now that, you know, I do need to talk about it at certain times, so, and he says, 'Well, you can,' but at some point he's worried it's going to completely dominate my life and if we're not careful it'll be his and he says it's not, he doesn't think that's healthy, you know, and no it's not.

The physical and mental changes that result from breast cancer and its treatment have an effect on their relationships. Research shows that while 42 per cent of couples feel closer, in 6 per cent one or other of them feels distanced (Dorval et al. 2005). Sexual dysfunction, which has emotional and physical roots (Huber et al. 2006) is common in breast cancer patients (Hartz et al. 2003). Snowdrop experienced a loss of intimacy and so for her the effects of cancer have brought great sadness:

My husband and I have been affected. He won't even talk about cancer. He won't even look at me any more, which is difficult. I am waiting for him to come to terms with, you know, how it's changed me really. 'Cos I've had to come to terms with it, so he's going to have to. I can't make him. He has to do that himself. He [husband] just works now to cover my wages, he just works and then sleeps when he's at home. Buries his head in the sand. Completely. [It's] hard.[tearful] Because he's not, I mean, before he used to be like a partner, you know – we'd do things, we'd share things; now I'm physically making him. It's like I will book a few days here or a few days there, just to get his company basically, otherwise he'd just stay at work all the time. He does love me still but just not in the same way.

Snowdrop sought help and advice from the breast cancer nurse regarding the loss of intimacy in her marriage. This was a difficult topic for many participants and Snowdrop had to 'steel' herself to broach the subject. Unfortunately the only advice Snowdrop received was a suggestion that she get some '*sexy underwear and make the first move*'. This concurs with Horndern's (2000) findings that healthcare professionals fail satisfactorily to address issues related to sexual intimacy.

While the expressions of love and support are positive, uncertainty dominated participants' life patterns. The fragility of life focused attention on relationships and brought a greater awareness of being loved, as Camellia and Jasmin exemplify:

I think I am closer to them [daughters] than perhaps I was before, in a way, although I still felt as if I was close to them then, but I think we're more close now...until I had this I didn't realise how much they loved me, if you know what I mean. Camellia

But it was an incredible experience generally because of the outpouring of love and, you know, I don't think one realised just how, how, how loved one was until something like this happens when people actually, you know, verbalise maybe what they have been thinking or subconsciously; they actually come out with it, so I think that is positive. Um, yeah, I would say that's a positive thing that has come out of it. Jasmin

7.8 Coping patterns

It was possible to recognise two of the three coping strategies described by Gonzalez and Lengacher (2007, Chapter 3, 3.3). A majority of the women in this study adopted active coping strategies, actively seeking out information and being involved in their treatment decision making. It may be that this is what led them to volunteer to participate in this study. However, two participants (Sweetpea and Orchid) had adopted a passive response, deferring to their surgeon and oncologist for treatment decisions. Both of these participants were suffering from depression and this may in some way account for their response. None appeared to have adopted an emotional avoidance strategy.

7.9 Conclusion: the breast cancer journey

Breast cancer diagnosis and treatments occurred some time before the patient participants entered this study. Most of the quotations in this section are from their one-to-one interview with me and, as such, represent their experiences 'from a distance'. This distance has allowed patient participants a reflective period to assess

how they experienced breast cancer and its treatments and how their life patterns have been changed by it. This chapter has shown both similarities and differences in the journey through breast cancer, reflecting many of the issues identified in contemporary literature.

Perhaps the most poignant quote that seems to capture an important commonality of the long-term experience of breast cancer and its treatments in this study comes from Poppy as she summed up the impact of breast cancer on her life:

'It stops you realising your dreams...'

The medical journey through diagnosis, surgery, chemotherapy, radiotherapy and hormonal therapies seemed to be a well-worn path, trodden by many women before, which each patient participant had to follow. It emerged for these women as a new direction, a path strewn with information, mis-information, fear and anguish; a path that took them away from their normal life patterns into a life moderated by hospital appointments, physical suffering and pain, and a loss of sovereignty over their bodies. This path led into a tunnel of treatments that closed around them and the women had to leave aspects of their old way of life (work, hobbies and pastimes) at the path side. Thus the tunnel stripped away parts of their previous identity and they become a 'patient'.

The pattern profiles illustrate how the cancer journey causes emotional suffering as it cuts through normal family relationships and responsibilities, denying peace of mind and surety of destination. The cancer path leads these participants through initial treatments and up to 5 years of hormonal therapies. Many experience ongoing difficulties and pain from their treatments, which prevent them from attaining restoration, resilience and wholeness. They live with chronic uncertainty and unmet existential and spiritual needs.

The women in this study received Spiritual Healing as a complementary therapy during their hormonal treatment, to see if it would assist them at this stage of their cancer journey. However, it must be remembered that the women who volunteered to take part in this study are not necessarily representative of the population of breast cancer patients, but were a self-selected group who actively sought help for unpleasant treatment side-effects (according the inclusion criteria). The following chapter looks at the next part of the women's journey through Spiritual Healing.

Chapter 8.

Presentation knowledge 2. Pattern manifestations: Spiritual Healing

'It is only when it gets better that you realise how bad it was!'

Foxglove.

8.1 Introduction

The breast cancer journey for the women in our study was interrupted by Spiritual Healing, but was it changed in any way? While the preceding chapter provided the context for the experience of Spiritual Healing, this chapter records the patient participants' presentation of their experiences of Spiritual Healing as another stage in their cancer journey. This chapter was constructed from using all study data as described in Chapter 5 and shown in Figure 5.3(p76).

In the preceding chapter the women's experiences of breast cancer used exemplars for each aspect of their experience that were drawn mainly from their one-to-one interviews with me. The experiences of Spiritual Healing within this chapter are drawn from the day-by-day experiences recorded in the patients' logs; the weekly session reports from the healers; my own field notes and in the women's reflections at their one-to-one interview with me. Thus some manifestations of the Spiritual Healing journey were recorded at the time of the experience and are therefore more 'raw' and 'of the moment', in contrast to the more distant, reflective and polished presentations of the breast cancer journey.

As in the preceding chapter all data from the one-to-one interviews are attributed to the individual participant and additional data are referenced according to their source. To preserve narrative coherence, patient participants are usually referred to as either 'participants' or 'women' and the healer participants as 'healers'.

Many of the participants had used Complementary and Alternative Medicine (CAM) to relieve the side-effects of their cancer treatments, concurring with contemporary findings of widespread use of CAM among cancer patients (Shukla and Pal 2004; Shapiro and Safer 2002). Although purchased analgesics were used to help with joint pains, self-prescribed CAM herbs and vitamins were frequently used by the women for other side-effects. None had used or considered using Spiritual

Healing for their breast cancer or treatment side-effects, although 3 (Camellia, Poppy and Paintbrush) had experienced Spiritual Healing previously. Indeed, none of the women had thought of Spiritual Healing as a CAM therapy.

8.2 Pattern profiles: joining the study

Because of recruitment difficulties, most of the women referred themselves on to the study. Even though most were not convinced that it would be of any benefit, they felt they had 'nothing to lose'. Foxglove, who was suffering from almost continuous hot flushes (up to 30+ a day), disabling joint aches, night sweats, exhaustion and weight gain, all of which she was finding difficult to cope with, joked at her consenting interview: *'If I get a cup of tea, a lie down and a good moan each week that will be good. Anything else will be a bonus!'* (Field notes 16/03/07). Foxglove reflected at her final interview: *'I was desperate, I didn't think it'd work, I really didn't...'*

There is no mention of expectations regarding Spiritual Healing in any of the patients' logs in the lead-up to their first healing session. At interview nearly all express an open-mindedness at the start. Yet most were sceptical that something totally non-invasive could be of any help to them, as expressed by Orchid, Sweetpea and Rose:

I'll be honest, I was very sceptical. Because I didn't see how, in my picture, that anybody waving their hands over me was going to make the symptoms disappear. Orchid

I mean, I didn't go with the thinking, oh, you know, 'That's going to be great,' or anything like that. I mean, I just went with a complete open mind, you know, and I thought, 'No, well, I've got nothing to lose, you know, really by doing it.' Sweetpea

Um, I went in with quite an open mind about it. Um, and if I'm honest, I was hoping it would make a difference, hoping, so I was positive. It was a positive thing, not going in thinking, 'Oh, this isn't going to work.' Rose

Some patients were aware of 'faith healing' from a recent television series which had shown 'miracle cures' and disreputable gurus. However, the fact that this was an 'official' study, and the healing sessions were located at the specialist research unit within the hospital, did allay fears that the healing offered was part of any religious cult. Fuchsia exemplifies this:

I didn't know anything about it at all, um, apart from obviously, if you like, the negatives that I'd, that you hear about the, um, you know, the American aspect of

faith healing – sort of, ‘You can walk!’ Sort of situation. Um, and, I mean, I sort of knew a little bit about it but, no, when I was offered it I thought, ‘Well, it’s not taking pills,’ um, it’s, and obviously where it was going to be, I thought, right, if it’s in the hospital, then it’s obviously okay. Um, and I thought, ‘Well, it can’t do me any harm.’ And I knew it obviously had nothing to do with religion and it’s – that it was really obviously to do with your inner faith as opposed to a religious faith, um, and so I was quite happy to go ahead with it.

The ‘medical’ link also helped Jasmin who received the information pack from her oncologist, before all recruitment through the breast cancer clinic was halted:

I saw my consultant for a check-up. He, he asked whether I’d be interested to, um, enter this research project about Spiritual Healing. And my reaction was, ‘I know nothing about it, um, I’m completely open-minded. I, I, yes, I will. I am perfectly happy to do it.’ At that stage I really wasn’t expecting any kind of benefits, but I have an open mind, so any kind of benefit that I had from it would be, would be welcome.

8.3 Pattern profiles: the Spiritual Healing sessions

8.3.1 The first Spiritual Healing session

The actual physical process of Spiritual Healing, as outlined on the healing flowchart (Figure 5.2, p72), was explained by me and the healer. Many women at interview talked of being curious during the first healing session, trying to ‘see’ what was happening, especially during the non-contact elements of the session, as Rose explains:

Well, I lay there thinking. It’s very difficult to relax ’cos you wonder what’s going on. I had my eyes closed obviously. Um, and I just wondered what she was doing. I think you’re more aware, I was more aware of thinking, rather than relaxing and going into it. I was thinking, ‘What’s she doing now? [laughter] I wonder what she’s doing. Where is she now? Oh, she’s down there now. Oh, right, she’s up there,’ you know. And I did – my eyes must have flickered open at one point ’cos I just wondered...

Several initially expressed a concern that they would not be able to relax during the healing session, as Snowdrop exemplifies:

I was never very good at relaxing before this and I even went to a relaxation class down at Macmillan, and I hated it. It was like, I had to lie on the floor and breathe and it was like I was drowning in my own breath and I thought, ‘Oh, I can’t do this. This is not me.’ So that was the only thing that really did panic me a bit. But I actually found it really easy, after the first one – it didn’t worry me at all.

8.3.2 Regular Spiritual Healing sessions

Once any initial concerns subsided, all of the women appeared to look forward to their regular Spiritual Healing sessions. While Spiritual Healing was available every

Friday, except when SCRF was closed for public holidays, many participants missed odd weeks because of prior commitments. This replicates normal Spiritual Healing practice where healees prioritise their commitments and choose when to have healing. Yet, while healees noted when they were missing a session, there were also few entries in the daily patients' logs regarding the anticipation of Spiritual Healing. These sentiments were expressed more at interview, where participants told of the place Spiritual Healing held in the pattern of their lives:

I, I would say [I saw Spiritual Healing] as a very peaceful interlude. And, you know, during this very busy time I was really looking forward to coming and spending an hour in here. Jasmin

I looked forward to it, 'cos it was something different. It was an experience that I've never had before. Orchid

I was always eager to get here and I think, I can't remember who said it but, um, one of them said, 'Oh, you, you know, you relax into it, you know, as soon as you're on the bed' and I said, 'Yes, 'cos it's so lovely.' Yeah, I look forward to it very much. Camellia

Indeed, many looked forward to their Friday healing time as 'me time', a time devoted to them, when they were able to concentrate on themselves. Poppy explained at interview that it was time away from family pressures and interruptions:

It was nice just to sit down and totally relax and nothing was going to impact on that, nothing was going to suddenly be... 'Oh, Mum, can you do this?' 'Mum can you do that?' Or the dogs would start or, you know, you, I mean, I always say you can't lie in bed here on a Friday and sleep but having sort of, having that deep, like, you go into such a deep trance and you relax, it's lovely. And you feel really rested afterwards.

And Fuchsia noted on her patient's log: '*Suddenly I had "me" time – made me feel very emotional*' (Log: week 1. Friday 19/10/07).

My field notes have recorded how most patient participants were so keen to start the healing session that they walked quickly from reception to the healing room, and on occasions it was difficult for me to keep up with them. Indeed, Poppy would rush to the healing room and get straight on to the bed, ready to start the healing, rather than sit in a chair for the consultation with the healer prior to Spiritual Healing (Field notes 27/07/07; 17/08/07; Session report 2. 27/07/07).

This contrasted with the more leisurely walk back down the corridor to the reception area. Indeed, the walk as we returned to reception became a time I shared

with the patient participants. After 3 or 4 sessions, it was noticeable that the women were more at ease, having become familiar with the routines of the research unit and Spiritual Healing, and would frequently chat in reception with me for 10 or 15 minutes. These chats often ended with a hug which, while it was common for them to hug the healers on arrival and departure, I had not expected. At the time of leaving many would express gratitude to me for allowing them to be part of the study (Field notes 03/08/07; 17/08/07; 21/09/07), which again was unexpected and caused me to reflect on my place in the study. Initially at the outset I had thought that, as a researcher, I would be able to distance myself a little from the patient participants, but their openness and expressions of warmth and gratitude moved me and I became much more a participant than I originally expected to be.

8.3.3 The sensations of Spiritual Healing

Benor (1994) noted that patients receiving Spiritual Healing may experience cold, heat or vibrations and the participants reported a range of differing sensations. Only a few of the patients' logs record how patient participants experienced the actual Spiritual Healing session:

Could really feel the warmth from Toni's hands – lovely. Violet (Log: week 3. Friday 20/09/07).

Yet at interview many talked of feeling heat from the healer's hands. The feeling of heat was pleasant and comforting, as Violet expressed at interview:

With Toni, the warmth in her hands was like a hot water bottle you want to take home.

This warmth was not expected by participants, although it is a common experience for the healers. Jasmin and Orchid checked the healer's hands immediately the healing was finished, to see if there was any reason for them to feel heat.

I was fascinated to notice that there actually were physical feelings involved, like this incredible heat that I felt, and when I actually felt Toni's hands afterwards, her hands were not hot. Now, how do I explain that? I can't. Jasmin

The healer's hands got very hot. So when they were actually touching my skin I could really feel the heat. But as soon as they lifted, it was gone. Poor Stephanie. I said, 'Can I hold your hand?' She must have thought I was away with the fairies or something. And, um, yeah, no, her hand was what I would call normal temperature when I held it afterwards, when she wasn't actually healing. Orchid

Other physical sensations were experienced by some, but not all. Camellia noted tingling sensations during Spiritual Healing (Session report 9. 23/05/07), in her patient's log and at her interview with me.

Busy day. Enjoyed healing. Very calm and relaxed after healing. Healing today. Felt very tingly during healing (Log: week 13. Friday 16/05/08).

I didn't feel much at first, the first couple of weeks, but then I gradually felt a tingling, I get a real tingling; in fact the last few sessions I was tingly right the way down, you know, when she was up here and right the way down – it was lovely. And it just made me feel, you know, really, really good.

Jasmin experienced a throbbing sensation (Session report 3. 08/03/07) that as a nurse she could not explain. At interview she elaborated:

Another thing I noticed was that I'm throbbing and it certainly wasn't my heartbeat because it was going at a different rate altogether, so there were, there were definitely kind of physical symptoms that I certainly couldn't explain.

Several participants had sensations which felt as though more than one healer/person was giving healing. These additional unexpected sensations did not seem to cause any disquiet. Patient participants reported them to the healers and they are noted on their session reports (Daffodil – Session report 4. 17/08/07 and Session report 9. 28/09/07; Orchid – Session report 8. 28/03/09; Poppy – Session report 4. 10/08/07).

Poppy 'could feel someone at her feet, keeping them warm' (Session report 10. 21/09/07).

Daffodil recorded in her patient's log: 'Blissful healing session. 3 hands on my body again!' (Log: week 7. Friday 07/09/07).

These experiences were discussed at the final interview when I asked about experiences of Spiritual Healing:

And with Stephanie again I felt more than one person, you know; sometimes there'd be 3 hands, I think. The first time it happened I was – I nearly opened my eyes. It was really strange, but it was nice and it – always I felt really peaceful. Daffodil

I know on one occasion – I can't remember which it, whether it was Stephanie or Toni – they'd had their hands on my head and then they moved further down, but it felt as though there was still pressure on my head. Now that I did find strange because there were only 2 of us in the room, and when you can feel that somebody's got their hands on your head and you know that somebody else has got their hands down by your knees, it's a very strange feeling. But apart from that, it wasn't scary. I wasn't scared. Um, bemused. Orchid

Rose spoke of seeing colours during Spiritual Healing. These colours were noted by Stephanie (Session report 7. 28/09/07; Session report 9. 19/10/07) and also in Rose's patient's log.

This session was lovely – felt very good after – chilled + happy ☺ Saw colours for the first time blue/green. Some purple (Log: week 9. Friday 28/09/07).

9th healing session today – was good – saw colours, green mainly – felt good and happy/relaxed after (Log: week12. Friday 19/10/07).

Rose described the experience of seeing colours in more detail at our interview:

I particularly noticed with Stephanie a couple of times, latterly – the last two probably with her – um, colours; I didn't see colours at first. Tell other people and they go, 'Oh, that's mumbo jumbo.' You know, they can't understand it, but they really began to sort of, like, think that, you know, there was something in it.

8.3.4 Immediate responses to Spiritual Healing

The immediate responses to Spiritual Healing could not be predicted. For some there would be no immediately apparent response to their initial healing session, for others there was an immediate physical reaction which they attributed to Spiritual Healing.

First experience, um, it was very pleasant, um, I was nice and relaxed and surrounded by nice people; I thoroughly enjoyed it. But I do remember that first evening and night, I had, I felt absolutely dreadful. I really felt ill. And I really didn't know what was going on and I didn't actually connect it up with Spiritual Healing at that point; I just thought, 'What is going on. What, what's wrong?' Um, I don't know what went on but it could be, um, that subconsciously I released tensions inside me or I let go or whatever, I don't know. But certainly, um, that was a grim experience. And following that I had the other sessions and I never experienced that again. Jasmin

Other participants had an immediate emotional response, as Fuchsia explains:

I found, um, that after that first session, um, I, I was a little bit disturbed, um, because I felt as if a weight had been lifted. And, um, I remember I sort of got into the car and I burst out crying and [husband] said to me, 'You're supposed to be happy after this not...', but it was just, you know, I just felt... emotional release and, um, I don't know, I just, I just felt as if as I say, a weight had been lifted. And I felt tired. I actually felt exhausted. Came home and I just wanted to go to sleep, you know, I just felt as if everything had been – I was drained, all those emotions had been drained from me but, um, and then I felt, on the Saturday – 'cos I went on the Friday – on the Saturday following I felt a bit sort of uplifted. You know, it, um, and I felt like that afterwards too on subsequent sessions.

8.3.5 Early manifestations of Spiritual Healing

The participants' holistic responses to Spiritual Healing can initially seem muddled as they are presented in a flow of experience. In order to assess any effects of Spiritual Healing I have, where possible, divided the presentation of reported experiences into the categories that Spiritual Healing claims to affect: mind, body and spirit. It must be recognised, however, that this is purely for analytical clarity as improvements in one category for a patient participant may have an effect in other categories. This can be seen where changes in the physical (body) are accompanied by changes in sense of well-being (mind).

8.4 Pattern profiles of Spiritual Healing: body

8.4.1 Hot flushes and night sweats

As noted in Chapter 7, all of the participants complained of hot flushes (occurring up to 30 times a day) when they joined the study. By the third week of Spiritual Healing many of them reported a decline in or cessation of hot flushes. For those who did not experience a complete cessation of hot flushes, there was a continuous decline in their frequency and severity throughout the course of Spiritual Healing, but, more important, they became easier to cope with, as Orchid and Violet exemplify:

Flushes not a problem. Felt fine – very busy day, going on holiday (shopping).
Orchid (Log: week 2 Thursday 24/01/08)

In fact, well, they're virtually non-existent. Yeah, virtually gone, the hot flushes.
Violet.

And would you put that down to the healing or...? Fiona.

Well, it's happened since the healing started, so, yeah, I would think so. Violet

Some found that stress brought their hot flushes back, but again they were not as severe and did not cause as much distress as before Spiritual Healing. Fuchsia exemplifies:

I had hot flushes, yes. They have – that's another thing that has definitely improved, is my daily hot flushes. I still find, if I get slightly agitated, um, I'll sort of think, 'Gosh, here we go!'

Hot flushes were often accompanied by night sweats, which also decreased or stopped during Spiritual Healing as Camellia and Rose explain:

I get them [hot flushes] very slightly at night now; don't get them at all during the day, which is bliss, because they were really quite severe and, um, and I can't say

they're really strong ones at night now. I think the healing started it all off and 'cos I was, I seemed a lot better during the day, just having, like, feeling hot but not dripping wet, if you know what I mean. I don't seem to get it during the day now at all, which is brilliant. Camellia

I had night sweats. Um, but no, I don't, they don't get me down. I just think, 'Oh, God, here we go again!' Whereas they were beginning to get me down, they were getting me down. Rose

Snowdrop noted her sleep and waking times most days in her patient's log and her sleep pattern is noted on several session reports, indicating the importance she attributed to 'a good night's sleep'. Snowdrop reflected at interview how her night sweats and her sleep had improved during her course of Spiritual Healing:

I sleep better. 'Cos I was waking up. I mean, to start off with on the Tamoxifen we would change the bed; I'd have to get up and change the bed, it would be that wet. I don't know, um, some days I would wake up – and I, I mean this is before [Spiritual Healing], – I would wake up and I would feel still asleep; I don't know how to describe that. Yesterday I did have a few night sweats; but I had the occasional sweats and the occasional bad nights, but I was sleeping, after going to bed, from the time I'd gone to bed to around 3, 4 o'clock solidly, which was wonderful.

8.4.2 Tiredness

Tiredness was also noted as a side-effect independent of night sweats and, while this is a known side-effect of chemotherapy or radiotherapy (Bower 2006; Mock et al. 2005; Bower et al. 2003; Wratten et al. 2003; Bower et al. 2000), most of our participants who complained of fatigue and a lack of stamina linked it to poor sleeping patterns, as Rose exemplifies:

I've had different sleep patterns since it's all happened [breast cancer]. I mean, I, on the sheets [patient's log] I've recorded that. You know, certain patterns, they're changing.

Spiritual Healing has been shown to assist sleep (Vaghela et al. 2007; MacDermott and Epstein 2001; Sundbolm et al. 1994) and our participants found their sleeping patterns improved during the course of Spiritual Healing, as Camellia exemplifies:

I was having terrible, terrible time sleeping. Really was, before. Used to go to bed and, um, didn't used to go to bed until sort of 12, 1 o'clock at night because I knew if I got to bed earlier I'd just lie there and toss, and even going to bed I still couldn't get to sleep. And you, you know, you're still awake at 3 o'clock in the morning. And that's how I was. But since I've had Spiritual Healing, I've, I want to go to bed now and I want to go to bed. If I'm still up at 11, that's late; it's only because I've wanted to watch something on television. I'm usually wanting to go to bed at sort of 10 o'clock now, which is lovely. That's been a real benefit, real benefit to me because I was having such a horrible time before, really horrible time.

Improved sleep meant that several patients stopped taking their sleeping tablets, which was a milestone in moving away from cancer, as Sweetpea exemplifies:

Sleeping well every night. No more sleeping tablets and that 'can't wake up' feeling. I look forward to every day (Log: week 10. Tuesday 01/10/07).

8.4.3 Joint aches

Joint pain in hands (fingers and wrists), arms, knees, feet, pelvic and hip bones and back is associated with taking aromatase inhibitors (Burstein and Winer 2007).

Spiritual Healing has been shown to help patients with pain (Pohl et al. 2007; Tsang et al. 2007; Vaghela et al. 2007; Vitale and O'Connor 2006; Miles 2003; Olson et al. 2003; Schmehr 2003; MacDermott and Epstein 2001; Sundbolm et al. 1994).

Joint aches were experienced by all of our participants and while hot flushes were perceived as unpleasant and embarrassing, joint aches appear to be the side-effect which impacted most dramatically on their life patterns, as Foxglove exemplifies:

I was really crippled with joint pain, walking, anything, sitting, lying down was painful. Reading a book I had to – I couldn't hold the book; I could hardly write or use the computer, it was very painful, so everything I did was extremely painful.

Indeed, the field notes from our consenting interview noted the difficulties Foxglove had in walking, sitting or standing and her problems using the pen to sign the consent forms. Foxglove's reaction to Spiritual Healing was rapid, as she explains:

And I came for my first session and 50 per cent of my joint pain disappeared. And I can remember, that's just in 40 minutes; and I can remember sitting with my friends – we thought about going [out] with friends and I'm sat there and A [friend] said I kept looking round, expecting it to all come back [laughter]. So, over the weeks, for about 13 weeks altogether (the 10 sessions wasn't it?), something like that, the joint pain has all virtually gone. And, um, it comes back a little if I'm tired or when I had the urine infection that I needed the antibiotics for – it came back then, but not...nothing like it was and had been for a year before I started having Spiritual Healing. Foxglove

For others the easing of specific joint aches was less rapid, but all recorded an improvement and noted activities they became capable of. Fuchsia noted: '*Finger joints less painful ☺*' (Log: week 7. Tuesday 04/11/07) and: '*Realised joints not aching so much ☺*' (Log: week 7. Wednesday 05/11/07). Stephanie noted on Fuchsia's session report: '*Joints seem easier since last session – started knitting for the first time in four years – all fingers easier*' (Session report 8. 07/11/07).

Although Fuchsia did log her knitting she also remembered it in her final interview, as a sign that things were 'getting back to normal':

I had not knitted for about 4 years. Because I had joint ache. And, because with my eyes that was the only thing that I – I suddenly thought, I wonder if I can, and yes, I knitted a cardigan for a 3-year-old that would fit a 6 –year-old, but that’s beside the point! [laughter] But I finished the garment. And I handed it over with buttons and everything else. Yes. And then I knitted a hat! Fuchsia

8.4.4 Other side-effects of breast cancer treatments

Two participants suffered side-effects which are less common but equally wearing. Mouth sores are a possible side-effect of chemotherapy (American Cancer Society 2007) and Daffodil reported a dry, sore mouth (lichen planus) at her first healing (Session report 1. 27/07/07) which cleared by the end of her Spiritual Healing sessions. Indeed, Daffodil noted on her patient’s log: ‘*Occurred to me that my mouth is now not a bit sore – first time in weeks*’ (Log: week 11. Wednesday 02/10/07). Since chemotherapy Jasmin had suffered thrush and a vaginal discharge, requiring many visits to her GP. Her 10th session report (15/06/07) shows: ‘*Has not been to GP about thrush at all since Spiritual Healing started.*’

8.4.5 Long-standing physical health issues

While women joined this study because of the side-effects of their treatments, several also had long-standing health issues. As Spiritual Healing is non-diagnostic and non-directional, these health issues were also affected by the healings. Quite often changes in these symptoms were noted as a dawning realisation of their absence or decline. Violet struggled with shoulder pain and carpal tunnel syndrome in both wrists and at her final interview she reflected how, while she still had some pain in her shoulders and wrists, she was more able to do things:

Yes, a few weeks ago [daughter] brought [granddaughter’s] school cardigan over; a button had come off and, of course, youngsters can’t sew these days, can they? Brings it over to Grandma and I just couldn’t do it – my hands went totally numb; I couldn’t hold the needle. My Mum at 85 had to do it ’cos I just couldn’t. But last week her trousers came down and I was able to sew them up, so that was good. And I’ve made my Christmas cake! Violet

Fuchsia had suffered from bowel problems since she started her cancer medication, which required frequent visits to the toilet. ‘*Realised today had change in bowel movement – once instead of 4 times ☺. Can this be as a result of healing?*’ (Log: week 2. Thursday 01/11/07). This change is also noted in Session report 3. 02/11/07: ‘*Bowels improved – now normal; previously ran to loo a lot in the morning. V. pleased.*’

Camellia had several aches and pains which she found Spiritual Healing helped to ease:

'Cos I've got shoulder problems and, um, knee and hip problems and back problems but, um, I've got to have another shoulder operation. Fiona: I did notice that on some of the notes they've put that you've had extra healing on the shoulder or the knee. Did you find that helped that? Camellia: Yes, I did, yes. It seemed to ease it a bit, yeah, it did and, um, especially my feet 'cos my feet are bad all the time. Right foot really bad. And that, I used to walk out quite good, you know, compared to walking in! [laughter].

Several patient participants had back pain which Spiritual Healing eased, as Rose and Snowdrop explain:

I did actually say to her [healer], could she try and concentrate on my back 'cos it had been really bad. I'd not mentioned it to her before. Um, and she did on that occasion and, do you know, it's been a lot better since. It has. You know...a lot better. Um, I don't know whether it's just one of those things, but I've definitely noticed a difference. I mean, I don't feel it – I'm sitting here now. Rose

Snowdrop damaged her coccyx in a trampoline accident as a child and has suffered pain ever since. Spiritual Healing eased her back pain, although it did return intermittently:

[The coccyx] hadn't played me up at all until recently. But it did relieve that pain on my coccyx. Toni actually worked on my back and we'd done the healing and she'd done obviously the complete thing, and then I got off the bed and I sat on a chair and she worked some more on my back. And that was quite wonderful too. And she doesn't actually do anything, apart from touch, but it was so much looser. Yeah, it's amazing. Snowdrop

8.4.6 Energy

All patient participants recorded having more energy in their logs and this was also noted by the healers in the session reports. They reported more energy at interview too. The immediate impact of feeling less tired, less achy and having more energy was that participants glimpsed their old life patterns and actively engaged in old activities: Fuchsia played with her grandchildren, crawling around on the floor. Foxglove did her gardening, cutting the grass, weeding and clearing out her pond. Violet started to care for her granddaughter again and help her daughter with housework. Camellia began visiting National Trust properties and gardens again. Sweetpea started baking and going on regular outings, including to the races. Such engagement with old and familiar activities was a boost to morale. Participants enjoyed the activities and were happy to have re-engaged with some of their old,

pre-breast cancer life patterns, even though initially such activities left many very tired.

8.4.7 Familiarity with body responses

All daily patients' logs at the start of the course of Spiritual Healing concentrated on the physical (body) impact of healing. This focus on the physical may have been because the inclusion criteria required participants to be 'suffering from the side-effects of treatment', thus concentrating on the physical as an area of interest, or it may have been because the study was taking place within a hospital setting that they felt their physical state was the focus of interest as it had been with their orthodox medical team. It may be that as physical concerns subsided there was a growing awareness of other impacts of Spiritual Healing. Indeed, as the physical effects subsided some women forgot all about them and it was only at interview that they reflected on some of the health issues they had joined the study with. Paintbrush explained at interview how new feelings became 'accepted' as the course of Spiritual Healing progressed:

I can certainly remember after the first one [feeling a] bit like I was sort of walking on air at the hospital. When you first start having them [Spiritual Healing sessions], I think I was actually more aware of that, that chill, content, serene feeling afterwards and that energy and that, um, you know, just, you know, 'life's okay' sort of state. But after, you know, after having [several sessions], when it becomes more routine, you don't notice it as much because maybe it's just that way anyway.

8.5 Pattern profiles of Spiritual Healing: mind

Like Fuchsia, whose initial response to Spiritual Healing was tearful, some participants found the healing sessions acted as an emotional release and they cried either in the session or immediately afterwards. With this release, participants reported that a weight had been lifted from them. The tears were not tears of sadness and frequently the women were unable to explain why they were crying. Sweetpea's patient's log noted: '*Found myself crying at session but I don't know why*' (week 5. Friday 24/08/07).

Although the Spiritual Healing did not resolve all the physical concerns, it did impact on participants' overall well-being and they felt more able to cope.

Violet explains:

I think it's restored, or helped to restore my self-confidence. I feel more positive, I think, possibly than I did before I started it [healing]. I wished it had been able to do something about the shoulder but I think it just tends to be for your overall well-being and I think that's definitely helped.

8.5.1 Calmness

One of the most noticeable mind manifestations that all the women recorded was a feeling of calm, relaxation and inner peace. While all talked of feeling relaxed physically during and immediately after their Spiritual Healing session, the calm and relaxed mental state continued throughout the week.

Spiritual Healing has been shown to alleviate stress and anxiety (Tsang et al. 2007; Vitale and O'Connor 2006; Shore 2004; Miles 2003; Schmehrer 2003; Benor 2002; MacDermott and Epstein 2001; Dixon 1998) and for some this helped them to deal with potentially traumatic events. Fuchsia suffered with cataracts, a possible side-effect of taking hormonal therapies (Cancer Research UK 2008a; Cancerbackup 2008), and while on the study had cataract removal surgery on both eyes. Fuchsia recorded her experiences in her patient logs:

☺ *Waiting for cataract op. feeling quite calm* (Log: week 6. Tuesday 27/10/07).

☺ *I used the breathing technique for relaxing during op. I am sure it helped* (Log: week 6. Thursday 29/10/07).

For others the calmness impacted on the way they dealt with everyday incidences. Rose spoke of 'having words' with her husband and instead of '*flying off the handle, was calm and almost serene in dealing with the situation*' (Session report 3. 17/08/07). Rose expanded her description of this calmness at interview:

I think that I'm calmer, um, I don't get quite so stressed, um, I feel it's [Spiritual Healing] just calmed the whole thing down, I don't...you know, it...smoothes round the edges, if you like; you don't feel, you know, raw, so raw any more. It does, it smoothes it over a bit. I think probably my husband thinks I'm a little bit more calmer [sic] and a little bit more laid back.

The calmness allowed them to regain some of their 'old way of being', as Violet explains:

I don't think I'm quite so short-tempered as I was. No, I'm not so short-tempered but, and by and large, as long as things run along smoothly, I don't get so tired. I can generally sort of enter into – I've got my sense of humour back, I think sometimes when you, you know, I try to keep a sense of humour. I've always had a bit of a warped sense of humour, and that helped at times.

Participants all reported coping with their breast cancer and its treatments as ‘life goes on’ and two of them were in the process of buying and selling houses and moving to new homes: a stressful time ordinarily, but additionally stressful for Jasmin and Camellia, who were also dealing with the side-effects of their breast cancer treatments. The inner calmness which Spiritual Healing gave them helped them to cope with the ups and downs of moving house:

I feel it's kept me a lot calmer. I feel a lot more relaxed about things, um, and it hasn't made me worry. I've had a lot that I could have worried about. I've really found the healing very, very helpful to me, I think, because I've gone through a very stressful period. It's kept me very calm, yes. And, um, yes, 'cos I think otherwise, I think I'd have been going round in little circles at times. Camellia

Jasmin, who was in the process of moving to Dorset and selling her London flat, noted: ‘*Felt good and serene despite intense provocation caused by umpteenth flood upstairs [of London flat]*’ (Log: week 3. Friday 15/03/07). The flat sale fell through in week 4 and Jasmin noted: ‘*Flat sale fell through at last minute. Devastated – betrayed.*’ (Log: week 4. Friday 22/03/07). At her Spiritual Healing session Toni recorded: ‘*Feels she is coping remarkably. Feels she is in control, so relaxed and let go – is something she could never have done on her own*’ (Session report 4. 22/03/07).

At our interview Jasmin reflected on her house move:

If I try and look back at this particular period of my life when life was hectic, to say the least, what with trying to sell flats and their being sold and falling through and...and...doing the actual packing and then moving and the whole thing falling through again and living between London and Hampshire and all that, my life was a vast amount of stress and I didn't feel stressed to any great level.

8.5.2 Distress

It is well documented that life-threatening events, such as cancer, can prompt psychological distress (McBride et al. 2000) and up to 25 per cent of treated breast cancer patients will suffer depression in the 3 years post diagnosis (Burgess et al. 2008). Although most of our participants experienced high levels of stress and anxiety, only Sweetpea suffered with depression which she attributed to her second cancer diagnosis. Orchid had been diagnosed with depression prior to joining the study, but this was linked to pre-existing issues and not directly to her breast cancer.

Research has indicated that Spiritual Healing can help patients with depression (Pohl et al. 2007; Vaghela et al. 2007; Brooks et al. 2006; Vitale and O'Connor 2006; Shore 2004; Miles 2003; Schmehr 2003; Dixon 1998). For Sweetpea Spiritual Healing helped with *'her head'* and empowered her to cope with family life. Prior to Spiritual Healing, Sweetpea spent most of her time in her home, feeling she could not be bothered with family activities. She lost interest in planning family outings, which she had previously enjoyed, and felt unable to join in family discussions or entertain visiting friends. Her cancer and subsequent depression caused her to feel, *'Oh well, there's no point in doing anything.'* However, during her course of Spiritual Healing Sweetpea's patient's log shows a slow progression back towards an old life pattern. Week 3 entries include: *'I made a cake for the first time for over a year'* (Sunday 03/08/08) and *'Was out for 5 hours today and didn't feel too tired'* (Wednesday 07/08/08). Sweetpea and her family went to the races for the day in week 4 and this had special meaning for her, as she explains:

We always go in August. When my mum was alive we always used to take her, and that was my aim. All the time I kept thinking, 'Oh, I do hope we can go this August to the races.' And, you know, that's what sort of made me think, 'I've got to get better 'cos I want to go there.' [laughter]. Not for any reason than it was in my head. That was a milestone, you know: if I could do the races I would be, it would be all right [laughter]. You know. We did make it...yeah, we made it twice actually.

At interview Sweetpea tried to explain the impact Spiritual Healing had on her life pattern and how she no longer used her *'bit of elastic'*, which she had used constantly while she was depressed:

My bit of elastic – but I've still got it, I've still got my elastic and it's still on the side and every now and then I'll have a little fiddle, but I used to have it constantly, and my hands were sore. I mean, they'd bleed sometimes, my nails, where I just, I could not go without it. I used to think, 'Oh, if I lose that – I mean, it's going to, you know. And I would go to bed with it, tied round my fingers, and my fingers would be nearly blue in the morning 'cos I, where it had got so tight, you know. But I just, just didn't, and I haven't had it, I haven't had it for weeks. I found it [Spiritual Healing] absolutely wonderful. But it has been a complete and utter surprise to me. How well I felt. I can't describe the difference I think it's made to my head. That is, you know, my thoughts, my head, the way I am, the way I think, everything. I think it's made such a difference. I can't, I just cannot, I would never have believed it in a million years.

While for the purpose of analysis I have separated the body and mind impacts of Spiritual Healing, participants did not always make such distinctions at the time of

their healing sessions, although on reflection at interview some did recognise the different types of impact. Jasmin exemplifies:

I think in retrospect it's been a very helpful, um, a very helpful experience, um, and I think it has actually helped resolve issues that I may have had and I think on the whole, um, I'm just very glad that I did try this. It's obviously very difficult to quantify what benefit one has from it all because it isn't measurable, but purely going by feelings, um, I, I have felt very well during this period when I had this healing, um, physically but especially mentally.

8.6 Relaxation

Relaxation as an impact of Spiritual Healing category appears to span 2 categories (mind and body). It is a well-documented effect of healing (Pohl et al. 2007; Vaghela et al. 2007; Brown 1995). Despite initial concerns about being able to relax, all of our participants talked of feeling relaxed (body and mind) during their Spiritual Healing sessions and this feeling seems to have persisted through the following few days, in some cases lasting the week until the next Spiritual Healing session.

8.7 Pattern profiles of Spiritual Healing: spirit

For the women in this study, the experienced physical improvements allowed a return to some old activities, which impacted on their mental well-being and was noted at the time. However, a spiritual impact of Spiritual Healing seems to have been recognised by some only towards the end of the course of Spiritual Healing, or by others in retrospect once the course of healing was completed.

The meaning of spirituality is very personal and defined by each individual. Thus this is the most personal and intimate manifestation of Spiritual Healing. Trying to find the language to describe 'the spiritual' proved challenging for all of the women and as a consequence difficult for me to capture here. So I decided, in congruence with my desire to let the voices of women be heard, to use their words directly to explain their spiritual manifestations of Spiritual Healing:

But I think the inner peace that came with the Spiritual Healing – um, I've certainly changed a lot in myself since I've had the Spiritual Healing. Calmer. Um, it's this peace, I can't describe it. I cannot, I can't describe this inner peace that I have, even when I'm feeling really lousy. I need to go to bed at half past six; I wouldn't get upset about it, I'd go to bed at half past six and I'd get into bed and snuggle up [laughter] put the television on and find something to watch and make the most of it. Instead of fighting everything all the time. Foxglove

Went on the Friday; on the Saturday following I felt a bit sort of uplifted. You know, it, um, and I felt like that afterwards too on subsequent sessions. Fuchsia

I don't know, but I always feel elated, really, I suppose is the word. I think I could conquer the world when I come out [laughter]. And I just, I suppose that's why elated would be the word to use really. Sweetpea

I think the whole process, um, made me or kept me serene and, and peaceful and able to cope with what was going on. Jasmin

Actually, in fact, I worked it out afterwards, you know, after the Spiritual Healing I'd feel energised. Foxglove

Oh, I'd say it's blissful. Absolutely blissful. Daffodil

8.8 Long-term pattern profiles of Spiritual Healing

8.8.1 Fear

The data showed that the fear of cancer's return became part of our participants' life pattern, concurring with Fredette (1995), but after Spiritual Healing it was no longer at the forefront of their minds day to day. At interview few participants remarked directly on their fears, but it was apparent that it no longer sculpted their lives in the way it had previously and they were able to plan ahead and see a future for themselves. Poppy exemplifies:

I was always frightened it was going to come back. But now I don't take any notice.

Previous research (Payne et al. 1996) shows that regular mammograms and smear tests rekindle the fear, and this was the case for all the women, as Rose's patient's log exemplifies:

Felt OK at first, but after doctors – tearful and scared. I feel my body is letting me down again – no longer a friend. Was told last smear 6 months ago was abnormal. Had another smear – 10 weeks to wait for the result (Log: week 7. Thursday 13/09/09).

While several participants expressed concern that once the study healing sessions were complete they would return to their previous way of being, the initial effects of Spiritual Healing were maintained up to the final interview which took place 2 – 3 weeks after the final Spiritual Healing session. Sweetpea exemplifies:

But I was so worried when it was my, you know, [last session of healing] and I thought, 'Oh, please don't let me' – I may have written that down on the slips [patient's log]. 'Please don't let me go back to what I was before,' because it was just awful, you know, it was horrible, I couldn't explain it. I could just see no

further than it was how I'd been and I could see no further than cancer and dying and, you know, you know what I mean, and thinking, 'Oh, what am I going to do?'

8.8.2 Work

Poppy and Daffodil had continued to work full-time as much as possible throughout their treatments; others worked part-time or were off work until their health improved. While work for some was enjoyable and may previously have been a *raison d'être*, they now took time to review their work/life balance and where financially possible worked fewer hours or gave up work altogether, as Foxglove and Fuchsia exemplify:

It [breast cancer] has changed my attitude to life. I used to be a complete workaholic and now I'm more concerned about the fact that I haven't got quality of life rather than I can't quite do my job. So everything's completely turned around. Where I tended to think more about work, I want more quality of life and I am actually seriously considering – I can't really do it for a couple of years, but if things don't really greatly improve over a couple of years, I shall retire from work. I can afford to do it and I can have quality of life. Foxglove

I also think that because I had decided that there's more to life than work and I was coming up to 60, I thought, 'Oh right, I'm retiring. I'll finish work.' I was only working part-time anyway. Fuchsia.

For others, work was part of who they used to be, so returning to work was an important goal, as Snowdrop and Jasmin exemplify:

I teach PE at school and trampolining is my speciality, yeah. Yeah: I used to be active, yeah. I don't do, I haven't worked at all. I want to go back to work but I know that I'm not going to be able to do it. So I don't know; I'm going and try and go back after the May half term and just do, like, a couple of days or something, just to see how it goes, but the physiotherapist said I'm never going to be able to support somebody in a harness. So I'll just have to find a new job I guess...At school I have to get my own equipment out. And the trampoline – to get a trampoline out when you've only got school children to help you. I mean, I didn't used to ever get the children involved anyway because it's too much of a responsibility. And I just won't be able to do that, I know I won't. At the leisure centre it's got out for me, so it's not so bad, and I always have an assistant there. So, yes, I can be there vocally perhaps. Snowdrop

I was, um, a bank nurse beforehand and, yes, I have done some work. Um, but life is complicated at the moment because we're trying to move house and everything else, so I haven't done a lot of work but, um, I certainly feel up to it, I certainly feel well enough to go back and throw myself into it. So, once we get ourselves sorted out, um, house-wise and all that, I think, yes, I might well go back to work again. Jasmin

Two participants lost their jobs during the time they were on the study. They both felt Spiritual Healing helped them to cope with this, as Paintbrush exemplifies:

I can't, I don't have a way of comparing it with, you know, the same thing without healing. But I actually think it allowed me, I don't know, you know, that, that, that chilling, that slowing-down process, space to think through, and say, 'Don't be stupid.' And I actually think maybe the healing helped. It gave me, and I don't know if it's a confidence or, you know, I don't know how to put that in words better other than, yeah, I think it did help it.

8.8.3 Leisure

Leisure took on a new importance for all the women and most seemed to seize any opportunity to take part in leisure activities:

In fact my husband has just bought himself, and passed his test for a motorbike and I'm climbing on the back. You know, and I'm thinking, what, at 55, I mean, what am I doing? But, I mean, why not? Was out on it yesterday for the second time and I'm thinking, Oh hey, I'm getting quite into this! Rose

I was struggling to have any kind of quality of life, even when I was off. But now when I'm off, I go off. I visit Winchester Cathedral and Christchurch Priory and Wilton House and a friend comes down to stay and we have a good time. Okay, by 3 o'clock we're wanting to be home – 5 hours out is enough for both of us – and, um, by half-past six it's jamas [pyjamas] on and by 8 o'clock we're fast asleep [Laughter]. But we have – we really go out, we have a really good time when I do those kind of things. I couldn't have thought of driving down to Weymouth, I couldn't have thought of driving up to the Peak District, as I've done twice, since I've had the, started the Spiritual Healing. Foxglove

8.8.4 Intimate relationships

While breast cancer's impact on intimate relationships is well known and the loss of a breast can threaten a woman's sense of femininity, for one patient Spiritual Healing helped her sex life. Paintbrush felt that since Spiritual Healing she was more relaxed and content and her sex life had improved:

And I think it's because that sense of peace and contentment, I think it improved my sex life [laughter]. Yes. Just more accepting, you know, in just, it's that sense of everything's, you know, I'm okay. And I feel good. And also that gives you that sort of space to clear your head and, you know, get rid of the things that are on your mind and worrying you and I think that's, and then you're just going to think, 'Whoa, it's been a while,' and you become more aware of your sexuality in that sense.

8.8.5 Perceptions of life

At interview, the women were asked to reflect on any long-term impact of Spiritual Healing. The term 'improved quality of life' was used by many and this was

reflected in their desire to take every opportunity to enjoy life. Thus there was a reprioritising apparent in all aspects of their life patterns – work, leisure and family life – concurring with the findings of Bertero and Wilmoth (2007).

When reflecting on the treatment phases of breast cancer, participants talked of awareness of their own mortality and of the out-pouring of love from family and friends. Yet, as their health improved, many spoke of the family simply returning to old ways. The women spoke of feeling empowered by Spiritual Healing and found they had a new attitude towards some aspects of family life, as Snowdrop and Violet explain:

I'm in, I've got more control over things, yes. Life was dictated to me before. You are, you're Mum; you will get up, you will do this, you'll do that, you'll go to work, you'll come home. Now I get some input into my life. Yeah, I choose. Snowdrop

The main thing, I can't stand any hassle, I find, since it, and I'm not prepared to put up with it either. Whereas before I would have gone along with it and, you know, got all fraught, I won't put up with that now. My daughter thinks I'm there, I think, at her beck and call. Um, I still am at her beck and call, but I will sort of speak up a bit now. Violet

The experience of living day to day through all the treatments meant that many participants had not wanted to think too far into the future or to make plans.

However, as their sense of well-being increased they started to plan ahead, as

Sweetpea and Snowdrop exemplify:

Fiona: You've booked a holiday now, haven't you? Sweetpea: Yes, we have; not until June, but we have. C [daughter] found it on the internet. It's very nice and you have to book it up because it's a one off...she said, 'Oh, they're all booked up for May, and that, so I said, 'Well, you better get in quick. Get June'. And, you know, while we've got the chance, that's why we've done it, you know. Sweetpea

I used to plan everything; I couldn't live without a plan. Then I found, well, I have just done it now, I couldn't plan a holiday even, since cancer. I would look at the computer, find something for tomorrow and think, 'Yeah, I feel okay, I'm going to go.' I couldn't think, 'Ooh, I really want to do so and so next year, or, it just, it just, I just couldn't do that...well, I have just booked a – I'm taking the grandchildren to Florida next Easter. Snowdrop.

8.8.6 Use of GP support

Several participants had used their GP for emotional support during their cancer journey, but after Spiritual Healing they reported seeing their GP much less, as

Foxglove exemplifies:

I would sit and talk to him [GP] and he was like a support system, he was very good. He's an excellent GP, and he was very, very good. But once I went to the Spiritual Healing I felt I didn't need it and so I never, I've not visited him at all.

8.8.7 Adherence to hormonal therapy

Because of the decrease in side-effects participants were more content to take their hormonal therapy for the next few years, as Jasmin explains:

I just know that I've got to take it for a while to come but I'm not sitting here counting days because my symptoms really have improved that much, so, and possibly part of it has been due to Spiritual Healing because certainly, um, the symptoms that I complained of, um, when I started have become much less over the period of time that I have been having that treatment. So I can only draw one conclusion from that: it [healing] certainly has helped.

8.9 Patient participants' commendations

All patient participants said they would recommend Spiritual Healing to other breast cancer patients, although there was no consensus regarding when it should be offered. Several felt they would have benefited at the diagnosis stage, while others would have liked Spiritual Healing during chemotherapy and radiotherapy. All felt that there was confusion around the name 'Spiritual' as it could be misunderstood and linked to religious faith-healing, witchcraft or voodoo, and that could put other patients off using it.

Some women talked of planning to go for a 'top up' in the near future to ensure they maintained their new life pattern, or of contacting a Spiritual Healer in the future if they start to lose their sense of well-being and their ability to cope. Only Daffodil and Orchid did not plan to seek out further Spiritual Healing. Daffodil felt it had done its job and there was little time for her to give over to Spiritual Healing, but it was something she knew about and could re-engage with should the need arise in the future. Orchid was still battling with her depression and caring for her husband, so did not feel able to engage in other activities at this time.

8.10 Summary of presentational knowledge

All of the patient participants in this study felt they had benefited from Spiritual Healing. There was no indication of any difference in reported outcomes between the two patient participants (Jasmin and Foxglove) who had seen only one healer

and other patient participants who had seen two or three different healers during their course of 10 sessions, which might be taken as an indication that the healing and not the healer was responsible for any changes they noted. As in the preceding chapter, unique experiences of Spiritual Healing are presented here in presentational knowledge (for example, Rose's and Daffodil's experiences of receiving Spiritual Healing; Jasmin's and Fuchsia's responses to their first Spiritual Healing session; Snowdrop's long-term health issues). Yet while there were variations in how the Spiritual Healing was experienced, there were many commonalities in both mind and body responses to Spiritual Healing, all of which appear to have been positive. It is notable that all of the women took up all of the available sessions and there was no evidence of any negative effects as a result of Spiritual Healing.

While the effects have been categorised by me to demonstrate the impacts of Spiritual Healing, it is clear that they are experienced and should be understood holistically, with the potential to affect all aspects of being: physical, emotional, spiritual, functional, social. The women in this study, in charting their experiences of Spiritual Healing, did not categorise their responses but reflected the holistic impact of Spiritual Healing on their whole life pattern. So while they recognised the restrictions, pain and challenges that breast cancer and its treatments had given them (Chapter 7), patient participants presented their lives in a more positive way (enjoying more activities; returning to work; planning for the future) after receiving Spiritual Healing.

This chapter and the preceding chapter have used interview transcripts, together with field notes, patients' logs and healers' session reports extensively, to ensure the data presented are a true representation of the patient participant experiences of breast cancer and Spiritual Healing, thus ensuring rigour (Sandelowski 1986) and safeguarding validity (Ratcliff 1995). The next chapter presents a thematic synthesis of the presentational knowledge from Chapters 7 and 8, to provide propositional knowledge that reflects the commonalities of experiences of living with breast cancer and the impact of receiving Spiritual Healing.

Chapter 9.

Propositional knowledge – a synthesis of presentational knowledge

‘Nothing is meaningful as long as we perceive only separate fragments. But as soon as the fragments come together into a synthesis, a new entity emerges.’

Piero Ferrucci (1982). *What we may be – Techniques for psychological and spiritual growth through psychosynthesis.*

9.1 Introduction

The propositional knowledge in this chapter was created through synopsis and thematic synthesis of all forms of presentational knowledge. During the collection of presentational data it was apparent that, while each patient participant had a complex and unique life pattern, there were many commonalities in the patient participants’ experience of breast cancer and its treatments, as well as the short- and long-term impact of Spiritual Healing. The commonalities across the participants’ life patterns are shown in the propositional matrices Table 9.1 (p153) and Table 9.2 (p162), which were constructed using a UAI concepts of pattern formation focusing ‘on experience, perceptions and expressions associated with living phenomena’ (Cowling 2001, p34). Both the commonalities and essential differences are highlighted within the narrative content of this chapter. As I discussed in Chapter 5, I have adapted the method of presenting knowledge and chosen to show the patient participant experiences in categories that capture the stages of the breast cancer and Spiritual Healing journey.

The pattern matrices summarise all common information from participants about the environmental and social context of living, including real or perceived barriers to self-actualisation. All information is deemed relevant and viewed and understood contextually, not separated into academic categories for independent analysis, but separated into experiential categories for ease of presentation. The propositional matrix for breast cancer (Table 9.1) shows the shared pattern manifestations of breast cancer from diagnosis, through treatments to long-term adjuvant hormonal therapy, as reported by a group of women who elected to receive Spiritual Healing.

Table 9.1 Propositional matrix of shared pattern manifestations – breast cancer

Diagnosis	Treatments – surgery	Treatments – chemotherapy/ radiotherapy	Treatments – hormonal therapy	Long-term manifestations of medical responses
<p>Change date Enforced pattern change Huge shock – no fit with profile of breast cancer Loss of certainty Speed of medical intervention Disclosure Privacy Fear of cancer</p>	<p>Fear of cancer First stage Get rid of cancer Lumpectomy? Mastectomy? Reconstruction? Right choice? Returning home Waiting for surgery results Clear margins? Living with surgery scars Less sexually attractive</p>	<p>Fear cancer may not be cleared Personal battle Chemotherapy Right choice? Well-known side-effects Dread of side-effects Chemo is a full-time job Seemingly unending Hope it works One day at a time Radiotherapy Unexpected burns – raw meat Extreme pain/ distress</p>	<p>Fear cancer may return Less medical support Hot flushes Joint aches Night sweats Tiredness Oncologists not interested in side-effects Weight gain Don't like to complain Constant reminder of cancer Frightened to miss taking tablets</p>	<p>Fear cancer may return Permanent change of life pattern Cancer stops you realising your dreams Uncertain future My body has let me down Loss/regrets Medication ritual Physically can't pursue activities Time is precious Cancer is with me every day Scarred body Loss of intimacy</p>
<p>Experience:</p> <ul style="list-style-type: none"> • Discovery of a lump • Become breast cancer patient • Shock • No adjustment time • Loss of certainty • Knowledge of other cancer deaths • Speed of medical processes 	<p>Experience:</p> <ul style="list-style-type: none"> • Surgery – mastectomy or lumpectomy • Reconstruction choice • Removal of lymph nodes • Discharge after 24 hrs • Returning home changed • Living without a breast or scarred • Loss of intimate relationships • Waiting for results of surgery 	<p>Experience chemotherapy:</p> <ul style="list-style-type: none"> • Choice • Oncologist recommendations • Known side-effects • Physically tough • Loss of hair • Joint aches • Tiredness • Nausea • Chemobrain' <p>Experience radiotherapy:</p> <ul style="list-style-type: none"> • Badly burnt • Pain 	<p>Experience:</p> <ul style="list-style-type: none"> • Less clinical contact • Shock at side-effects • Hot flushes – up to 30 per day • Tiredness • Joint aches • Nausea • Night sweats • Disturbed sleep • Oncologist trivialised side-effects • Hurried and insensitive consultations • Fear of cancer return 	<p>Experience:</p> <ul style="list-style-type: none"> • Being treated like you still have cancer • Uncertainty of the future • Continuing physical effects • Lifestyle change • Diet change • Awareness of media coverage of cancer • Sense of loss/regret • Unable to work • Unable to pursue hobbies • Loss of intimacy • Greater awareness of being loved

<p>Perception :</p> <ul style="list-style-type: none"> • Breast cancer patient from now on • One day fit and healthy; next day a wreck • No time to prepare or adjust • I don't fit the profile – no family history • It's not something I have catered for • Life at risk • How will others handle the diagnosis? • Little time to reflect 	<p>Perception :</p> <ul style="list-style-type: none"> • Fear of surgery • Mutilation • Choice influenced by others • Get rid of the cancer • Alone after surgery • Fragile body • Too old for reconstruction • Reconstruction as mutilation • How will my body be perceived by others? • Less sexually attractive 	<p>Perception chemotherapy:</p> <ul style="list-style-type: none"> • Chemotherapy will kill the cancer • Oncologist knows best • Loss of mental agility • Managing hospital appointments is a full-time occupation • Unending and repetitive chemotherapy • Dominates life <p>Perception radiotherapy:</p> <ul style="list-style-type: none"> • Burnt to a frazzle 	<p>Perception :</p> <ul style="list-style-type: none"> • On your own • Unending treatment • Very tired of all the side-effects • Constant reminder of the cancer threat • Oncologist not interested in side-effects • Complaining is perceived as ungratefulness • Oncologist too busy to deal with the impact of side-effects • Tablets prevent cancer return • Overriding perception of continuing risk 	<p>Perception :</p> <ul style="list-style-type: none"> • Cancer is a constant companion • Still at risk • Cannot move on • Physical effects a constant reminder • Awareness of things they don't want to lose • Awareness of things they haven't done • Time is precious and limited • Not the same person • Make changes to prevent cancer returning • Cant realise previous plans • Unable to talk to family about cancer • Felt closer to family
<p>Expression :</p> <ul style="list-style-type: none"> • I remember the exact day and date • Disbelief – how could this happen to me? • Sense of knowing • Awareness of mortality • Difficulties in informing family • Choices of whom to tell • Getting on with it 	<p>Expression :</p> <ul style="list-style-type: none"> • I remember the exact date of my surgery • Deep sense of loss • Subjugation to life-saving medical processes • Minimising medical interventions • Panicky • Wanted to run and hide • Could not 'join in' • Terrific sadness • Choice of clothes – make even more effort to look nice • Fear of the unknown 	<p>Expression chemotherapy:</p> <ul style="list-style-type: none"> • Cover all my options • Scared witless • Distress • Couldn't remember a thing • It's tough • Turn inwards <p>Expression radiotherapy:</p> <ul style="list-style-type: none"> • Stayed at home • Could not wear anything on the burns 	<p>Expression :</p> <ul style="list-style-type: none"> • Mentally and spiritually wearing • Counting down the time • Prevented from doing everyday activities • Weight gain • Selecting oncologist • Talk to breast cancer nurses/other patients • Don't bother the oncologist • Tablet-taking ritual 	<p>Expression :</p> <ul style="list-style-type: none"> • On your mind every day • Medication ritual • Living with imperfect body • No patience to deal with trivia • Changed attitude to life • Change diet and lifestyle • Don't plan too far ahead • Reliance on others for homecare • Financial reliance

9.2 Propositional knowledge: the breast cancer journey

Chapter 3 outlined contemporary literature regarding breast cancer and highlighted the medical pre-occupation with the physicality of breast cancer and its treatments. I concluded that the literature had neglected the impact of breast cancer on women's life patterns. Breast cancer is the thief of certainty and the narrative accounts illustrate how diagnosis and treatments rob women of their physical well-being and certainty in the future. It is clear that the diagnosis of breast cancer is life-changing, a forced change that is not anticipated or planned for. Indeed, none of the participants in this study had perceived themselves as 'at risk' for breast cancer and so were not prepared for the diagnosis or the medical processes that moved rapidly, taking precedence over previous life patterns, sculpting them into breast cancer patients.

9.3 Common physical responses

Patient participants reported physical experiences of their medical breast cancer treatments that reflected many of those documented by other researchers and outlined in Chapter 3. These include:

- After surgery – pain
- During and after chemotherapy – pain, joint aches, nausea, fatigue, hair loss
- During and after radiotherapy – pain and burns
- During hormonal therapy – menopausal symptoms of hot flushes, fatigue, nausea, joint aches and night sweats

Although participants were aware beforehand of some of the possible side-effects of their treatments, most were unaware just how wearing their treatment regime would become. The women who had radiotherapy had no idea that they would be so badly burnt, and those who received chemotherapy were unaware of the length of time the treatment would take, or of all the potential side-effects. None was aware of the array of potential side-effects from taking hormonal therapies, or that the side-effects would be so long lasting and impact on their lives to such an extent.

Other issues became apparent in this study. Several participants gained weight (a common side-effect of hormonal therapies) but attributed this to their own behaviour – giving themselves 'treats' while undergoing treatment. While they

seemed to feel these treats were justified at the time, they complained that it was hard to lose the weight now. The women felt their body was no longer reliable. This was exacerbated by health issues that, although medically known to be possible side-effects of cancer treatments, were not attributed to their cancer treatments by patients. Rheumatism and joint aches were linked by the women to age and/or bodily decline, rather than being seen as side-effects of chemotherapy (Loprinzi et al. 1993) and/or hormonal therapy (Ganz 2001). Likewise radiotherapy has been shown to cause fatigue (Mock et al. 2005; Wratten et al. 2003; Bower et al. 2000), but the women attributed their tiredness to poor sleep patterns.

One of the criteria for inclusion on to the study was that women should have bothersome side-effects to their adjuvant hormonal therapies, but it became clear that, as one treatment had followed another, it was not always possible simply to allocate a side-effect to just one treatment. For example, the menopause and menopausal symptoms may be induced by chemotherapy, the withdrawal of hormone replacement therapy and/or adjuvant hormonal therapies; all can have similar on-going side-effects (Ganz 2001). While the physical side-effects of treatments were intrusive in the lives of the patient participants, they were given little or no recognition by their doctors. Indeed, at a meeting I had with one breast care team I was told that their patients did not have side-effects as they were given medications that '*dealt with all that*'. The data support the observation that the impact of these side-effects is trivialised, as exemplified by the oncologist's response when Foxglove asked how long her side-effects would last: '*5 to 7 years – I suggest you get used to it.*' Women responded to this attitude either by selecting a clinic doctor that they felt would be more understanding of their concerns, or by not discussing it at all. Those who did not discuss it felt it seemed ungrateful to complain to doctors who had saved their lives, or that it was not appropriate to 'bother' such a busy person. Instead they referred to the breast cancer nurses, other patients, friends and the internet for information.

9.4 Common emotional responses

To cope with the side-effects of treatments, all of the women seemed at times to 'turn in on themselves', drawing on inner strength and focusing on getting through the moment. Indeed, there were occasions when coping moment by moment was all

they had the strength to do. Throughout the narratives is a sense of ‘getting on with it’; a personal struggle with a body that had let them down (by getting breast cancer) and with the body’s responses to life-saving medical treatments.

With breast cancer there is not a gradual decline in health, as with ageing, but a sudden change from being fit and healthy at the point of diagnosis to being a cancer patient thereafter. However, the full emotional impact of breast cancer is not instant. The shock of diagnosis is instant but there is a growing awareness of the implications of breast cancer over the ensuing months and years, as old life patterns are lost or adapted to incorporate breast cancer and its treatments.

9.4.1 The birth of fear

The data illustrate that fear is born at the point of discovery and diagnosis of cancer. Fear becomes a constant companion, affecting every aspect of life and every thought. Fear is dynamic and changes as treatments progress and patients adapt. Initially fear focused on their breast cancer and its treatments. Participants expressed fears around their choice of surgery and the actual surgical procedures. Although pain after surgery was to some extent expected, none of the patients was prepared for their early discharge from hospital with draining tubes still in place. Indeed, returning home so soon after surgery, feeling very fragile and without time to adjust to their new physical state, caused a sense of panic, fearing the unknown regarding their health and their ability to cope.

After surgery, fear intensified as the women awaited the results of surgery to ensure that all the cancer had been removed. Once clear margins had been established, patient participants’ fear focused on the side-effects of chemotherapy and/or radiotherapy. After completing these initial treatments, when patient participants started taking long-term hormonal therapy, fear mutated to a fear of cancer’s return.

Why a woman gets breast cancer is not known and the contributory factors change as different sciences seek to explain the disease. The Office for National Statistics (2009) shows breast cancer is linked to a woman’s reproductive history, use of oral contraceptives or hormone replacement therapy, obesity and alcohol consumption. Yet none of the patient participants felt they fitted into the at-risk groups, as they

perceived them. It seems if it were possible to attribute breast cancer to ‘something’ or ‘some action’ that patient participants could avoid in the future, it would relieve some of the fears expressed around the possible recurrence of cancer.

9.4.2 Loss and regret

Linked to fear there was an undercurrent of loss and regret. Participants felt their body had let them down and spoke of losing their breast with deep sadness, expressing the loss as a bereavement for which they grieved. They also lost their autonomy as the medical processes took control of their lives, creating treatment routines that must be followed and hospital appointments that must be attended. The loss of life’s certainties, the loss of their previous life pattern and the loss of a planned future, as a result of breast cancer, exasperated their sorrow. The women rarely expressed fear, loss or regret in their daily logs and it was only during the one-to-one interviews that all of them expressed, often tearfully, their sense of bereavement.

Throughout the narratives there was a sense that breast cancer is a personal journey, a traumatic struggle for which women must find inner strength. Within cancer there have been many studies looking at emotions and emotional suppression resulting from psychological distress, denial or hopelessness (Falagas et al. 2007). This study found that patient participants did suppress emotions, but this suppression was not linked to a sense of hopelessness or denial of their cancer; they simply wanted to cause less worry to family and friends and to deal with their disease in their own (private) way; ‘getting on with life’ as much as possible.

9.4.3 Emotional support

Gonzalez and Lengacher (2007) found the most common type of support given to breast cancer patients was emotional support in the form of communications of compassion, caring and concern, and this study found participants received their emotional support from family and/or friends. The level of support was not linked to the strength of the relationship prior to their diagnosis, in contrast to previous research which made such links (Gonzalez and Lengacher 2007; Shapiro et al. 2001). A few participants’ family members and one husband found it difficult to know how to deal with their loved one’s breast cancer, reflecting the findings of

Harmer (2006), and at times seemed emotionally distant and unsupportive. Yet the majority of our participants felt more aware of being loved. Contrary to the findings of Holmberg et al. (2001), those not in a long-term relationship did not appear to be sadder, angrier or more hurt than others. They found the love and support offered by friends or geographically distant family very comforting and reassuring. Indeed, there were times when they expressed relief at being able to be unwell alone, perhaps remaining undressed and ungroomed, without having to consider how that might impact on a partner or family.

9.4.4 Intimacy

Several participants talked of a loss of intimacy, with increased sensitivity around their partner viewing or touching the scarred breast or the missing breast area. Concurring with previous research (Arndt et al. 2005; Kroenke et al. 2004; Fallowfield et al. 1986), there does not appear to be any link between the type of surgery (lumpectomy, mastectomy, reconstruction) and loss of intimacy. The results from this study are mixed. Regardless of surgery type (mastectomy or lumpectomy), the women felt there was a period of adjustment in their relationship, and for some there was the development of a new intimacy that accommodated the scarred or missing breast. For others that aspect of their marriage continued to be missing and this was a source of sadness and emphasised their sense of being alone in their breast cancer battle. Only one had reconstructive surgery in the hope of regaining her pre-cancer intimacy with her husband, but her loss of all physical interactions continued after reconstruction, which was a great sadness for her.

9.5 Spiritual responses to breast cancer

While there were variations in experience, it was common for the women to concentrate on the physical and emotional responses to each stage of their treatment and none reported a spiritual response to breast cancer. It seems that, although all were aware that they could die from breast cancer, while they were undergoing treatments their focus was on getting through each day, coping with the treatments and their side-effects. This left little time or energy to address their spiritual needs or concerns. Indeed, the spiritual impact of breast cancer was not addressed at interview until I asked patient participants about their belief systems. This may be because spirituality is not usually discussed in the context of breast cancer, but it

may be indicative of the physical priorities of participants and of orthodox medicine at the time of diagnosis and treatments.

9.6 The experience of life pattern changes

It is clear from the data that breast cancer was part of every day for the women in this study, and that there were constant reminders of their changed health status. The daily rituals of tablet taking acted as a constant reminder of their status of 'cancer patient', concurring with Payne et al. 1996. In some instances family members checking patients had taken their tablets reaffirmed they were breast cancer patients and denied the privacy of 'getting on with it'.

The women on this study were in the age range 52 – 66 years and as such grew up in a post-war era where media propaganda idealised images of the large-busted, fuller-figured woman such as Jane Russell and Marilyn Monroe. This idealised image of womanliness potentially heightening their awareness of their changed body shape (for women who had mastectomies there is a breast missing and for those who had lumpectomies there is the scarred and misshaped breast). All participants had to change their previous style of bra and several encountered problems finding a suitable bra that could either incorporate a prosthesis, or comfortably accommodate their new, post-surgery shape. There was no support or advice available to assist patient participants in this aspect of living as a breast cancer patient within the breast cancer clinic and help had to be sought through other patients or from the internet. None of the patient participants wore low necklines and many made an extra effort to 'look nice' and changed their choice of clothing to allow for their changed body shape.

The loss of physical well-being, with many patient participants tiring easily, meant they were less able to pursue old activities and had to tailor their activities to reflect this. Great sadness accompanied the loss of previously enjoyed family activities and hobbies, and the change from family care provider to being cared for.

9.7 Propositional knowledge: the Spiritual Healing journey

While patient participants were invited to join the study because they were suffering from the side-effects of their hormonal therapy, they came with physical and

emotional baggage from their breast cancer journey and also health issues not linked to breast cancer. As far as the study was concerned this was not problematic as Spiritual Healing is believed to flow to where it is needed, unlike targeted therapies that focus solely on specific areas of concern. The propositional matrix (Table 9.2, p162) shows the shared immediate and long-term mind, body and spirit pattern manifestations of breast cancer patients receiving Spiritual Healing.

Table 9.2 Propositional matrix of shared pattern manifestations – Spiritual Healing

Spiritual Healing	Long-term manifestations of Spiritual Healing
<p>Physical relaxation Physical sensations Emotional release How can it work? Side-effects of hormonal therapy improved Smoothes around the edges More energy Able to cope Feeling calm and mentally relaxed Inner peace Serenity</p>	<p>Previous effects of healing maintained Side-effects of hormonal therapy improved More energy Able to cope Feeling calm and mentally relaxed Inner peace Quality of life Control over life Review of work/life balance Getting on with life Seeing a future Fewer GP visits Improved intimacy</p>
<p>Experience</p> <ul style="list-style-type: none"> • Desperation (life with side-effects) • Curiosity – what is healing? • Deep Relaxation • Heat from healer's hands • Physical sensations during healing • Emotional release • Decline or cessation of hot flushes • Decline or cessation of night sweats • Sleep improved • Joint aches eased • Long-standing health issues eased • Feeling calm • Less depressed 	<p>Experience</p> <ul style="list-style-type: none"> • Decline or cessation of hot flushes • Decline or cessation of night sweats • Sleep improved • Joint aches eased • Long-standing health issues eased • Feeling calm • Less depressed • Empowerment • Re-engagement with relationships

<p>Perception</p> <ul style="list-style-type: none"> • Difficult to relax • 'Me time' every Friday • Can't explain it • Relaxation becomes the norm • Hot flushes not a problem, no longer embarrassing • Less tired • Sleep patterns have improved • Joint aches eased • Long-standing health issues eased • Feeling calm • Less depressed • Fear improvement won't last 	<p>Perception</p> <ul style="list-style-type: none"> • Joint aches eased • Long-standing health issues eased • Feeling calm • Less depression • Quality of life most important • Seize every opportunity • Awareness of mortality • Optimistic about the future • More energy • More relaxed • Fear improvement won't last • Need a 'top up' healing • Less anxious about cancer's return
<p>Expression</p> <ul style="list-style-type: none"> • Continuing with hormonal therapy • Trying to see what's happening in first session • Eager to get to 'me time' • Tears of emotion • Feel weight lifted • Can engage in 'old' activities (knitting; sewing; baking; outings) • Not so stressed • Less short-tempered 	<p>Expression</p> <ul style="list-style-type: none"> • Continuing with hormonal therapy • Feel weight lifted • Can engage in 'old' activities (knitting; sewing; baking; outings) • Not so stressed • Less short-tempered • Reprioritising chores, going out when offered the opportunity • Can see a future (Buying new furniture; redecorating; planning holidays) • Support system from GP not needed any more • Seek out healers

9.8 Common ‘body’ responses to Spiritual Healing

Participants reported that the side-effects of cancer treatments were either completely alleviated, or much improved and less intrusive after Spiritual Healing. Although concerns regarding the ability to relax were expressed at the first Spiritual Healing session, physical relaxation was reported by all of the women. Joint aches either completely stopped or participants experienced much less pain. Hot flushes and night sweats stopped or became less frequent and severe and thereby less bothersome. Improved sleep meant several participants could stop taking medication to aid sleep and enjoyed a ‘good night’s sleep’ for the first time since the start of their breast cancer journey. Some long-term health issues were resolved during the course of Spiritual Healing; others improved but were still present at the end of the 10 healing sessions. No new symptoms or unpleasant or negative feelings were reported.

9.9 Common ‘mind’ responses to Spiritual Healing

As with any new experience, the first Spiritual Healing session was approached with curiosity and a little trepidation. Subsequent sessions were often eagerly anticipated. Relaxation is a well-documented effect of Spiritual Healing (Pohl et al. 2007; Vaghela et al. 2007; Brown 1995), but what is not documented is the effect such relaxation has for the healee. The relaxation was not just the physical letting-go of body tension, but also mental relaxation and a letting-go of emotional stress. This was sometimes experienced as a tearful interlude at the end of the first session of Spiritual Healing, when patient participants spoke of an emotional release as though ‘a weight had been lifted’ from them. After subsequent Spiritual Healing sessions patient participants felt ‘chilled’, calm and elated. These responses were common across the group of patient participants and appear to be more than a response to 40 minutes’ physical rest. Spiritual Healing seems to have had a cumulative effect and patient participants reported feeling calmer, less anxious and less short-tempered as their course of Spiritual Healing progressed.

9.10 Common ‘spirit’ responses to Spiritual Healing

Often patient participants found it difficult to find the words to explain the new sense of being they experienced after Spiritual Healing. While some spoke of calm or peace, others talked of a sense of serenity and a new sense that they can cope

with life. These senses lifted some anxiety regarding the possible return of breast cancer, but the fear of breast cancer's return never completely faded. It would appear from the words expressed that the term 'spiritual', as in Spiritual Healing, is appropriate.

Surprisingly none of the patient participants felt that having breast cancer had altered their belief systems. It might be expected that there would be either increased religious activity, such as prayer or church attendance, among those who maintained a faith system, or the rejection of a faith that allowed breast cancer to happen to them. None of the women who had a deity-based religious belief system asked, 'Why me?' or blamed God for their cancer. Yet, while breast cancer brings human mortality into sharp focus, few focused on existential issues or changed their belief pattern.

9.11 General life pattern changes

The inclusion criteria for the study required that all the patient participants had completed their initial curative treatments for breast cancer and had been on long-term hormonal therapy for at least 6 months. In fact all the patient participants had been on their hormonal therapy for over a year and in some cases over 2 years. This time lapse between incurring the side-effects of treatment and the start of Spiritual Healing allowed any natural decline in side-effects to take place. Patients were already journeying towards a life pattern that accommodated their side-effects and any available social support was already in place. This implies that the changes reported are more likely to be attributable to Spiritual Healing than to the effects of natural changes over time.

At the first few healer consultations, the physicality of breast cancer was the key focus for the women. There are several speculative explanations for this. First, they had been recruited into the study because they had bothersome side-effects from their hormonal therapy. Second, breast cancer was at the forefront of every aspect of their daily life, with the constant reminders from the tablet rituals, the side-effects of treatment and the long-term physical and mental scarring. Third, participants might have been socialised into the patient role by other hospital interactions and thought that the required focus would be on the physical. However, it became apparent as

Spiritual Healing progressed that other aspects of daily life and activity were reported. Again, there are two potential explanations for this: the healers openness to hearing about all aspects of a patient participants' life and the fact that Spiritual Healing alleviated many of the side-effects of treatment, which enabled the women to focus on other functional and social aspects of life, rather than just 'getting through'. These two explanations are not mutually exclusive. However, it was evident from the narratives that the decline in the impact of physical side-effects and the energising effect of Spiritual Healing meant that many women started to re-engage with their old life patterns. Not all these ways of being were open to them, because of the physical limitations of breast cancer. However, engaging in any aspect of the previous 'healthy' self allowed the women to focus beyond getting through breast cancer to a new life pattern, and was a boost to their morale. They regained a belief in a long-term future and an interest in their environment (exemplified by holiday plans, the purchase of new furniture and the redecoration of their homes). Alongside this there was a decline in visits to the GP for support.

Co-existing with this engagement with a longer-term future and concurring with contemporary research findings (Bertero and Wilmoth 2007; Kroenke et al. 2004; Ferrell et al. 1999), there was acknowledgement that time is a precious, and possibly limited, commodity. Participants spoke of reprioritising life with a new work/life balance and a 'seize the moment' attitude, whereby activities were not put off for another time (as previously) but every opportunity enjoyed as it was presented.

Old patterns of behaviour also started to become apparent in family life, as family and friends reverted to former patterns of behaviour that existed before the cancer journey. This proved difficult for those who still felt the need to have their breast cancer acknowledged and wanted the space to express health concerns. In this regard the Spiritual Healing sessions offered a place to share their concerns and reflections on their breast cancer journey. While it was not the aim of this research to understand the mechanisms of Spiritual Healing, this suggests that some of the positive benefits attributed by the participants to Spiritual Healing itself could also be attributed to the non-specific effects of 'me time', the opportunity to share experiences with an empathetic and impartial healer.

It is not currently known how long Spiritual Healing effects last, as it seems to vary with each patient. Some participants noted they ‘need healing’ in their patient’s log only a few days after a Spiritual Healing session, while others felt the effects lasted between sessions. At the end of their 10 healing sessions, all but one patient participant expressed concern that the effects of healing would not last and some were keen to continue with Spiritual Healing beyond the confines of the study. Irrespective of initial scepticism, social background and religious belief system, without exception all the participants claimed they benefited from the Spiritual Healing they received, as detailed in their own words in presentational knowledge (Chapters 8) and earlier in this chapter. None felt the need to have a respite from their treatment side-effects in the form of a ‘drug holiday’ while on the study.

The categories of the matrices in this chapter were created by me from a synthesis of the patient participants’ presentational knowledge of breast cancer and Spiritual Healing. Each category acts as a bridge between the previous life pattern and the next, and shows the evolutionary progression of a life journey through breast cancer and Spiritual Healing. In order to present this knowledge in other forms that may reach out to different people, I created a storyboard and a poem. These were verified by the patient participants and the healers. Exemplars of responses from patients, healers, nurses and fellow academics are used to illustrate participants’ responses to both the storyboard and the poem.

9.12 The storyboard

The storyboard that follows is a visual representation of the matrices. The pictures that form the collage are all representations of the patient participants’ life pattern including hobbies, family life, moving house and physical perceptions of femininity.

The first panel is the life pattern prior to breast cancer with representations of breasts and underwear, family, socialising and holidays. It also includes activities related to individual patient participants: horse racing (Sweetpea); gardening (Foxglove); baking (Sweetpea); grandchildren (Violet); visiting gardens and National Trust properties (Camellia); aerobatic flying (Foxglove); skiing (Paintbrush); selling houses (Jasmin, Camellia); trampolining (Snowdrop); swimming (Paintbrush); knitting and sewing (Violet, Fuchsia, Snowdrop); surfing (Foxglove).

There is a gap before the next panel. This reflects the blankness of life at the moment of diagnosis, the void before the medical processes of curing cancer start. The second panel, in black and white, represents the starkness of life and possibly death with breast cancer. The pain, the drugs, the procedures become the daily focus of the patient participants. 'Normal' life has disappeared, lost in the seemingly endless medical interventions of breast cancer. This panel also shows the birth of a fear, a raw fear that is to become a constant companion.

The third panel shows the parts of the life patterns that have been taken by breast cancer and the start of adjuvant hormonal medication. The tendrils of fear affect every part of the panel now, as they affect every part of the patient participants' life at this stage. This panel has muted colours to show how the attempts at re-engagement with old life patterns lack their previous vibrancy.

The final panel shows the impact Spiritual Healing had on the life patterns. The tendrils of fear are more spaced out to show that, although fear is still present, it is not part of everything but comes to the fore now and again, when patient participants engage in particular activities. While some of the gaps created by breast cancer are filled with a new acceptance, some remain just empty. There are also pictures added which indicate new life patterns – for example, fruit indicating dietary changes adopted by some patient participants.

A copy of this storyboard now hangs in the Harry Edwards Healing Sanctuary in the room they use for their cancer support groups.

9.12.1 Comments

Some of these comments were anonymous, but where a respondent put a name this is shown after the quotation.

I found the storyboard extremely indicative of the many emotions I felt during the journey. Violet

I love your storyboard. It describes my situation perfectly. Fuchsia

Very well presented – the first section everyone’s normality, then the black and white of the cancer journey, then slowly back to as much more normality, making you a much stronger person. Anon

Very true to life. I like the way you show how the fear is never quite gone, we just learn to live with it. Yet life is even more beautiful. Anon

I really like the poster. The first part shows normal life, black and white is colourless and bloodless – displays ‘fear’ well. Third panel v. effective showing how only part of life is returning. 4th panel eye catching – love the purple. The storyboard shows all my thoughts and is brilliant. Daffodil

Very visually descriptive of the life journey. Anon

Intriguing – thought provoking and a true reflection on the cancer journey. Well done. Jasmin

Very thought provoking. Poster shows before, The fear, After and ‘as time goes on’. Anon

I like the storyboard very much. It has been well thought through and delivers much more impact than that of a lengthy document. I like the way you have shown colour in life pattern and then cancer in black and white and then gradually brought back colour and normality into the recovery pattern. It is very much like that, the dark

areas become less and less over time, and I feel Spiritual Healing helped this process. Rose

The storyboard is a bit more appropriate to me (than the poem). Foxglove

I think this is very visually descriptive of the cancer journey and certainly that of the ladies from the study. Fear and letting go of fear is central to the theme and progress of the cancer journey. Toni

The storyboard is very good, all the things that we take for granted are there. From my own personal experience, everything you are born with, I thought I would keep. Everybody knows one day they will die but to be told when, like many cancer patients, is totally horrifying. To have to plan your own death because you know when it is going to be. Cancer changes your life and your body and the storyboard shows this really well. The Spiritual Healing helps you to accept all these changes, takes much of the stress and pain and the different problems your body encounters with the new journey it has to take. The healing definitely helped me to accept this new path I had to take and has helped me to become stronger. Snowdrop

Not all the patient participants agreed with the story board.

I found the storyboard quite confusing and bit too busy. Sweetpea

Paintbrush felt that there should be a representation of God on the board, with His influence shown as tendrils reaching into every aspect of cancer and recovery.

9.13 The poem

I wrote the following poem to capture my experiences as an onlooker watching women on their cancer journey. I wanted to show my participation experiences and to reach out to the reader in a different way.

Should I hold your hand when you hear your body has deceived you and your safe world is no more?

Should I hold your hand as you become patient; diagnosed, cut, poisoned, burnt, managed, treated?

Should I hold your hand as you struggle through treatments with uncertain outcomes and fear holds your heart?

Should I hold your hand when the image you see in the mirror taunts your frail femininity?

Should I hold your hand when you reach for 'normal' but 'normal' eludes you?

And who will hold my hand, for my fears for you my beloved are overwhelming?

Fiona Barlow

October 2008

9.13.1 Comments

The poem was shown to the patient participants and healers and their comments are as follows (again some of the comments are anonymous).

T [husband] and I read the poem together and found it very apt, as it truly captures the whole spectrum of emotions the whole family experience, especially your partner. Violet

Very lovely, shows a great understanding of being in the shoes of those who are unwell. The word 'managed' is very apt. The last sentence displays vulnerability, which is touching. Stephanie

Very moving and shows how illness is just as frightening for those who love you as it is for you. This poem gave me a lump in my throat. Anon

May I have copy of the poem please – it rings my bells. Jasmin

Very moving and insightful. Anon

I particularly like the poem. You have cleverly captured and used all the information that we patients have given you, i.e. diagnosis, treatment, feelings, etc. depicting this in a poem showing it from a completely different perspective from that of the family member/ friend/carer. I felt quite emotional when I read this. Well done!! Rose

Poignant and emotive, paints a picture. For me it works better than the picture. Anon

I felt the poem was very moving and poignant (sorry re spelling), reflecting the struggle of the cancer patient and their supporter and how difficult it is to know what to do. Also who helps the helper? Toni

The poem made me cry. Sweetpea

The poem brought a lump to my throat. Daffodil

The poem is also very good – a few words saying a lot of things. Snowdrop

Not all patient participants agreed with the poem.

Up to the last stanza I could only think how God or Jesus not just held my hand, but held me in both hands, enveloped me with His presence and power (healing) all the way through. But the last stanza doesn't fit, as God is not overwhelmed or has fear, only peace. Now that life is pretty much back to normal I have to work extra hard at keeping Him close. I would end the poem with –

Please hold me tight and never

Leave me through this journey.

You're the only one who can go with me. Paintbrush

9.14 Conclusions

Previous studies of Spiritual Healing that have addressed the quality of life of women with breast cancer have focused on its physical, emotional and functional consequences, using a battery of quantitative outcome measures administered periodically throughout the study to measure predefined quality-of-life variables. Through the use of UAI it has been possible to capture and integrate women's experiences of Spiritual Healing in the context of breast cancer, unconfined by predetermined criteria. The lack of disciplinary boundaries has provided a holistic view of women's experiences. The presentational knowledge, synthesised here as propositional knowledge, makes it clear that all of the women in this study benefited from Spiritual Healing. No patients reported any negative experiences associated with it.

The final chapter provides practical knowledge for the future care of breast cancer patients in the 21st century.

Chapter 10.

Practical knowledge

'When the body is ill, life is experienced through the lens of that illness.'

B. Trowbridge (2006). *The hidden meaning of illness. Disease as a symbol & metaphor.*

10.1 Introduction

The aim of this study was to identify any positive or negative effects of Spiritual Healing within the context of women's experiences of breast cancer. While the majority of breast cancer research has addressed the medical and physical aspects of the disease, I identified that it had not encompassed the total experience of women whose lives are sculpted by breast cancer and its treatments. This has particular relevance to this study because it is important to be able to capture the full range of effects of Spiritual Healing in a holistic way. This qualitative study has focused both on the experiences of being a breast cancer patient and the experience of receiving Spiritual Healing, using a participatory method to capture all aspects of both. The results offer new insights into the lived experience of the disease and its treatments, and provide new information about the nature, range and extent of responses to Spiritual Healing.

The findings support many previous observations concerning the physical, emotional and social impacts of breast cancer in women. These have been elaborated to reveal the extent to which women continue to struggle with these in the long term. Clearly, this study gives no insights into the extent of these continuing problems within the population, since it is possible that the women in this study represent a small and unique sub-group of the population which is sufficiently concerned to seek help in the form of Spiritual Healing. However, in spite of the assertions to the contrary by some of the doctors encountered during this study, the literature would indicate that the adverse consequences of treatment described by the women are both common and intrusive.

The responses to Spiritual Healing observed in the data from this study appeared remarkable. I witnessed these for myself as the participants left the healing room. My observations were supported by those of the healers, were present in the daily

logs kept by the women and elaborated upon by the women at interview. Reports of reduction in a range of physical symptoms were common, but even more notable were the reports of calmness and acceptance that appear to reflect the emotional and ‘spiritual’ effects of Spiritual Healing. All of these improvements helped to restore functional and social aspects of the women’s own lives. Clearly, it is not possible to change practice or introduce new interventions in the absence of reproducible evidence. Therefore it is important to consider these observations in the context of a critical review of the strengths and limitations of the study.

10.2 Strengths and limitations

This was a small study that involved a self-selected group of women. Therefore, no claim is made that the findings represent the experiences of all breast cancer patients. However, there are good reasons to claim that the findings represent the experiences of women who might potentially benefit from Spiritual Healing as a complementary therapy for a range of problems commonly associated with breast cancer and its treatments. The participatory approach used facilitated the sharing of intimate and emotionally sensitive information between the women, the healers and the researcher. The fact that all were women probably helped to establish a bond and the sharing of ‘women’s talk’ allowed access to aspects of the patient participants’ life patterns that might not have been available to a male researcher. The triangulation of data from a variety of immediate and retrospective sources, including observational and self-reported data, helps to demonstrate the trustworthiness of the data.

Four healers took part in the study and, during their sessions of Spiritual Healing, most patient participants had healing from more than one healer. There were no apparent differences in their reports between the two participants who had one healer and the reported outcomes from those who had two or three healers. This suggests that explanations for the effects of Spiritual Healing may go beyond the benefits of having a one-to-one relationship between patient and healer.

There are always limitations in attempts to capture findings that reflect holistic ways of being, using a written and academic form. The study attempted to overcome this by the use of alternative representations of knowledge including the form of a

storyboard and a poem. These representations were checked and commented on by the participants to demonstrate trustworthiness. Rigour was addressed in this study through continuous researcher reflection and regular communications with participants to ensure the study reflected the wholeness, uniqueness and essence of their life pattern as breast cancer patients receiving Spiritual Healing. The analytical process remained faithful to the words of the patient participants as demonstrated by extensive use of direct quotations and extracts from all forms of data collected (patient participants' logs, session reports, field notes and interview transcripts) in the presentational knowledge in Chapters 7 and 8. All participants (patients and healers) verified the emergent findings to ensure my understandings were an accurate reflection of the experiences of the women in this study.

The UAI method seeks to be co-operative and therefore non-hierarchical, equalising out the power between the researcher and the researched; empowering the patient participants. Yet it must be recognised that such empowerment is difficult to achieve and may in fact be an illusion. Within this study, any anticipation on the part of the patient of the healer's knowledge and ability to make them feel better immediately puts the healer in a position of authority. As the researcher who organised the study, I may have had power conferred upon me by healers and patient participants, so although ideally this study seeks to be non-hierarchical, in reality this was difficult to achieve. At best, a sense of being a vital part contributing to the whole was achieved, through researcher deference to the knowledge and experiences of the other participants, which in turn may, or may not, have given individual participants a sense of empowerment. Below, I consider potential biases from each perspective in turn.

10.2.1 Researcher participant

I was the only researcher participant, so any personal impact I had on the other participants cannot be measured against other researchers. While the non-judgemental environment I sought to create allowed the participants to share intimate and emotionally difficult information, there was always a risk of 'researcher pleasing'. By researcher pleasing I mean that the patient participants might have wished to give me the results they thought were required. In order to avoid this, none of the participants (patients or healers) was aware that I was Reiki

Master. Also the continual reflective process and member checking would have highlighted researcher bias. In reporting any negative participant responses, this study sought to minimise any respondent pleasing that could have gone unnoticed, especially in the light of my own healing experiences as a Reiki Master. Indeed, I ensured that my supervisors were aware of my prior experiences of Spiritual Healing, so they would be able to challenge any evidence of biased intrusions, particularly during data analysis and presentation.

10.2.2 Patient participants

The criteria for patient recruitment were that they were breast cancer patients suffering from the side-effects of their cancer treatments. While qualitative research does not depend on a representative sample, the patient participants were self-selected, white women over 50 years old, who were able-bodied. Thus any differences in life pattern for patients are who are racially or ethnically different, younger women and non-able-bodied women were not addressed by this study and further research is required for these groups. It is not possible to compare the needs of the women in this study with breast cancer patients who might not choose to volunteer to participate in a study of this kind. Thus the presentational and propositional knowledge shared by our participants may not transfer to other breast cancer patients. All the participants were women and it must be recognised that a small number of men also suffer breast cancer and its treatments and this was not addressed by this study as it was anticipated that the issues for men would be different from those of women. Thus further research is required to gain knowledge of the impact of breast cancer and Spiritual Healing on male patients.

10.2.3 Healer participants

All the healers who worked on the study were female. This was not an intentional gendering; indeed, there were two male healers who started the approval process but for various practical reasons did not take part in the study. Therefore this study cannot indicate the extent to which the benefits of participation might have been due to a bonding between women.

10.3 Unanticipated study outcomes

The main purpose of this chapter is to summarise the findings that directly answer the research question. However, in considering the practical implications of these findings, it is impossible to ignore the problems that I encountered from orthodox medicine during recruitment into the study. It became very apparent that even such a non-invasive complementary therapy as Spiritual Healing was not likely to be embraced by some of the doctors in the breast cancer team. I can only speculate why this might be, but it is clear from the literature that currently there is a climate of academic mistrust between CAM and conventional medicine (Lewith et al. 2009). This may be based on misconceptions about what exactly Spiritual Healing is, or it may have been based on the lack of ‘acceptable evidence’. Medical practice is rooted in the philosophy of positivist science and while ‘the term evidence-based medicine has a ring of obviousness to it’ (Goldenberg 2005, p 2621), the nature of the evidence used in most medical research is very restricted to measures of cure, morbidity and mortality. It was clear from the literature review in Chapter 2 that we had little idea of all the aspects of life Spiritual Healing could affect. This study has identified the potential for Spiritual Healing to affect a wide range of outcomes, including physical, emotional, spiritual, functional and social. But these findings do not fulfil the criteria applied to scientific evidence at the present time, and there are considerable methodological challenges to overcome if such evidence is to be obtained in the future. However, observational studies such as this represent an important stage in acquiring an evidence base and it is therefore of concern that it encountered the difficulties described. This is all the more concerning in the light of the women’s accounts of treatment effects and the attitudes of those treating and caring for them during this process.

While medical science seeks better treatments and increased survival, it would appear that the medical gaze has to some extent disengaged from the human experience of living with breast cancer. It seems that while the body is ‘under attack’ from cancer, the main medical response is counter-attack and the individual woman, upon whose body the battle is mapped, is lost in the fervour of battle and medicine’s focus on victory over disease. The physical fallout in terms of side-effects has to be borne by women, who often feel their responses to the war are trivialised or ignored and whose voice, as a consequence, is silenced. My use of the

military metaphor in this context reflects ideas that are omnipresent in the media when referring to illness, disease and their treatments. My view that the woman at the centre of the battle is ignored reflects a feminist view of the medical structures that surround patients. Although not mentioned within the narratives, such ideas enhance medical stature and may subconsciously feed and sustain the tendrils of fear that attach to every aspect of women's life. In contrast, the non-judgemental approach of Spiritual Healing and the environment in which it is conducted may offer a refuge from the constant vigilance urged by the medical campaign.

Informal discussions with cancer physicians revealed a sense of helplessness in the face of failure to cure the disease and subsequent rejection of the idea that those working in complementary therapies could do any better. Wu et al. (2008) suggested that medical authority is slowly being eroded as physicians tailor treatment regimes to individual patients. Concurring with a growing body of evidence (Travaline et al. 2005; Kennedy 2003; Coulter 2002; Dowsett et al. 2000; Keonig 2000; Ellis 1999), the women in this study all wanted a patient-centred approach that recognised their individual needs. While the paternalistic 'doctor knows best' approach of many surgeons and oncologists was reassuring at diagnosis, and some patient participants found comfort in a continuing paternalistic approach, for many it became less acceptable as treatments progressed. They did not want simply to be passive and grateful recipients of healthcare, but sought to be fully informed about the treatments and possible ways to alleviate the side-effects. This change in patient needs was not recognised by the oncology team and patients' desire to be fully informed was not satisfactorily addressed. Overall, this finding highlights the need for each patient to be viewed as an individual human being and their care tailored to fit the experiences of the disease in the whole woman, not just her physical state.

Many patients found it difficult to discuss their side-effects with their doctor. While patients and doctors have the shared goals of removal of tumours (surgery); killing any remaining cancerous cells (chemotherapy/radiotherapy) and preventing cancer's return (hormonal therapy), specialist doctors do not appear to share other matters of importance to patients. Women whose life patterns are severely disrupted by the side-effects of treatments have physical, emotional and spiritual concerns that are

not shared by their doctors. It appears that once the patient's cancer is under control, many specialist doctors feel they have achieved their goal and can do no more. The experiences of the side-effects of treatment outlined in Chapter 7 are medically undervalued and women are often left to cope alone, prevented from fully participating in life at a level they had maintained prior to cancer, drawing on inner strength, frequently surviving one day at a time. This study has shown that Spiritual Healing does offer the potential to help women deal with these effects, thus supporting what should be a key medical aim to improve patient well-being, not just longevity. Even in the absence of a body of scientifically verifiable evidence, the findings of this study illustrate the potential benefits of complementary medicine working alongside orthodox medicine to improve mind, body and spiritual outcomes of breast cancer patients.

10.4 Conclusions and recommendations

The study at the centre of this thesis investigated the impact of Spiritual Healing in the context of women's experiences of breast cancer. Women recruited into the study had experienced the physical and emotional traumas of breast cancer and suffered from side-effects from initial treatments and from long-term hormonal therapy. Thus a wide range of potential impacts of Spiritual Healing were available for study based on immediate and reflective reports written in the women's own words, as well as observational data from the healers and my own informal observations as researcher.

All of the women reported positive responses to some degree and none reported a single adverse reaction or event during the study period. They reported that Spiritual Healing helped them with the physical and emotional legacy of cancer as well as that of on-going cancer-related treatment, thereby allowing them to re-engage with aspects of their previous life patterns that had been lost to breast cancer. Thus, functional and social benefits were observed in addition to the physical, emotional and spiritual benefits that might have been expected, based on the tenets of energy medicine outlined in Chapter 2. In particular, they reported emotional unburdening and a heightened sense of general well-being after their initial Spiritual Healing session that continued throughout their time on the study. Some women also found relief from additional long-standing health issues. Women were no longer

continuously held by tendrils of the fear that had pervaded every aspect of their lives. Instead, they noted a sense of serenity, peacefulness and inner peace and a belief in their long-term future. They also felt a sense of enhanced spiritual well-being. These positive effects helped the women to cope with the negative effects of long-term life-saving medical treatments. All of the women in the study said that they would recommend Spiritual Healing to other breast cancer patients. In hindsight, some patient participants felt it would have been useful at diagnosis, while others felt Spiritual Healing would be more useful after surgery or during chemotherapy/radiotherapy. All felt it had been useful while they were undergoing long-term hormonal therapy. Clearly timing is a matter of personal preference.

Recruitment into this study was difficult. It clearly proved very problematic for some medical staff, and even direct recruitment was not strong. Several participants commented that the term 'Spiritual' in Spiritual Healing might act as a disincentive for those who associate such healing with a particular religion, belief system or the occult. It might prove difficult to address this using an educative approach to dispel myths for health professionals unless or until the intervention demonstrates the standard of proof required by evidence-based medicine. In terms of the public, it is more complex achieving a standard of proof, although publicity of such proof would be beneficial. While the name Spiritual healing may hold certain erroneous assumptions for some members of the public, and changing the name might seem to be an easy solution, I would anticipate that Spiritual Healers would not embrace such a change, and there is the conundrum. Language is a very powerful but often subtle conveyor of meaning that is difficult to change. Clearly the Harry Edwards Healing Sanctuary, which sponsored this study, uses the term Spiritual Healing, but it is not clear if Reiki would be subject to similar levels of ignorance or prejudice. Therapeutic Touch, although a different form of energy therapy, has become more acceptable within the field of nursing, if not medicine, and this may be explained by claims of a 'scientific' explanation of its conceptual framework.

However, while the underlying paradigms for orthodox medicine and Spiritual Healing are essentially very different, the declared focus of both is the well-being of the patient. In contrast to the beliefs of some doctors, Spiritual Healing is a complementary and not an alternative therapy. It does not seek to usurp medical

authority in the management of physical health, but to work alongside it to enhance the patient's quality of life. Its chief advantages are that it is non-invasive and is usually available free of charge to those unable to afford it.

In recognition of the desirability of gaining acceptance within orthodox medicine, the study was originally conceived as the first stage towards a scientific trial of Spiritual Healing. The findings have already been used to inform the development of a healing-specific outcome measure (Bishop et al. 2010), in answer to the criticisms in Chapter 2 that medical outcome measures fail to capture the range of outcomes observed as a result of healing. The next step will be to conduct a 'gold standard' trial of Spiritual Healing to demonstrate any benefits over 'attention', 'placebo' or usual care. However, as highlighted in Chapter 2, questions remain regarding the duration of healing effects and a clear understanding of the mechanism of healing that would facilitate the identification of a suitable placebo intervention. Indeed, until such understanding is available, future quantitative studies may have to focus on Spiritual Healing in comparison to usual care.

In conclusion, this qualitative study has clearly demonstrated the potential of Spiritual Healing to improve physical, emotional, spiritual, functional and social quality of life for those facing significant health-related problems. Given these findings, practitioners working with those facing the challenges of diseases such as cancer should feel reassured that referral to a Spiritual Healer may confer tangible health benefits across a range of domains, some of which appear to be overlooked by conventional medical care. There is no evidence from this study, or the reviewed literature, of any harmful effects, provided the recipient has no expectation of cure. The experiences of conducting this study indicates there is a need to reassure those working within orthodox medicine that Spiritual Healing is a safe complementary therapy that seeks to support the aims of medical treatment, not undermine it.

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