An exploration of how the timing of colostomy following spinal cord injury impacts on the individual

Michelle Louise Boucher

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Abstract

An emerging phenomenon in one UK spinal injury unit is the earlier choice for colostomy formation following spinal cord injury. This represents a perplexing deviation from professionally developed guidelines and widely accepted practice. With no existing theory to account for this change, research was performed with those choosing colostomy formation at differing time points following injury. The aim was to understand more about individuals' experiences and the patient-initiated phenomenon.

Starting with an appraisal of the Wider Landscape in which the phenomenon emerged, the research journey was made using constructivist Grounded Theory. Four major categories were discovered. **'Experiences of Loss'** were found to result from bowel management practices. Reactions to this were either to 'get used to it' and '**Progress into Suffering'**, or to 'reject guidelines'. The decision to undergo colostomy formation then arose from either a 'continued lack of choice' in those who progressed into suffering, or as an 'active choice' for those who rejected guidelines. Common to all was the transformative experience which colostomy brought of '**Being Alive Again'**. The fourth major category, '**Failure of Care'**, was understood and developed in relation to the wider Ideological, Professional, and Institutional contributions to these failures.

The patient-initiated scientific revolution, which the choice of earlier colostomy formation represents, was found to stem from a rejection of professional bowel management guidelines developed through a biomedical lens which prioritises normalising physiological function. This clashes with insider perspectives which prioritise lifeworld goals and seek a bowel management method which will best accommodate the achievement of these goals.

This research presents new knowledge in an area not previously described. It is hoped this will make the choice of colostomy, found to transform *'Loss'* and *'Suffering'* into *'Being Alive Again'*, more widely known about and available for those living with a spinal cord injury.

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Special thanks go to the twelve participants who freely shared their experiences. Your words have echoed in my mind over the years, and you are a constant inspiration to keep going and get your important message out to the wider community of those with spinal injury.

Dedication

This thesis is dedicated to three of those participants, who I was so sorry to learn have passed away before completion of this research. With their relatives' permission, I name them and dedicate this thesis to Ken Barnes, Gary Leer, and David Turner.

"And whatever you do, whether in work or deed, do it all in the name of the Lord Jesus, giving thanks to God the Father through him." Colossians 3:17

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Section One:

Setting the Scene

Chapter One: Introduction

1.1 Introduction to the research field

This study focuses on individuals with Spinal Cord Injury (SCI) who choose to have a colostomy formed instead of more traditional methods of bowel management, and the timing of this choice. It arises from observation of this choice being made earlier following SCI in one UK regional spinal injury unit, at the novel time of during inpatient rehabilitation in the immediate months after injury. Although colostomy formation is an intervention permitted within clinical guidance discussed in the next chapter, it is not usual for it to occur at this early stage. This deviation from generally accepted practice is of interest and raises questions relating to clinical guidelines, professional practice, and patient choice which will be developed and explored in this thesis. The novel choice for earlier colostomy is of interest to investigate, as preliminary investigation reveals that knowledge is presently lacking.

This chapter will begin by contextualising the change in practice and identifying the gap in knowledge. The research aims and the question will be stated, and the chosen methodological approach discussed. The professional background of the researcher is introduced and their involvement in the area being studied. The final section of this chapter will provide an overview of the thesis.

1.2 Problem area for research and the gap in knowledge

Colostomy formation is a bowel management method included in national and international clinical guidelines for those with a neurological deficit which creates difficulty maintaining bowel function. This includes those with a neurological deficit resulting from SCI. The guidance produced by the National Institute for Health and Care Excellence (NICE) states that colostomy should be considered in those with SCI only when faecal incontinence severely restricts lifestyle and all other non-surgical and surgical methods have been considered (NICE 2007, 2020a). It is usually performed many years after SCI and only when all other options have failed (Edgar 1999; Randell et al. 2001; Coggrave et al. 2012; Cooper et al. 2019). Until recent years, practice within the spinal unit being studied has been aligned with these recommendations.

From 2013, a new trend was observed and has been described by this author, of individuals with recent SCI choosing colostomy at a much earlier stage (Boucher 2016). These newly injured inpatients, still undergoing inpatient rehabilitation and adjusting to life with a spinal injury, have not yet encountered the chronic bowel care problems which have traditionally led to colostomy being chosen, and have not yet exhausted all other options for bowel management as clinical guidance advises.

A literature search found relatively few studies concerning colostomy formation following SCI, and none describing it being chosen so early. Reasons why individuals are making this choice are unclear and curiosity about the new phenomenon was aroused. In an area in which there is relatively little research, and in which a variation from clinical guidelines has emerged, not enough is known about outcomes for patients. Questions emerged about the advisability of performing a colostomy so early after SCI. Might this lead to more complications related to the spinal injury or the colostomy? Would individuals regret making this choice so soon? What about accepted professional wisdom which has counselled individuals to go home and get used to living with a SCI before making decisions which will further alter their body? Should this deviation from accepted practice continue? Why are people choosing a colostomy so early?

As more questions emerged and preliminary literature searching was performed, no answers were found. A gap in knowledge was identified concerning those with SCI who choose a colostomy soon after injury. The preliminary literature search formed the starting point of the research journey and is developed in Chapter Two as an exploration of the Wider Landscape of the clinical context in which the phenomenon of those requesting a colostomy earlier has arisen.

1.3 Research aims and the research question

With so much not known, research and research methodology were needed which would produce a better understanding of why individuals make the choice to have a colostomy either early or later following SCI, and how this has impacted on their lives. Without this understanding, the other emerging professional and clinical questions could not be fully

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formed or answered. In tandem with the decision to perform research which would deepen understanding of choices, research aims and the question were developed.

The research aims are to:

- Explore choices made related to bowel care management
- Explore reasons for the decision to have an early colostomy
- Discover differences in experiences between those who have early or later colostomy

The research question is:

'What are the experiences of those living with SCI in relation to choices about bowel management?'

These aims and the question are designed to facilitate an openness to discovery and are appropriate for the starting position of research in an area where little is known, and the emergence of a new phenomenon is puzzling to professionals observing it. More detail about the journey of deciding methodology, research aims, and the research question is found in Chapter Three.

1.4 Methodological approach

The preliminary literature search found relatively few studies which investigate having a colostomy following SCI, and none concerning those with SCI choosing a colostomy in the early months following injury. With relatively little knowledge available the research design needed to be exploratory in nature (Rendle et al. 2019). The population of those with SCI who choose a colostomy is small, as will emerge in discussion of the Wider Landscape, and research which has been performed has therefore tended to have small sample sizes. The lack of existing knowledge, research aims and a question which seek to increase understanding of insider choices, and the small target population, guided the choice of methodological approach and methods for this research.

Several potential methodological frameworks were considered, and more detail is given about the journey to deciding the most appropriate framework in Chapter Three. The research aims and the question and reflecting on the personal ontological and epistemological position of the researcher, led to the decision to use a Grounded Theory methodological approach. This was narrowed to a constructivist Grounded Theory approach due to the position of the researcher as an involved professional, with this position now further explained.

1.5 Professional background of the researcher

The researcher is a Stoma Care Clinical Nurse Specialist (SCN) involved in the care of patients undergoing colostomy formation, including those with SCI. The role of the SCN includes preoperative counselling, specialist nursing care and patient teaching, education and liaison with health care professionals, developing discharge plans, and giving ongoing support to new and established patients (RCN 2009). Having worked in this area for several years, the researcher has extensive professional knowledge and experience in this role.

The NHS Trust in which the researcher works contains one of the UK's regional spinal injury units, and so part of professional knowledge and experience is in the area being researched. In comparison with the small numbers of individuals with SCI having a colostomy documented in other research, this unit has performed a large and increasing number of colostomy operations over the years on individuals with SCI, as will emerge in later discussion of Findings. This means the researcher has considerable knowledge of the specific area being studied.

This clinical professional knowledge means the researcher does not approach the research field as a *tabula rasa*, or blank slate, but as an involved professional. An approach within Grounded Theory was therefore required which could accommodate, incorporate, and even embrace the professional knowledge of the researcher. The risk of researcher bias this engenders, and measures taken to reduce this are discussed in section 4.7 of the Methods chapter.

The audible voice of the researcher in constructivist Grounded Theory research is considered a valid component in bringing to life research findings. Constructivist Grounded Theory acknowledges that the final research will report the researcher's involvement in the phenomenon rather than the actual phenomenon itself (Charmaz and Mitchell 1996). The researcher's experience in the area being studied will add unique insight and understanding to research findings. Whilst representing a single interpretation of the phenomenon being described, the researcher's professional knowledge will aid the development of new theory. Theory will be grounded in insider experiences and shaped by professional knowledge. It will make sense to both insiders with SCI who choose a colostomy, and those involved professionally for whom this emerging deviation from guidelines is currently puzzling and potentially concerning.

1.6 Thesis overview

This thesis is divided into two sections. Chapters One to Four will Set the Scene for the research, and Chapters Five to Thirteen discuss Findings. Chapter Two starts the research journey with a more detailed exploration of the Wider Landscape in which the new phenomenon has arisen. This is not a formal literature review, but a perusal of the context of the clinical area, explored to aid understanding of the research problem. Areas of interest and relevance are discussed. These include the nature and incidence of SCI, and the impact it has on bowel function and management. Current clinical guidelines are explored, and here the puzzling anomaly of earlier colostomy is located, and the first clues are found in identifying reasons for the deviation from accepted practice which this represents.

Chapter Three marks the departure from this starting point and traverses the journey to deciding which research methodology to use. The perusal of competing methodologies which could have been adopted is described. The journey towards the choice of constructivist Grounded Theory is related to the developing personal position and growth in understanding of the researcher. As differing methodologies are considered in the context of research aims and the question, and the positionality of the researcher, justification is provided for the final choice of constructivist Grounded Theory.

Chapter Four provides detail of the research process and methods used. This chapter contains sections detailing data collection, data analysis, and theory building. Explanation is given of each, and examples from the research are included as illustrations. Ethical considerations are discussed, including treatment of dilemmas which occurred during the research. Measures to ensure quality and rigour in the research are described.

As will become evident, the research and this thesis adopt a non-traditional approach to extant literature. This thesis does not contain a traditional Literature Review Chapter, and extant literature is treated as further data to shape theory once it has emerged, rather than as a foundation on which to build. As this approach is unusual and potentially contentious, section 4.5 is devoted to explaining and justifying this treatment of literature, and how it was used to shape theory and influence the structure of the thesis.

In the second section of the thesis, Findings are presented as six Findings and Theoretical Discussion Chapters. The first three discuss major themes of '*Experiences of Loss*', '*Progression into Suffering*', and '*Being Alive Again*'. The last three consider the final major theme '*Failure of Care*', and this is divided into chapters discussing the Ideological, Professional, and Institutional '*Failure of Care*'.

Chapter Twelve provides Further Discussion related to research findings. The extent to which the research question and aims have been met are reflected on and findings are contextualised within the extant literature. The original contribution to knowledge, implications of the research, early developments from it, limitations, and areas for future research are discussed. Chapter Thirteen will provide concluding remarks.

1.7 Chapter Conclusion

This chapter has introduced an emerging phenomenon of individuals with SCI in one UK spinal injury unit choosing to have a colostomy as a method of bowel management much earlier following injury than has previously occurred, in a divergence from accepted clinical guidelines. As a novel phenomenon, a gap in knowledge has been identified, and research aims and a question have been identified which seek to develop current understanding.

Constructivist Grounded Theory has been identified as an appropriate methodology which will allow co-construction of new theory grounded in insider experience and shaped by the researcher as an involved professional expert. With an overview of the thesis provided, the research journey now starts with an exploration of the Wider Landscape in which the phenomenon and the gap in knowledge have arisen.

2.1 Chapter introduction

The opening chapter introduced that following SCI bowel function is disrupted and there exist clinical guidelines which describe methods to manage this. Curiosity about an observed trend towards the choice for colostomy formation much earlier than these guidelines suggest in one UK spinal injury unit inspired research to understand more about this. Research aims and a question have been formulated to explore the emerging phenomenon using a constructivist Grounded Theory approach to increase understanding in an area where no theory presently exists.

Attention now turns to setting the scene and explaining the context of the phenomenon and the starting point of the research journey. This chapter will start by explaining the scope of this discussion of the Wider Landscape, and why this is not intended as a more traditional literature review. Context will then be discussed by exploring the nature and incidence of SCI and how it is managed. The socially imposed norms of bowel function are briefly considered, and explanation given about the physiological disruption which occurs after SCI. The way in which bowel function is managed clinically following SCI is discussed, and the use of guidelines by professionals and organisations introduced.

Following this, the damage and complications which can arise from widely utilised 'conservative' methods of bowel management for those with SCI are explored. Information is presented about the permissible option of colostomy formation, how this is formed, and complications which may occur. A potential dichotomy of perceptions about the role of colostomy starts to emerge between professionals and those living with SCI. In a final section, more detail is given about the emergence of the increasing trend towards 'early colostomy' in one UK spinal injury centre.

2.2 The wider landscape of bowel care following spinal injury

This chapter has been deliberately labelled and constructed as a perusal of the Wider Landscape relevant to the area being investigated, and is not a formal and more usual literature review. The intention is to invite the reader to observe some of the context in which the phenomenon inspiring curiosity has occurred. It is a more detailed illustration to help the outsider make sense of the experiences of the participants who will be introduced in later chapters. Further exploration of extant literature was undertaken at a more advanced stage in data analysis in accordance with the methodological approach chosen and as it became appropriate. The potentially contentious approach to the use of literature in this research and non-inclusion of a formal literature review is discussed in more detail in section 4.5 of the Methods chapter.

The Wider Landscape was explored at an early stage in research, prior to development of the research question and aims, and reviewed and updated at its conclusion. The purpose of this preliminary examination of contextual literature was to support the development of the research question and aims, and to increase understanding of SCI and bowel function and the clinical guidelines which have been produced to help manage this. It was in searching literature related to SCI and colostomy formation it was discovered that the observed phenomenon of the earlier choice for colostomy had not been described elsewhere. A gap in knowledge was revealed and this absence in theory guided development of the research aims and question. The context and Wider Landscape of the research is now explored.

2.3 Spinal Cord Injury

2.3.1 Definition, classification, and causes

Spinal Cord Injury has been defined as a:

"... temporary or permanent neurological deficit attributable to disruption of the normal functioning of the spinal cord, including: motor deficit, sensory changes, and/or autonomic nervous system dysfunction." (Copley et al. 2020, p.255)

The spinal cord contains neural pathways which communicate between brain and body, and these are interrupted when SCI is sustained. Injuries tend to result in at least some permanent loss of function. Loss is related to the nature, level and completeness of the injury (discussed shortly), with the neurological evaluation performed 72 hours after injury being the most reliable predictor of how much function will return (Scivoletto et al. 2014). Unlike

other body tissue, spinal cord tissue cannot repair itself, and so damage and loss of function is currently incurable (Ramer et al. 2014; Zhu et al. 2021). Different levels of the spine contain nerves which control different parts of the body, with sections of the spine divided into cervical, thoracic, lumbar, and sacral regions (see Figure 1).



Figure 1: Spinal cord segments and body representation (Nascari and Sved 2019)

The higher the level of injury, the more function and control is lost. Injuries to the cervical spine can result in lack of movement to all four limbs and breathing may be affected. Injuries lower in the thoracic and lumbar spine may mean loss of movement in the legs, with preserved function of the arms. SCI is classified in several ways:

- The level at which the spine is damaged (e.g., damage at cervical vertebrae 6 is termed C6 injury)
- Whether injury is complete (i.e., all sensory and motor function is lost) or incomplete (i.e., some sensory and motor function is retained)
- Using the American Spinal Injury Association (ASIA) score (a standardised neurological impairment scale) (Winter et al. 2014; Waddell et al. 2020).

These classifications are helpful to understand and make comparisons and inference about experiences of individuals with differing types and levels of spinal injury.

Causes of SCI are either traumatic (due to an accident), or non-traumatic due to conditions including tumours, degenerative disorders, vascular events, and inflammatory/autoimmune responses (New and Sundararajan 2008; Rodger 2019). Discerning the incidence of either type of cause is problematic due to inconsistencies of recording and reporting data observed whilst exploring contextualising literature. Several researchers quote a World Health Organisation (WHO) factsheet stating that traumatic SCI accounts for up to 90% of all SCI, but information sources are not provided and it is admitted there is no reliable source of global prevalence (WHO 2013). Contrary information draws on the findings of multiple studies which suggest that the incidence of non-traumatic SCI is likely to be much greater than traumatic ones (New and Biering-Sørensen 2017). As the purpose of this review is to provide context, inconsistencies are observed but are not overly problematic, as a general picture emerges which is sufficient for this purpose.

2.3.2 Incidence and causation

Recording inconsistencies also make it difficult to ascertain reliable statistics for annual incidence of SCI and the level of the spine at which these injuries occur. Research findings appear to concur that the majority occur at the cervical spine level, with a large European database of 250,584 people with SCI finding that 45.42% occur at the cervical level, 29.43% at the thoracic level, 23.81% in the lumbar spine and the remainder occurring in the sacral region (Hasler et al. 2011). This was the most recent data which could be found from this database, and it is not known how prevalence may have changed in the intervening decade. In a poster abstract presented at the British Society of Rehabilitation Medicine annual meeting, Kumar (2017) suggests a higher figure of 60% of SCI injuries in the UK as occurring at the cervical level. His finding is derived from a UK database set up in 2013 only accessible to registered NHS spinal injury professionals (NHS 2013). It is not known if more recent data differs.

Mindful of reporting inconsistencies and the presence of conflicting information, data relating to prevalence of SCI was further scrutinized. SCI is a rare event, and incidence and

causes of SCI vary between countries. For example, in the US the incidence is reported as being as high as 54 cases per million population, of which more are attributable to violence (10-25%) and road traffic accidents (40-50%) when compared to other countries (Sekhon and Fehlings 2001; Singh et al. 2014; Jain et al. 2015). In the European database of 250,584 cases, between 1988 and 2009 the three main causes registered were falls (46%), road traffic accidents (40%), and violence and sporting injuries (4%) (Hasler et al. 2011). Prevalence of SCI is recorded as being lower in the UK than the US, although it is not known how much this difference is attributable to the recording inconsistencies detailed. McDaid et al (2019) use data from NICE and a Scottish longitudinal study to suggest an annual UK incidence of 16 cases of traumatic SCI per million population and 2-3 cases of non-traumatic SCI per million.

This equates to more than 1,200 new cases per year, with 40,000 people estimated to be living in the UK with SCI (Liu et al. 2014; Winter et al. 2017; McDaid et al. 2019). The UK spinal injury charity Aspire believe this to be higher at 2,500 new cases per year, and 50,000 people living with SCI, an increase they attribute to improved reporting and record keeping, and the inclusion of non-traumatic SCI (Aspire 2020). The research by McDaid et al (2019) uses a simulation model to calculate lifetime costs for a single spinal injury to average £1.12 million, with 71% of this publicly funded and the remainder borne as reduced employment and carer time required. McDaid et al's (2019) analysis demonstrates difficulties of obtaining reliable and consistent data to use in economic modelling, and data is drawn from a smorgasbord of national and international sources.

Considering age and gender, 79.8% of individuals with SCI are male and many have noted that the age at which injury occurs is increasing (Ahuja et al. 2017). This is thought to be due to increasing longevity in Westernized countries, meaning there are growing numbers of elderly people with greater propensity for sustaining spinal injuries through falls (Singh et al. 2014). This trend is illustrated using the Trauma Audit and Research Network's data by Kehoe et al (2015) which shows that in the UK the mean age of patients suffering major trauma (but not specifically SCI) has risen from 36.1 years in 1990 to 53.8 years in 2013.

2.3.3 Management of SCI

After initial emergency and life-saving management in the local hospital setting, specialist advice is sought from the linked spinal injury unit after a SCI has been sustained. In the UK there are twelve such units, with one being within the researcher's hospital (NICE 2016). Once neurological status is stabilised, there will ensue an inpatient rehabilitation period aimed at maximising independence prior to discharge home, ideally within one of the spinal injury units (NICE 2016). NICE do however circumspectly state that care will be guided by a spinal cord injury unit rather than being provided within one.

Length of stay in a spinal injury unit is typically one to nine months in the UK, and one of the aims of this rehabilitation period is to establish a regime to effectively manage bowel function (QENSIU 2015). Length of stay may be related to the classification of the spinal injury and is impacted by the development of any complications such as pressure sores or infections (New et al. 2004; Gedde et al. 2019). In the unit where this research was undertaken, it has been observed by the researcher that discharge from the spinal unit is frequently delayed due to a lack of availability of intermediate residential care if the patient's own home requires adaptation or cannot accommodate a wheelchair, or for a package of care in the person's home to become available.

2.3.4 Effect on the individual

Many parts and functions of the body are affected by SCI, with common problems including bladder, bowel and sexual dysfunction, spasticity, increased risk of pressure ulcers, cardiovascular and respiratory complications, and paralysis (Anderson 2004; Pryor et al. 2013; Rodger 2019). The ability to work, relationships and social well-being are also affected, and these can be further complicated by difficulties with bowel function (Smith and Decter 2015; Bølling-Hansen et al. 2016; Kennedy and Hasson 2016; Braaf et al. 2017). Waddell et al (2020) describe how every aspect of life is altered following SCI, listing physical, psychosocial, independence, sexuality, and leisure, all of which can lead to a decrease in Quality of Life (QOL).

2.4 Bowel management following SCI and its evidence

Attention now turns to specific consideration of the profound effect that SCI can have on bowel function. Commonly, there is slower transit of stool through the colon, lack of awareness of a full rectum, and the inability to control muscles needed to expel stool from the bowel, with continence and problems relating to bowel function termed Neurogenic Bowel Dysfunction (NBD) (MASCIP 2021a). Symptoms of NBD vary according to type and level of injury, although constipation, obstruction and incontinence are frequent complications (Hughes 2014). Bowel management issues impact greatly on the lives of those with SCI and are frequently described as constituting one of the greatest areas of loss and reduction in QOL (Waddell et al. 2020). Eighty percent of individuals with SCI have some degree of bowel dysfunction (Johns et al. 2021). This demonstrates that bowel management problems affect the lives of many individuals living with SCI.

To address this disruption to function, bowel management programmes are established during inpatient rehabilitation following SCI to facilitate regular bowel emptying and maintain continence, with management purportedly tailored to individual need (Hughes 2014). Clinical guidelines and advice related to bowel management are produced in the UK by bodies including the Multidisciplinary Association of Spinal Cord Injury Professionals (MASCIP), NICE, the Royal College of Nursing (RCN), the Nursing and Midwifery Council (NMC), NHS England, and NHS Improvement (NICE 2007; NHS Improvement 2018; Nursing Midwifery Council 2018; Royal College of Nursing 2019; MASCIP 2021a).

The most extensive and detailed guidelines for bowel management are those produced by MASCIP and NICE, with the MASCIP document used as a teaching resource in the researcher's spinal unit (NICE 2007; Slater and Williams 2013; MASCIP 2021a) Both documents suggest a progressive stepped strategy, with MASCIP giving the greatest depth of information and practical clinical management detail. International guidance concurs with that in the UK (Pryor et al. 2013; Fisher et al. 2018). The focus of all the guidelines are interventions to aid physiological management of bowel function. The most used and advocated interventions are usually termed 'conservative', with a small number of other interventions termed 'invasive', including colostomy formation. The origin of and evidence for these frequently used terms is elusive. Where mentioned, non-physiological elements such as psychological

support are described in terms of 'coping' and 'fostering acceptance' (NICE 2007). This emphasis on physiological management of bowel function will emerge as important as the research unfolds in later chapters. NICE, MASCIP, and other forms of guidance are now considered in more detail.

2.4.1 NICE guidance

NICE describes its role as including the production of evidence-based recommendations developed by independent committees, including professionals and lay members, and consulted on by stakeholders (NICE 2021a, 2021b). NICE commissions The National Guideline Centre (NGC) to develop evidence-based guidelines. The NGC is 'hosted' by the Royal College of Physicians, and members are experienced physicians (National Guidance Centre 2021). Committees producing guidelines comprise lay members, carers, doctors, nurses, pharmacists, and other allied health professionals.

The guidance covering neurogenic bowel management following SCI forms a section in the 'Management of Faecal Incontinence in Adults, guidance number CG49' (NICE 2007). The committee which developed this guideline in 2007 comprised a nursing professor, a geriatric physician, a colorectal surgeon, representatives from incontinence charities, a gastroenterologist, a clinical development nurse, a specialist physiotherapist, and a continence advisor. Expert advisors to this group comprised surgeons, a consultant in neurological rehabilitation, a midwife and an obstetric advisor, a dietician, a psychologist, a specialist radiologist, and an occupational therapist (NICE 2007). A stoma nurse specialist or representative from a stoma support group were not amongst the group, despite the benefit their knowledge and experience may have brought concerning one of the relatively small number of interventions available for bowel management following SCI. Applications to join guidance groups are advertised when they first form, but the selection criteria and process are not known.

The guidance was reviewed and left unchanged in 2018 because the evidence base and clinical practice were not felt to have progressed, and it is admitted that recommendations in this and other bowel management guidelines are largely based on consensus and trial-and-error because of inadequate quantity and quality of evidence (Christensen et al. 2008; NICE

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2018). A contradiction emerges at this early stage that guidance which purports to be evidence-based acknowledges its own evidence base to be weak.

Changes to the guidance suggested (and rejected) in the NICE review in 2018 came from manufacturing companies seeking to have their own products included in the guidance. This illuminates how industries have access to involvement in and seek to influence guidelines, presumably from a commercially driven perspective. Other potentially interested and perhaps more altruistic parties may not enjoy similar access.

NICE guidance advocates a progression through sequential steps to achieve satisfactory bowel habit. Interventions begin with 'conservative' methods of modifying diet and use of medication, and progress through digital rectal interventions and 'coping strategies'. If unsuccessful, more 'invasive' methods of irrigation can be trialled before final consideration of surgical options including colostomy if incontinence or time taken for bowel emptying imposes major limits on lifestyle (NICE 2007). Offered as guidance formed from a weak evidence base, rigid adherence is not required. During the 2018 guideline review, topic experts advised that uptake and implementation of the recommendations is low. This may account for how a change in practice towards earlier colostomy in one spinal unit has flourished. Fisher et al. (2018) similarly found that in the absence of consensus, variations in bowel management practice can arise between spinal units. NICE guidelines can be perceived as a starting point from which practice develops and evolves. Questions about their usefulness and relevance are raised when unchallenged practice and innovation start to deviate significantly from them, as is occurring in the phenomenon of the choice for colostomy at an early point post injury.

In the 2018 NICE guidance review, Randomised Controlled Trials (RCTs) and non-randomised comparative trials were sought to evaluate clinical and cost-effectiveness of the differing interventions available for those with SCI (National Collaborating Centre for Acute Care 2018). In the absence of any specific evidence being found, the Guideline Development Group (GDG) decided:

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"After consulting with expert advisors and participating in a consensus development exercise the GDG decided to recommend that this group follow a progression of management steps to establish a satisfactory bowel habit. In addition, the GDG recommended that those patients that could not achieve this should consider other alternatives such as coping strategies." (National Collaborating Centre for Acute Care 2018, p.113)

When specifically searching for evidence related to surgical options, only a small number of RCTs with small cohort numbers and a lack of long-term results were identified. Despite this lack of available evidence, and without examining other types of evidence such as that from exploratory and qualitative research, the group further decided that:

"A stoma should be considered for people with faecal incontinence that severely restricts lifestyle only once all appropriate non-surgical and surgical options, including those at specialist centres, have been considered...Although no evidence was retrieved for this recommendation, the GDG made the above recommendation after consulting with expert advisors and participating in a consensus development exercise." (National Collaborating Centre for Acute Care 2018, p.126)

A 'consensus' method of deciding the structure of bowel management guidelines by an evidence-based institution is surprising and raises questions. Factors which may influence the decisions reached including professional roles and power differentials between the group members are not known. This adds to concerns about the self-confessed weak evidence-base, questionable motivations of some parties which seek to influence guidelines, the potential non-inclusion of important groups, and the low uptake of these guidelines. Multiple problems are indicated with these guidelines and questions raised about their usefulness and relevance.

2.4.2 MASCIP guidance

In the UK, more detailed practical guidance for bowel management following SCI is produced by a MASCIP. MASCIP was formed in 1998 as a multidisciplinary professional association with the objective of providing a national forum to promote standards, foster research, develop services, and lobby commissioners and providers of healthcare on issues of significant professional concern (MASCIP 2021b). Their guidelines for the management of NBD published in 2012 were reviewed and updated in 2021.

The 2021 version states guidance to have been reviewed for clinical relevance, but detail is not provided of how or by whom this review was performed. Line by line comparison of the 2012 and 2021 versions reveals the only changes to be additions relating to new guidance for manual evacuation (with terminology changed to 'digital removal of faeces' (DRF)) since a patient safety alert was issued related to this procedure, and the addition of two new medications to treat constipation (NHS Improvement 2018; MASCIP 2021a). The published trend towards earlier colostomy in this UK centre is not referred to in the 2021 version (Boucher 2016; Boucher et al. 2019). Seven references are added relating to the patient safety alert and medications, but otherwise there is no new information or change in wording, and no evidence of a search being performed for new knowledge which may have emerged in the intervening years since the 2012 edition.

MASCIP guidelines for bowel management following SCI were developed by nurse specialists in urology, continence, spinal injury, and specialist care agency directors, with representation from many of the UK regional spinal injury units. In addition to their own clinical experience, they draw from an extensive range of national and international medical and nursing research in dietetics, neuroscience, spinal injury and coloproctology. Evidence cited includes randomised trials of different bowel management strategies, abstracts from specialised international conferences, systematic reviews, and government, NICE and NHS documents.

MASCIP guidance concurs with other clinical guidance that diet, routine, and manual rectal interventions should be the primary methods of intervention (Coggrave and McCreath 2007; NICE 2007; Pryor et al. 2013). Some sources used by MASCIP including research by Kelly (1999), Branagan (2003) and Rosito (2002), contain evidence of the acceptability and benefits of colostomy formation and report the finding that many participants wish they had the colostomy performed earlier. Despite this evidence, MASCIP guidance is that colostomy usually be considered at a later stage. This could suggest selective use of evidence in the creation of guidelines influenced by the personal and professional lens through which research is viewed. Alternatively, it may reflect as NICE suggest that the quality of evidence

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is inadequate. The MASCIP panel does not include stoma care nurses, and although it is stated that guideline development groups include representatives from charities, the contribution from service users in developing this guideline is not known (MASCIP 2021c). It is not known how the panel was formed, but the inclusion and omission of groups of people will influence what evidence is assessed and how, and the shaping of guidance.

2.4.3 The pyramid of bowel management interventions

National and international guidance agree a progressive and (usually) sequential stepped approach to bowel management, which was first modelled as a pyramid by Christensen et al (2006) during an international conference, a model which continues to be widely used today (Christensen et al. 2006; Emmanuel 2019; MASCIP 2021a). (See Figure 2).



Figure 2: Pyramid of bowel care interventions by Christensen et al 2006 in (MASCIP 2021a)

Investigating this pyramid model, no evidence could be found of how it was developed and by whom. Without this evidence, it is assumed to have been created by the presenters of the conference paper, healthcare professionals, with unknown involvement of those for whom the model is designed. There is no evidence of the model being tested, and yet it has become popularly described and quoted. A modification to this model emerged from a commercially sponsored expert panel review of the intervention of transanal irrigation (Emmanuel et al. 2013). This is shown in Figure 3.



Figure 3: A proposed stepped approach to treatment of bowel dysfunction (Emmanuel et al. 2013, p.734)

In this adaptation of the pyramid of interventions, light grey layers are described as representing 'conservative' interventions, the mid grey layer to represent 'minimally invasive' ones, and dark grey layers to represent 'more invasive' options. Again, it is not known how these levels of invasiveness were discussed and assigned, and in the absence of this detail it is assumed to have been agreed between the panel experts without service user involvement. This modified and untested model has since been adopted and used by others (Thomas 2014; van-der-Steeg et al. 2018). This is concerning as it adds to the emerging picture that guidelines for bowel management are based on weak evidence, and popularised models are developed without testing or the involvement of those affected by them.

2.4.4 Bowel management interventions

To further understand bowel management interventions, explanation of each is now given. In the pyramid model, level one and two interventions are generally considered 'noninvasive' or 'conservative.' Those in level one include modifications to diet, lifestyle alteration, and use of medication. Level two interventions comprise rectal interventions of digital stimulation, digital evacuation, suppositories, and enemas. In digital stimulation (used by 35-50% of those with SCI) a gloved lubricated finger is inserted into the rectum and slowly
rotated to initiate defecation; in manual evacuation (used by 56%) the finger is inserted into the rectum to break up and remove stool (MASCIP 2021a).

Higher level interventions are considered increasingly invasive. Transanal irrigation is colonic irrigation via the rectum, with a tubing system used to instil water into the colon which after a period of time initiates evacuation of stool (Mekhael et al. 2021). For antegrade colonic irrigation a surgical operation is performed to create an opening through the abdomen into the appendix or caecum (Whiteley and Stewart 2020). A catheter is inserted into the opening and fluid flushed into this daily to empty the bowel. In nerve stimulation, electrodes are implanted to control bowel function (Johns et al. 2021). In the final intervention of colostomy, an operation is performed to divert the bowel through the abdominal wall, and this is discussed in more detail later in this chapter. Systematic review demonstrates that most patients use multidimensional bowel management programmes from the lower two levels (Krassioukov et al. 2010; Hughes 2014; MASCIP 2021a). It appears the needs of most individuals are met using the lower two levels of the pyramid.

2.4.5 Other guidance

Other less detailed bowel management guidance exists, including that produced by the professional bodies listed in section 2.4. The same terminology concerning 'conservative' and 'invasive' interventions are frequently used. For example, the RCN advises that 'conservative' options be the first line treatment (Royal College of Nursing 2019). In addition, some UK centres have published their own guidance (Coggrave and McCreath 2007). All guidance examined concurs with a progressively stepped management approach.

The pyramid model has been extensively adopted, with only one other model found in which Emmanuel (2019) describes a 'treatment hierarchy' to reflect the range and frequency of available options rather than indicating an evidence-based pathway. This is shown in Figure 4.



Figure 4: Emmanuel's treatment hierarchy (Emmanuel 2019)

The font size reflects the frequency of the options being used, with colours indicative of Emmanuel's perception of the nature of each option: green = conservative, orange = minimally invasive, red = invasive. Emmanuel does not suggest how this hierarchy be utilised, and frequency data is derived from a study of 227 UK individuals with neurogenic bowel disease, only 116 of whom had a spinal injury. His use of red has an association with danger, although this is not stated by Emmanuel, and the smallest font visually reinforces stoma formation as invasive and an option rarely utilised.

2.4.6 The weak evidence base of guidelines

Despite widespread use of the pyramid of interventions, reliance on level one and two measures, and the pervasive view of these as 'conservative' measures and stoma as the most 'invasive' measure, it is acknowledged that the types of evidence used to support these are considered low in quality (NICE 2007; Clark et al. 2018). The pyramid model itself appears to have been first presented at a conference. No further publication or references could be found relating to how it was developed or tested. This considerably weakens the validity and reliability of the model, and it is surprising to learn of the weak evidence base of extensively used models and guidelines.

A criticism of all the guidance and models discussed is their omission of consideration of how interventions, particularly the mainstay rectal interventions of level two, feel as experienced

by those requiring them. The impact these have on wider personhood, including the ability to work, to socialise and on intimate relationships are sometimes mentioned but are not adequately addressed. It is advised that lifestyle be modified to fit around bowel management. There is a pattern of reliance on medical models of health and health management, a concern to keep bowel function as 'normal' as possible by stool exiting through the anus, and use of what are considered (by health professionals) to be 'least invasive' methods. These are themes returned to later as the research unfolds, with bowel management guidelines revisited at the conclusion of the research in Section 12.4. Consideration is now given to what the experience of requiring help with bowel function may feel like to those with SCI.

2.5 Disruption of bowel function norms

Defecation is a very private bodily function, with the disposal of bodily waste highly circumscribed by social norms internalised and regulated from childhood, in which autonomy is expected (Hughes 1958; Gurney 2000). Housing design changes reflect increasing privatisation of bowel function as from the 19th century collective outside privies became household privies, followed by the integration of toilets inside houses (Kuper 1953; Kira 1974). A progression is observed with the trend for 'ensuite' bathrooms, further insulating defecation even from other household members. Kira (1974, p.93) asserts that: "*Urine and faeces ... are generally regarded in contemporary Western societies as filth of the worse sort,"* to be disposed of as quickly as possible and be completely disassociated with the act of producing them. Widely held beliefs that to be 'dirty' is a disgrace and 'cleanliness as next to godliness', have ingrained an association between being dirty and questionable morality (Jackson 1993). Following SCI, these norms of privacy and autonomy are disrupted, as damage to the nerves controlling bowel emptying mean independence is no longer possible, at least initially, and perhaps ever.

Regular rectal examinations and manual removal of stool will become the norm for many, performed to start with by known or unknown health professionals whilst lying in a hospital bed in a communal bay with other patients, with only a curtain for privacy. Episodes of incontinence can occur, and these can produce feelings of stigma (Goffman 1963; Charmaz 1987). The focus on physiological management within guidelines may represent a failure to

consider how interventions might feel to those experiencing them, and reflects the lens through which healthcare professionals perceive bowel management. This is discussed further in the Methodology and Findings chapters. Having started to consider what the insider experience of manual bowel interventions may be like, attention now turns to the complications which can arise related to bowel function and management following SCI.

2.6 Bowel function complications

Few large-scale studies of bowel complications following SCI exist, reflecting the small population of those with SCI. Research which is available demonstrates a high prevalence of bowel related complications due to both NBD and to bowel care interventions themselves (Craven et al. 1998; Johns et al. 2021). Quantitative studies utilising methods such as postal surveys and self-reported questionnaires are useful in providing indicative numbers of people suffering complications. One of the largest performed in the UK was Coggrave et al's (2009), in which 1,334 people with SCI participated. The researchers acknowledge the risk of response bias from the low 48.6% response rate, with the possibility that those who responded were disproportionately more likely to be those who were suffering complications. Results were that amongst other problems 39% suffered constipation, 36% haemorrhoids, and 8.1% autonomic dysreflexia (AD). AD is a potentially life-threatening rise in blood pressure in response to pain or discomfort and can occur due to NBD or bowel care interventions (Fehlings 2013; Williams et al. 2014). This large survey indicates that many suffer bowel management complications.

Longitudinal studies have found prevalence, severity and pain related to neurogenic bowel symptoms tends to increase with time after injury, as bowel function deteriorates and increasing time is spent performing bowel care, although Savic et al (2010) found QOL to remain stable despite this (Faaborg et al. 2008; Finnerup et al. 2008; Nielsen et al. 2017). In Savic et al's (2010) study an inconsistency of variables measured each time is acknowledged. An increase in colostomy over time is noted but as it is grouped together with the alternative intervention of nerve stimulation, meaningful inference is reduced.

Many studies have identified bowel management to be onerous and time consuming, whether performed independently or with assistance (Yu et al. 2008; Coggrave et al. 2009;

Bølling-Hansen et al. 2016; Nielsen et al. 2017). There is a lack of consistency and detail in how time taken to perform bowel care is measured, and methods used and length of time since SCI are not always stated. This reduces the quality and rigour of some studies. Time taken to perform bowel care is described varyingly. In Lynch et al's (2000) postal questionnaire, with 467 respondents, an average of 15-30 minutes was found. This compares to an average of 92 minutes in Yu et al's (2008) retrospective analysis of 41 participants interviewed as part of a life care plan assessment. Lynch et al (2000, p.723) in their research asked: *"How much time do you spend at the toilet for your bowels?"* This may be open to individual interpretation but can be assumed to mean the actual time spent on defecation. Other studies include the whole process of undressing/transferring/cleaning, which will vary according to injury type and is a more accurate reflection of the time involved. Most do not state what they mean by time taken to perform bowel management, making inference and comparison difficult, particularly when methods and purpose vary as in the studies above.

Other complications frequently reported include faecal impaction, anal fissure, prolapse, lack of independence, and feelings of degradation and distress (Craven et al. 1998; Luther et al. 2005; Williams et al. 2014). Braaf et al (2017), in semi-structured in-depth interviews with 22 individuals, found that bladder and bowel dysfunction affected intimate relationships and created strain and role changes for family and friends. Secondary analysis of semi-structured interviews of 50 women by Nevedal et al (2016) identified themes of lives controlled by bladder and bowel function and accidents relating to them. It is unsurprising that the bowel complications mentioned lead to studies frequently reporting a reduction in QOL. In some studies, this is formally measured using validated tools, in others it is identified as a theme or general statement made by participants. The different usage of the term QOL reduces comparability of study findings.

In seeking contextual information relating to bowel management complications, available research was found to vary greatly in methods and sample sizes. The lack of consistency of methods limits comparison and inference, and many studies are weakened by low response rates, and a lack of methodological robustness. It is, however, evident that bowel function and its complications are a major difficulty to many living with SCI.

2.7 The role and timing of colostomy following SCI

Attention now turns to consideration of the 'most invasive' option included in the pyramid of bowel interventions, a colostomy. A 'stoma' is the general term for an opening from the body and a 'colostomy' is a type of stoma which arises from the colon or large bowel and from which stool exits the body (Fortes et al 2012). A colostomy is formed surgically under general anaesthetic by creating an opening on the abdominal wall. The colon is cut and diverted through this opening, so that stool then exits passively through the colostomy, instead of being stored in the rectum and exiting from the anus. A disposable pouch is attached to the skin around the colostomy to collect stool (Henbrey 2021). Bowel management for a colostomy consists of removing the pouch, cleaning the skin, and applying a new pouch once or twice a day, a process which takes only a couple of minutes for those with good hand function or who have an assistant. Individuals with impaired functional ability who wish to perform this themselves will inevitably take longer.

Individuals with SCI who have a stoma tend to have this done due to physiological complications. It is usually performed many years after injury following prolonged use of lower-level bowel management interventions, in accordance with guidelines discussed. Cooper et al (2019) found that colostomy formation was mostly performed to aid healing of pressure ulcers and chronic wounds which, due to their proximity, can become contaminated by bowel motions (50%), for prolonged bowel care (34.6%), and other reasons such incontinence, constipation, and AD. In a hospital which contains one of only two spinal injury units in New South Wales, Australia, Cooper et al (2019) reported that only 43 individuals with SCI underwent stoma formation in a five-year period, demonstrating the small target populations typical of studies exploring this area.

Craven and Etchell's (1998) study used both quantitative and qualitative methods to discover more about stoma formation following spinal injury. Of the eighteen patients known to have had a colostomy in the Australian spinal injury centre at that time, only two elected to have it performed for bowel management whilst the rest had no choice due to their condition. This reflects that at this period it was usually performed to resolve intractable problems. For those who had their colostomy formed to treat a pressure sore, all but one chose to keep the stoma when given the option of having it reversed. This is a finding confirmed in other

research which demonstrates colostomy to be preferable to previously used bowel management regimes. Of interest, in Craven and Etchell's (1998) study is reference to one female patient who had *"actually sought out a doctor who was willing to perform this surgery for her"* (Craven and Etchells 1998, p.924). Not explored further by the researchers, this lady was perhaps a forerunner to the emergent phenomenon of increasing requests for earlier colostomy. In refusing to perform the surgery, it is conjectured that doctors' perceptions at that time was of surgery as invasive or as not conforming to professional guidance.

In Cooper et al's (2019) study with a 60.5% response rate, 26 participants completed a selfreported questionnaire. This demonstrated an average time lapse of 12.8 years (range = 1 -40 years) from the time of SCI to stoma formation. This is typical of the average time frame reported in other studies using quantitative methods (Craven et al. 1998; Kelly et al. 1999; Randell et al. 2001; Safadi et al. 2003; Coggrave et al. 2012; van Ginkel et al. 2021). The most recent of these, undertaken in the Netherlands, found a mean time from SCI to stoma of 17.6 years (range not stated) (van Ginkel et al 2021). With only 23 participants completing their online questionnaire, the small sample size is acknowledged, and their research ended earlier than planned due to the Covid-19 pandemic. What is not always clear from these studies is why there is so often such a prolonged delay before formation of a colostomy is considered.

The available research examined to contextualise the area of interest reveals that within an already small population of those living with SCI, an even smaller population exists of those who have gone on to have a colostomy formed. Research discussed reveals regional spinal injury units can be calculated as having an average of ten or less people per year with SCI undergoing colostomy formation (Cooper et al. 2019). Jiashou et al (2016) in their US study state most surgeons see less than one person with SCI having a colostomy per year. It is typically performed many years after SCI and predominately to resolve conditions and problems which develop over time. It is not described as an active choice early after injury, as has been observed in this researcher's hospital, with the exception noted but not explored by Craven and Etchells (1998). Numbers of those with SCI having a colostomy in the author's spinal injury unit were similarly low until an upturn was noted a few years ago. Details of this will be provided in the Findings in Chapter Five.

2.8 Outcomes following colostomy formation

Despite the limitation of the small populations involved, it appears that colostomy formation in those with SCI can lead to significant improvements in QOL, a reduction in bowel care complications, and high levels of satisfaction (Craven et al. 1998; Coggrave et al. 2012; Williams et al. 2014; Bølling-Hansen et al. 2016). Many studies report respondents wishing they had the colostomy earlier (Branagan et al. 2003; Bølling-Hansen et al. 2016; van Ginkel et al. 2021). Lack of detail persists in how it is assessed, but authors agree a significant reduction in time spent on bowel management. Munck (2008) reported a reduction from 5.95 to 1.5 hours per week, and Branagan et al (2003) from 10.3 to 1.9 hours. Rosito et al (2002) describe a considerable reduction from an average of 117 minutes/day spent on bowel care to 12.8 minutes in their study of 27 participants. Their questionnaire required a response of time taken as 'less than an hour/1-3 hours/or more than 3 hours', and it is not made clear how they converted these categories into average minutes.

Some researchers infer that hospital admissions related to bowel problems may be reduced after colostomy, and care issues related to receiving ineffective bowel care at home can be solved as bowel care becomes simpler and easier to perform (Rosito et al. 2002; Coggrave et al. 2012). Evidence for this, however, is not always provided. Several studies have examined QOL for those with SCI after colostomy formation, finding it does not worsen and can improve significantly (Craven et al. 1998; Randell et al. 2001; Rosito et al. 2002; Branagan et al. 2003). This may be related to gains in independence which some achieve through having a colostomy, the loss of autonomy and privacy in bowel care having been discussed earlier as counter to ingrained social norms (Kelly et al. 1999; Branagan et al. 2003; Boucher et al. 2019). The low quality of some available studies remains, however, problematic. Waddell et al's (2020) recent systematic review researching colostomy and QOL in this population, reported that of the 31 studies screened as relevant, only fifteen met their quality assessment criteria, and included only 488 people.

Other benefits to having a colostomy described by this researcher and others are increased freedom, being able to work and go on holidays, resolving incontinence, bowel care becoming simpler, and feeling happier about bowel care (Rosito et al. 2002; Boucher et al. 2019). MASCIP (2021a, p.19) and other guidance make reference to assessment of lifestyle,

psychological and emotional factors, personal goals, and cultural, sexual, work or educational role. It is not known in practice however the extent to which these are incorporated into planning bowel management and the weight they are given. Clinical guidance for bowel management is dominated by physiologically based assessment of needs. The earlier example provided by Craven and Etchells (1998) of the lady having to search for a doctor who would perform a colostomy demonstrates an instance of alternative factors historically not being considered during decision-making. Further research into assessment criteria, decision-making, and evaluation of bowel management programmes and how these may have changed over time would be of interest.

2.9 Risks and complications related to colostomy

Colostomy formation involves an operation on the bowel performed under general anaesthetic, and Stratton et al (1996) found patients with SCI undergoing bowel surgery to have greater morbidity than the general population. Their 44 patients cannot be meaningfully compared to the subjects of this research as they had undergone more extensive surgery for cancer, rather than a diverting colostomy as a choice for bowel management. West et al (2013) differ in concluding from their research that mortality and morbidity for surgery is similar for those with SCI to those without, and that stoma formation is therefore as safe. They considered surgery related to constipation, but with only 10 individuals with SCI meeting their inclusion criteria this is not convincing evidence. More comparable and recent studies are difficult to find, and with a small research population difficulties become evident when making comparison and inference from studies about the risk of colostomy formation to this group.

Complications of any colorectal surgery including colostomy formation can include wound infection, paralytic ileus, sepsis, and abdominal abscess, as well as general surgical complications including urinary and respiratory infections (Ramírez et al. 2011). Additionally, colostomy formation can lead to problems including skin excoriation, retraction, separation, hernia, rectal discharge, prolapse and stenosis (Watson et al. 2013). Negative outcomes following colostomy include dissatisfaction, with those least satisfied generally those who were not effectively counselled prior to surgery (Coggrave et al. 2012). Satisfaction or

dissatisfaction may relate to the degree of choice individuals had in having the colostomy formed, an area not always explored.

Complication rates have been reported as relatively high, with a frequently cited article by Branagan et al (2003) finding that 43.75% of their 32 participants experienced at least one complication. This researcher has noted, however, a lack of consistency in the categorisation and reporting of colostomy complications which makes interpretation of their true impact difficult (Boucher et al. 2019). More serious complications may lead to the need for further surgery (Craven et al. 1998; Branagan et al. 2003; Coggrave et al. 2012; Boucher et al. 2019). Some studies however include as complications issues such as leakage, skin issues, flatus, and odour (Coggrave et al. 2012; Bølling-Hansen et al. 2016; van Ginkel et al. 2021). This researcher, as a stoma care professional with expert knowledge in this area, would categorise these as resolvable management issues rather than true complications of surgery. Describing them as such means research data can be misleading as they are not complications from an operation in the generally understood meaning of the term. They would not, for example, be rated as complications on the widely utilised Clavien-Dindo classification of operative complications (Clavien et al. 2009). Importantly, despite experiencing complications, many participants state that they are still glad to have had the stoma and the presence of complications does not lead to individuals wanting a stoma reversal (Bølling-Hansen et al. 2016; Boucher et al. 2019). It appears patients are often willing to manage and live with some complications because of the apparent advantages of colostomy formation.

2.10 Perspectives of bowel management complications

With complications from both manual bowel management and colostomy common, the two appear to be apprehended differently by professionals. A large Danish study by Krogh et al (1997) yielded 424 responses with a relatively high response rate (72%). In finding 75% of those using conservative bowel management methods to experience incontinence, they counter this figure by clarifying that most patients only had a few episodes of bowel incontinence each month (15%) or each year (56%). These are still relatively high complication rates, and other studies have found that even when incontinence is infrequent, the fear of it continues to be an ongoing concern (Dickson et al. 2008). It appears that some

studies do not appreciate the effect incontinence has on individuals' lives, and this is not amenable to understanding from large scale studies using quantitative methods.

The research studied suggests that incontinence and other complications of non-surgical methods of bowel management are acceptable complications to the professionals reporting them, as guidance advises persisting with these if possible. They seem to be expected in clinical guidelines which suggest considerable time, effort, and self-discipline, together with alteration of diet and lifestyle are required to manage and accommodate bowel function (MASCIP 2021). The acceptability of complications to those experiencing them may differ, and this is not always explored. If the 75% complication rate were demonstrated for a single complication of colostomy, it is suggested professionals may apprehend this differently and display concern rather than acceptance.

More needs to be understood about how bowel management complications are perceived by and their acceptability to both professionals and those experiencing them. This will be considered further in exploration of the Ideological Failure of Care in Chapter Six.

2.11 Incidence and timing of colostomy

A relatively small percentage of those with SCI are believed to have a colostomy, with exact numbers not known. Numbers provided in some studies are obtained through searches of spinal centre and stoma nurse records, which are likely to give the most accurate reflection of actual numbers with a colostomy, but often this is not related to a percentage of the total number of patients with a spinal injury known to that centre.

An exception is the finding of this researcher from performing a hospital data search which established that between 2013 and 2016, 9.3% of all newly injured patients in the researcher's spinal unit chose to have a colostomy formed (Boucher et al. 2019). This percentage is higher than those quoted in other UK studies. If this rate were to continue, together with numbers choosing it at a later stage, this would in time result in larger percentages of those with SCI having a colostomy than is presently found.

Coggrave et al's (2009) statistic of 2.4% of those in the UK with a spinal injury having a colostomy is often quoted. Their source is the 48.6% of those invited who responded to a postal questionnaire. Nielsen et al's (2017) longitudinal Danish study of 109 participants found that 10% of respondents had a colostomy, and that over time the likelihood of having a colostomy increases. It is not known whether their higher proportion with a stoma is due to methodological differences, or whether there are variations between countries. The increased incidence of having a colostomy over time is reported to occur as bowel function progressively deteriorates and it becomes less likely that straining and drugs alone can manage bowel care effectively (Savic et al. 2010). This suggests that colostomy is more likely to be considered when treatment options are reduced rather than at a time when the patient might choose.

2.12 A schism between research evidence and practice

In accordance with the extensively used stepped pyramid model, colostomies have traditionally been performed for neurogenic bowel dysfunction as a last resort when other bowel management methods have failed, usually several years post injury (Coggrave et al. 2012). Researchers and professionals consistently convey this message:

"Stoma has a place in chronic neurogenic bowel management where other interventions have failed." (Coggrave et al. 2012, p.848)

"Few, if any, elect colostomies as a primary tool for management of neurogenic bowel." (Luther et al. 2005, p.388)

"[Stomas are] only indicated in patients with unsatisfactory response to conservative bowel care." (Nielsen et al. 2017, p.772)

"Being an invasive procedure with possible complications, a colostomy shuld only be performed when properly indicated." (Bølling-Hansen et al. 2016, p.287)

Bowel management guidelines and professional's sentiments appear to diverge from the decades of research presented in section 2.8 including systematic reviews. These have

indicated that patients find a colostomy easier, would have liked it formed earlier, and only rarely state they wish they did not have it or would not recommend it.

Despite these consistent findings, the dogma of colostomy as invasive and a last resort has persisted amongst professionals and researchers, and it is curious to apprehend this apparent stumbling block in progressing practise in this area. The perplexity of researchers is summarised by Luther et al's (2005) statement that:

"Results of our study run contrary to conventional wisdom that a colostomy results in adverse outcomes for persons with SCI and should only be considered as a treatment of last resort." (Luther et al. 2005, p.392)

It appears that professionals have been unable to move forward in response to this finding. Instead of progressing research to consider why there is a schism between conventional wisdom and patient reported outcomes following colostomy formation, they have remained bound within the constraints of their own perspective and guidelines. This research represents the first known exploration into this.

2.13 A new phenomenon

With professionals apparently perplexed and immobilised in the face of the repeatedly expressed satisfaction with and desire for earlier colostomy, a breakthrough has emerged in the form of a patient-initiated increase in demand for colostomy being observed in one of the UK's regional spinal injury units. In contravention of national and international progressively stepped bowel management guidelines and reliance on 'conservative' methods of bowel management, an anomaly has been observed.

Seen as principally occurring from 2013 onwards, a phenomenon started to occur of spinal unit inpatients choosing to undergo elective colostomy formation, within only weeks or months of sustaining their injury. Reasons for this phenomenon are unknown, and it is not known if this is occurring in other spinal units. Only one recent study has documented early colostomy being performed elsewhere, with Cooper et al (2019) describing professionals suggesting it at an early point when they consider it appropriate, a situation which differs from this one in which it appears to be being driven by patient demand.

Although contrary to guidance which suggests colostomy only be considered when other less invasive methods have failed, MASCIP and other guidance is ambiguous in advising sequential progression through levels of steps and yet acknowledging deviation from this may be appropriate. Possibly this ambiguity led to the situation of professionals experienced in and understanding the benefits of colostomy in those with SCI, becoming increasingly comfortable with performing colostomy earlier than is normal when making case by case decisions.

Longer-term outcomes and experiences of patients choosing a colostomy at this early stage are unknown. Understanding patients' motives, experiences, and the impact on their lives of earlier or later colostomy formation will add to the body of knowledge in this area and inform practice. Professionals have historically perceived colostomy formation as being a last resort to solve intractable physiological bowel management problem. The increasing demand for early colostomy in those who have not yet had reached this point suggests it is being chosen for other reasons, and these reasons need to be explored and understood as they represent a deviation from widely used professional guidelines.

2.14 Chapter conclusion

This chapter has furnished detail of the wider landscape to provide the context in which the observed phenomenon of early colostomy has arisen, and to describe the starting point of the research journey. This has included perusing the nature, incidence, and prevalence of SCI, with problems related to the accuracy of recording these identified. Explanation has been given concerning bowel dysfunction following spinal injury. The construction and content of clinical guidance for bowel management has been discussed, the emphasis on physiological management observed, and the frequently utilised pyramid of interventions illustrated and explained. It has emerged that guidance has a weak evidence base, and acknowledgement of this allows deviation from it, which has happened in the case of early colostomy flourishing in one UK spinal injury unit.

Both bowel dysfunction and bowel care interventions have been found to potentially lead to problems including incontinence, lengthy and painful bowel care, and a reduction in QOL. The role of colostomy has been discussed, and consistent findings stated of how individuals find problems are reversed, bowel management becomes easier, QOL is improved, and satisfaction with the decision to have a colostomy persists even if complications related to it are experienced. A stumbling block is identified for professionals and researchers in the frequently identified finding that individuals with SCI would have liked to have had a colostomy much earlier following injury. Professionals and researchers appear unable to progress practice in the light of this established finding.

Examining practice and research in this area has demonstrated bowel management following SCI to predominantly be performed and evaluated from a physiological perspective, and it has been suggested this perspective may differ from that of those living with SCI. Perspective is evidently of importance, and having surveyed the Wider Landscape at the outset, the research journey will continue in the next chapter to consider and appraise which philosophical perspective is most appropriate to meet the research aims and the question which seek to develop understanding of insider experiences. Four approaches are considered in relation to research aims and the question, together with the professional position and philosophical beliefs of the researcher, in the journey to deciding the most appropriate methodology.

3.1 Chapter introduction

The first two chapters have discussed an observed trend in one UK spinal injury unit towards a choice for earlier colostomy as a means of managing bowel function following SCI. In exploring contextual detail of the Wider Landscape, bowel dysfunction has been found to affect large numbers of those with SCI, and to have a profound impact on their wider lives. Exploring current guidelines, these have been found to be created by professionals with limited involvement of those they affect, and to be physiologically based with only passing reference made to the wider issues of people's lifeworlds. Despite their claims and popular perception, the evidence base of guidelines is found to be weak, and the widely used progressive stepped model appears to be untested. The lack of robust guidelines permits variation in practice, and the growing trend for early colostomy formation in one UK spinal unit is an example of one such variation.

It has been introduced that this research will utilise constructivist Grounded Theory to meet exploratory research aims to:

- Explore choices made related to bowel care management
- Explore reasons for the decision to have an early colostomy
- Discover differences in experiences between those who have early or later colostomy

The research question has been stated as:

'What are the experiences of those living with SCI in relation to choices about bowel management?'

This chapter will describe the journey and justify the intertwined decisions made about research methodology, aims and the question. The journey included consideration of four major paradigms of positivism, postpositivism, critical theory and constructivism (Guba and

Lincoln 1994). The passage to the decision to use a constructivist theoretical framework is discussed and how this relates to the growth in understanding and insight of the researcher.

The three main versions of Grounded Theory are explored – classic, evolved and constructivist. Constructivist Grounded Theory is demonstrated as the most appropriate theoretical framework in which to meet the research aims and answer the research question, match the researcher's personal philosophy, and accommodate co-construction of new theory between those experiencing events and the researcher as a knowledgeable professional in the field.

3.2 Factors guiding the choice of the research approach

The choice of research approach was decided based upon:

- the exploratory nature of the research
- the developed philosophical perspective of the researcher
- the positionality of the researcher

The need for exploratory research was demonstrated through discussion of the Wider Landscape. It emerged that little is known about the experiences and motivations of those with SCI in their desire for earlier colostomy and satisfaction with a colostomy despite any complications which may develop in relation to it. This known finding is contrary to conventional professional wisdom, cannot be explained or supported by clinical guidelines, and research has not been progressed in this area. It is suggested that the professionals writing guidelines and applying them may not adequately consider the wider lifeworlds of those who need them. With little existing knowledge there is a need for research in this area to be exploratory. Aims and the question were developed which would facilitate better understanding of these issues from the perspective of those they are affecting.

Initially, interest in the observed phenomenon had created clinical concern about potential unknown adverse physiological outcomes, and concern that those with SCI may later regret choosing an 'invasive' option which would further change the appearance of their bodies. Potential research aims and questions at this point were in relation to measuring quantifiable clinical outcomes. Through exploration of the Wider Landscape, it became apparent however that only nominal attention was being paid to the wider lifeworlds of those with SCI in relation to bowel management. As professional assumptions became visible in the Wider Landscape, and methodology was explored, researcher understanding developed and deepened. Initial physiological concerns were seen to stem from professional immersion in a biomedical perspective focused on the medical management of health and illness. The paternalism and homogeneity in assumed knowledge of what might be best for all those adapting to SCI was recognised and reflected on.

Exposure to alternative perspectives and reflection on personal beliefs led to a maturation of perspective and development of the research goals. These changed from a focus on physiological outcomes into seeking greater understanding of insider experiences. It was realised that to understand the choices individuals were making more was needed than to objectively quantify them. The shifting and then crystallizing of the researcher's philosophical position in the early stages of research planning and as understanding deepened is reflected in consideration of available methodological approaches which will be presented.

The final factor in deciding methodology was the positionality of the researcher as a SCN with years of experience and extensive knowledge within the area being researched. It was important to consider how this knowledge and experience would be treated within potential methodologies when deciding which approach to use, as it was not felt possible to completely set this aside. With these factors in mind and as a clinician new to being a researcher, differing approaches were considered together with their philosophical basis.

3.3 Methodological approaches and personal belief systems

Methodological approaches, also known as paradigms, reflect a person's understanding of the world, and are summarised by Guba (1990, p.17) as constituting 'a basic set of beliefs that guides actions.' Methodological approach needs to be decided through reflection on personal understanding of the world prior to commencing research as this informs why and

how research is conducted, ensures that outcomes make sense, and guides how quality and researcher voice are managed (Guba and Lincoln 1994; Kuhn 1996; Mackenzie and Knipe 2006; Denzin and Lincoln 2008, 2018).

Basic embedded beliefs considered when deciding the approach include personal ontology and epistemology (Borbasi et al. 2005; Hewitt-Taylor 2011; Holloway 2017). Ontology refers to beliefs about the nature of reality and what can be known as real and believed to be factual (Guba and Lincoln 1994). Ontological perspectives range from realist in which the external world is believed to be discoverable and to exist outside the influence of the researcher, to relativist in which reality is believed to depend on individual views and experiences of the world (Ryan 2018). Epistemology is belief concerning what can be known about the world and ranges from objectivism which considers it can be objectively observed and known, to subjectivism which believes there to be multiple and varied perspectives which come into existence only from our engagement with the world (Crotty 1998). Methodology relates to how knowledge is generated and stems from these ontological and epistemological beliefs.

A large array of methodologies exists. These range from realist objectivist ones in which the only way to generate knowledge is to observe and measure the world with as little interaction from the researcher as possible (e.g. experimental, verification of hypotheses), to relativist subjectivist methodologies where researcher and subject co-construction meaning (e.g. constructivist Grounded Theory) (Denzin and Lincoln 2008). The researcher's personal beliefs in relation to these were considered and understanding shifted from those first assumed.

The research area and provisional research proposal were initially viewed through a realist objectivist clinical lens in which a change in practice was observed, considered amenable to objective measurement and discovery of causation. This perspective stemmed from the researcher's training and professional work experience and culture. The identified lack of knowledge, the schism between professionally instigated guidelines and insider experiences, together with reflection on personal philosophy changed this perspective. A more relativist subjectivist perspective of the research problem developed, as it became apparent that the research area required understanding rather than quantification. With this matured stance,

the journey commenced to find a paradigm which could meet the developed exploratory research aims and answer the question, was congruent with a relativist subjectivist belief system, and which accommodated the researcher as a knowledgeable expert in the field being studied.

3.4 Exploring paradigms

Several paradigms are described in the literature, with a degree of variation in which are included and in terminology used. A plethora of approaches have emerged in recent decades which can appear confusing to the novice researcher. Guba & Lincoln's (1994) presentation of the four major paradigms as positivism, postpositivism, critical theory and constructivism was considered clearest in demonstrating key elements of and variations between paradigms, and these four were explored to determine which approach was most appropriate. Although described separately for clarity, some suggest a continuum from positivism to constructivist/interpretivist approaches (Rolfe 2006; Parahoo 2014). The four approaches are now considered.

3.5 Positivism

The origins of the first paradigm explored, positivism, are traced to 17th century philosophers Rene Descarte who held the realist view that scientific knowledge should comprise only that which cannot be doubted as true, and Francis Bacon who believed that the natural world should be understood through observation, systematic testing and empirical knowledge (Ryan 2018; Corry et al. 2019). These views influenced French philosopher and sociologist Auguste Comte to describe a similar perspective as a means to understand society and human behaviour (Comte et al. 1875). Comte termed this ontology 'positivism', to make it distinct from what he considered woolly thinking in this field at this time.

Ontologically, positivism is realist in perceiving people as subject to external social laws of cause and effect in the same way that nature is subject to scientific law. Epistemologically, the researcher and the researched are independent entities, with the researcher able to accumulate objective knowledge by observation and value-free enquiry, with neither influencing the other (McKenna 1997; Corry et al. 2019). Positivist methodology tends to

use experimentation in controlled environments, with the goal of discovering objective external truths which can be observed, described, explained, and predicted to identify general laws (McKenna 1997; Weaver and Olson 2006). Later thinking found positivism to be flawed in this goal. Scottish philosopher David Hume was amongst others who perceived that just because previous 'constant conjunctions' (where one event is observed to occur immediately and consistently after another) have occurred, does not mean that they will continue to occur in the future (Corry et al. 2019). This was seen as an inherent weakness of positivism as it could not be certain that knowledge it produced would not be invalidated through later discovery.

There was an initial appeal to the researcher as a clinician to a positivistic goal of discovering external causes for the change in practice and measuring outcomes which could then determine the advisability of early colostomy. On consideration however it was doubted that external social laws exist which govern this, and it was not felt possible that researcher and researched would not influence each other, particularly as a previous nurse-patient relationship may exist between the researcher and potential participants. The methodology was therefore rejected.

3.6 Postpositivism

Postpositivism is an adaptation of positivism and stemmed from the work of Austrian-British philosopher Karl Popper, who following the second world war sought to address the flaw within and strengthen the position of the positivist approach by modifying it. Natural laws and theories are viewed as a provisional estimation of truth, not able to be proved beyond doubt by verification, but which can be falsified (Popper 1972; Denzin and Lincoln 2018). Belief in value-free observable cause and effect was unchanged, but a shift from inductive (which creates theory from data) to deductive (which tests theory in specific cases) reasoning and theory production was made, using methods of proposing hypothesis, falsification, systematic observations, and blind trials to eliminate bias (Mackenzie and Knipe 2006; Corry et al. 2019). Where positivism seeks discovery of absolute truths, postpositivism has a modified ontological stance that whilst it is assumed to exist, truth cannot be fully known, and the goal of research is to produce an estimation of it (Denzin and Lincoln 2008; Creswell 2014; Denzin and Lincoln 2018). Scientific knowledge is considered always provisional. No

matter how frequently experiments demonstrate the same result the possibility remains that the hypothesis being studied will be falsified by future discovery.

An objective epistemology emphasizes subjecting research findings to external guardians of objectivity, e.g., through peer review. Methodology in postpositivism shifts in emphasis towards falsification of theories rather than discovery of truth (Guba and Lincoln 1994). The post-positivist approach is a bedrock of research in health sciences and was the approach assumed in the early stages of exploring the observed trend towards earlier colostomy.

Physiological outcomes could be measured objectively using statistical data concerning colostomy rates, length of time from injury to colostomy, and bowel care and colostomy complication rates. A questionnaire might ask why patients chose it when they did and gather satisfaction and quality of life data. This was attractive to the researcher's clinical background of training and working in an area dominated by the medical management of health. The desire to have a straightforward answer to the clinical question of whether early colostomy was advisable was the motivator for first engaging in research in this area. A null hypotheses relating to the research problem could be formulated, and data generated to test this and generalise findings using statistics (Forman et al. 2008). Understanding at this early point was framed by an ontology with defined causal factors and realist explanations, amenable to discovery within an objective epistemology and methodology.

Questionnaires used in published research were examined and it became evident there was no appropriate readily available validated questionnaire for the phenomenon being explored. There was no hypothesis to test, and it was realised that it was not known what questions needed to be asked to address the research problem. As research aims and the question evolved and crystallized, it was seen that a postpositivistic framework was not amenable to aims of understanding and exploring the phenomenon. To have started with choosing the method of gathering quantitative data was to have approached the research from the wrong starting point, and it was realised that initially it had been viewed through a clinical lens concerned with quantifying patient experience, finding straightforward answers, and ensuring safe practice.

Concurrently, reflection on personal ontology and epistemology led to awareness that the research area could not objectively be discovered and understood. The schism in understanding which emerged in the Wider Landscape chapter had demonstrated the need for subjective interpretations from those requiring bowel function interventions. There was a desire to know more about patient experiences and motivations, and these could not be discerned from closed questions and ticked boxes.

Positivist and postpositivist approaches with their emphasis on quantitative methodologies were embraced by social scientists as a means of advancing knowledge with greater validity and raising the status of their profession. They have been subject to criticism including that in experimentation they strip the context of phenomenon which may have influenced behaviour, and that human behaviour cannot be understood without reference to meaning attached to it (Guba and Lincoln 1994). This was the conclusion reached in relation to this research. The position and realised beliefs of the researcher together with the research aims meant it could not meaningfully be studied using a positivist or post-positivist approach without reference to its context and interpretation of participant experiences. A postpositivistic methodology was discounted.

3.7 Critical theory

Critical theory originated in the Frankfurt School, a group of German-Jewish academics from the 1920s, with the intention of challenging perceived oppression with key figures including George Lukacs, Ernst Block, Theodor Adorno, Walter Benjamin, Herbert Marcuse and Jurgen Habermas (Bronner 2011). The work of Karl Marx on class inequality was influential in the development of critical theory, with other approaches including feminism, queer theory, and critical race theory, all of which challenge the assumption that world views and power structures in societies are unproblematically democratic and free (Ryan 2018). Exploitation, subordination, and alienation are perceived and challenged in societal structures, and there is a belief that identity is influenced by social and historical forces (Denzin and Lincoln 2008). An important feature of critical theories is their goal of exposing inequalities and stimulating change, summarised by Karl Marx: 'The philosophers have only interpreted the world, in various ways; the point is to change it.' (Marx 1974 [1845], p.123)

In critical theory reality is shaped by social, political, cultural, economic, ethnic and gender factors, and a subjectivist epistemology considers the researcher and subject to be interactively linked and research shaped by their values. Guba and Lincoln (1994) describe this as blurring the distinction between ontology and epistemology, as reality is inextricably intertwined between the researcher and the subject through their interaction. Methodology requires a dialogue between the two and aims to inform and challenge inequalities.

Critical theory was only briefly examined as a potential framework, although the interactive relationship between researcher and researched was appealing to the situatedness of the researcher within the field. Primary concerns were to explore and understand experiences, not to identify power imbalance and oppression. Awareness grew at a later stage of external factors influencing the research field, but these were not perceived at the start of the research process. This approach was therefore discounted but may be of value in future research in this area.

3.8 Constructivism

Guba and Lincoln (1994) describe the fourth paradigm as constructivism. Constructivism is often intertwined with interpretivism, with Schwandt (1998) describing it as somewhat artificial to disentangle the two . Interpretivism aims to understand the meaning of social phenomena, and stems from the work, amongst others, of Italian philosopher Giambattista Vico in the early 18th century who opposed attempts to apply an empiricist scientific paradigm to the social world (Ryan 2018). Constructivism is traced to the work of 18th century German philosopher Immanuel Kant, who distinguished between things in themselves and what appears to our senses. Only having access to what we sense means the objective world is unknowable (Mackenzie and Knipe 2006). Constructivists focus on the construction of meaning related to knowledge, and use interpretive methodologies and methods to do this (Ryan 2018). These appeared appropriate methodologies for meeting research aims of understanding insider experiences.

Constructivism and interpretivism emphasise the world of experience as it is lived and felt by social actors and believe assumed objective knowledge and truth to be due to perspective, with knowledge and truth being created and not discovered (Schwandt 1998). Many approaches are described within constructivist and interpretivist paradigms. These include phenomenology which grew from Edmund Husserl's philosophy of studying experiences and consciousness, hermeneutics from Wilhelm Dilthey and Martin Heidegger's models of interpretation, understanding and communication, Max Weber's concept of verstehen (understanding of phenomenon and behaviour), and symbolic interactionism developed by Mead and Blumer which views behaviour as based on personal meaning (Mertens 1998; Ryan 2018). The goal of all constructivist and interpretivist approaches is to understand human experience and how it is viewed by the participant, from which theory is inductively generated (Mackenzie and Knipe 2006). This resonated with research aims of understanding and explaining the new phenomenon.

A further tenet of these methodologies important in consideration of the research approach to be used is that realities are multiple, alterable, and dependent on the individual perceiving them. Theory will be impacted by the researcher's knowledge and experience, and the interaction between researcher and participant (Guba and Lincoln 1994). Knowledge is coconstructed from these interactions inductively. This was compatible with the researcher's position within the field and prior relationship with the population being studied, and made these approaches suitable for co-construction of knowledge with participants.

Having journeyed through consideration of four main methodological approaches and reflected on personal beliefs, the philosophical understanding of the researcher was a relativist and subjective one. The exploratory nature of the research aims and the question, the matured philosophical stance of the researcher, their position and experience within the field, and the fact that little was known about the area to be researched, guided the adoption of a constructivist/interpretive methodological framework to perform the research.

3.9 Exploring constructivist/interpretivist approaches

Having determined that a constructivist/interpretivist paradigm was most appropriate, methodologies within this paradigm were explored. Surveying the array of potential

methodologies as a novice researcher can be disconcerting. Those described most frequently and with clearest distinction were phenomenology, ethnography, and grounded theory, and these were the ones appraised for suitability.

Phenomenology, in which human experiences are explored to reveal and clarify their features, would meet the research aims of exploring human experiences (Holloway 2005). The approach does not however include consideration of wider environmental and societal factors and their interplay on the area being researched (Küpers 2009). As an approach which explores the lived experience of people, rather than seeking to understand why they make decisions, this would not be able to meet the aim of understanding choices and decisions and the reasons for the change in practice.

The focus in ethnography of describing a people or culture and researcher immersion in the world of those being studied would be helpful in developing understanding of the community of people with a spinal injury, with its emphasis on how individuals perceive and attach meaning to aspects of life (Atkinson 2001; Denscombe 2014). This would in practice have been hard to achieve however, as the researcher is already known to some as a healthcare professional, with the risk of both researcher and participants remaining tethered in their previous roles (Goodwin et al. 2003). Additionally, it was realised that those with SCI are not a homogenous group. Those with SCI come from a variety of cultures and social groups, and differing levels of spinal injury mean their functional abilities and experiences of bowel management are also variable. The desire in this research was to understand the decisions and choices individuals make, and the focus of ethnography on studying culture was incompatible with this.

The third methodology considered was Grounded Theory. This is an inductive methodology which creates theory grounded in data produced by investigation (Denzin and Lincoln 2008). This was immediately resonant with aims of building knowledge and theory in an area where there is presently little known. It appealed to the researcher's desire for explanatory theory for the phenomenon which would be of practical value and potentially amenable to future testing and modification in a wider healthcare context.

This methodological approach suits the nature and purpose of the research aims, is suitable for research which seeks understanding of a local context, it meets the desire to develop explanatory theory grounded in reality, and is suited to exploratory research (Denscombe 2014). Openness to emergent unanticipated areas of inquiry as they become relevant is permissible, and it is amenable for pursing imaginative new ideas which may occur and lead the research into new areas (Bryant 2017). It is not known why the phenomenon is occurring, therefore an approach which is open to pursuing novel or unexpected findings is advantageous.

Exploring Grounded Theory further found it to encompass different philosophical perspectives. These are now discussed together with the development of Grounded Theory, in relation to deciding the most appropriate position to adopt.

3.10 Exploring Grounded Theory perspectives

Grounded theory was developed in the 1960s by Barney Glaser and Anselm Strauss, as they collaboratively studied death and dying in hospitals (Glaser and Strauss 1967; Charmaz 2014). At this time research was dominated by positivist and postpositivist assumptions with a focus on deductive methods to test rather than develop theory (Higginbottom and Lauridsen 2014; Bryant and Charmaz 2019). Qualitative research performed within constructivist/interpretivist frameworks was perceived as lacking rigour, producing theories of limited usefulness, and criticised as being impressionistic, anecdotal, unsystematic, and biased (Charmaz 2006; Timonen et al. 2018; Bryant and Charmaz 2019). Glaser and Strauss in grounded theory developed a unique, revolutionary, and robust methodology which gave qualitative research explanatory power through theories which made sense, had scientific rigour due to having visible and replicable processes, and raised the status of social scientists (Charmaz 2014; Bryant and Charmaz 2019). This echoes the work of Comte in his desire for positivism to be a means of understanding social behaviour which countered the 'woolliness' of such research in his time (Comte et al. 1875). In its earliest form, Grounded Theory sits well within a positivist philosophy.

Philosophically, Glaser and Strauss brought together differing perspectives. Glaser's history was in quantitative research within a positivistic perspective which recognises the

importance of systematic analysis of data. Strauss' background was in symbolic interaction, which studies human conduct and interaction, and recognises the importance of understanding behaviour and the meanings people give to their experiences (Chenitz and Swanson 1986; Aldiabat and Le Navenec 2011; Higginbottom and Lauridsen 2014). Their perspectives were complementary in producing a methodology which both met demand for quality and rigour and produced theory resonant with human experience and useful in gaining understanding in a wide range of disciplines.

The goal of Grounded Theory is to inductively discover theory about basic social processes, 'grounded' in the data and intricately linked to it, which lead to a more comprehensive understanding of the world through linking of abstract concepts (Glaser and Strauss 1967; Charmaz 2013; Denscombe 2014). The observer starts from a position of openness, is attentive and exploratory as they gather rich data, and they do not attempt to prove or disprove preconceived ideas, but rather allow areas of importance to the participant to emerge (Mills et al. 2006b). As when first considering positivist and postpositivist paradigms, the notion of an explanatory theory which produced understanding of the change in practice was appealing to the researcher.

Further exploration of Grounded Theory methodology revealed it to not be limited to use within one philosophical paradigm, but to be amenable to use across the continuum of perspectives (Charmaz 2013; Timonen et al. 2018). It can be used by researchers with differing questions and perspectives, and the researcher needs to use the version which is congruent with their own philosophy, reflects the relationship between researcher and participant, and can meet research objectives (Mills et al. 2006a; Higginbottom and Lauridsen 2014; Singh and Estefan 2018). Exploring the range of Grounded Theory approaches with reference to research aims and researcher positionality will justify the choices made in this research.

Its use across differing perspectives started with differences in understanding which emerged between Glaser and Strauss in the decade following their 'discovery' of Grounded Theory. Strauss, together with Juliet Corbin, developed an 'evolved' version of Grounded Theory, and over the intervening decades it has been further modified and developed by others so that

it now comprises several distinct strands. Many studies which purport to use Grounded Theory are criticised for a failure to identify which version is used and lack quality and rigour in clearly explicating methodology (Bryant 2021). Awareness of this criticism has ensured careful explanation here. The three main versions with their respective proponents are Glaser's classic Grounded Theory, Strauss and Corbin's evolved Grounded Theory, and Charmaz's constructivist Grounded Theory (Denzin and Lincoln 2008). Most versions of grounded theory fall readily into one of the three main versions, and these are now considered.

3.11 Classic (Glaserian) Grounded Theory

Although Glaser and Strauss did not make explicit their theoretical framework, in its classic form Grounded Theory assumes an objective reality amenable to neutral observation, exploration and discovery, and so is located within a positivist framework (Aldiabat and Le Navenec 2011; Bryant and Charmaz 2019). Reality is external and knowable, and social processes which underly phenomena are amenable to discovery through objective exploration (Glaser and Strauss 1967; Glaser 1978; Bryant and Charmaz 2019). An important tenet of classic grounded theory is the neutrality of the observer. Objectivity is essential, and the meaning of data and underlying social processes will emerge inductively, as they exist apart from the observer (Denscombe 2014). For this reason, Glaser and Strauss insisted on not reviewing the literature before data analysis is advanced, so that the researcher approaches the area of interest as a *tabula rasa*, a blank slate, with no preconceptions or prior knowledge, so that emerging theory is uncontaminated.

Considering this ruled out the use of classic Grounded Theory. The researcher is an involved and knowledgeable professional in the area being studied, and it would be difficult to reflexively identify and set this knowledge aside. It was also felt not desirable to do so, as researcher knowledge could illuminate potential avenues of research interest. In disallowing researcher knowledge an inconsistency is revealed in opposition to the frequently quoted dictum attributed to Glaser that 'all is data' (Glaser 2007). Philosophically, it was not felt there was an objective discoverable social law at play amenable to discovery. Reasons for the change in practice were thought likely to be more complex and individual decisions arrived at for an array of reasons.

Detailed methodological guidance is absent in classic grounded theory, and this has led to criticism by some that it lacks rigour and rules in data collection (Clarke 2014; Timonen et al. 2018). A further criticism is the questionable practicality that has been raised of approaching investigation as a *tabula rasa*, as researchers are likely to investigate areas of interest to them and in which they already have knowledge. For nurse researchers working as experts in their field, nursing knowledge can be instinctive and unconscious, and therefore difficult to define and detach from (Benner 1982). On a pragmatic level, further difficulties of not engaging with extant literature arise from the usual requirement to perform a literature review when developing a research proposal.

3.12 Evolved Grounded Theory (Strauss & Corbin)

The first departure from classic grounded theory emerged as Strauss, and then Strauss and Corbin, developed it towards a method of verification and introduced detailed steps for data analysis (Charmaz 2014; Denscombe 2014; Timonen et al. 2018). This shifted the methodology towards postpositivism. There was movement away from the belief of the amenability of external objective reality to being discovered, towards the provisionality of what can be discovered. Although belief in a knowable external reality is maintained, Strauss and Corbin (1998) were cautious that an observer could ever truly apprehend it.

They continued advocating observer neutrality but accepted subjectivity as inevitable and suggested the researcher be aware of preconceived ideas and set these aside as far as possible. To maximise objectivity and minimise bias, extensive and systematic methods for analysing data were introduced, with an additional layer of 'axial coding' (Strauss and Corbin 1998; Denscombe 2014). This echoes the aim of postpositivism in natural science to control all possible confounding factors and eliminate researcher bias, and here it was not felt possible or desirable.

Glaser has remained consistent in the logic of the original version of classic Grounded Theory (Morse et al. 2016). Strauss and Corbin, however have been observed to oscillate along the paradigmatic continuum, and in more recent work they endorse the reflexive role of the researcher and soften the rigidity of their methods, moving further along the continuum towards constructivist philosophy (Corbin and Strauss 2015; Timonen et al. 2018). Glaser has

been scathing in his criticism of Strauss and Corbin's departure from the original version of Grounded Theory, and accused their extensive subjecting of data to procedures as forcing it into preconceived categories rather than allowing categories to emerge, and producing conceptual description rather than a theory (Glaser 1992; Charmaz 2014). It is interesting to observe the modification of grounded theory towards provisionality of knowledge, in an echo of the historical move from positivism to postpositivism.

3.13 Constructivist (Charmazian) Grounded Theory

Classic and evolved Grounded Theory were the two contested Grounded Theory methodologies until the mid-1990s when 'second generation' versions were developed by students of Glaser and Strauss (Higginbottom and Lauridsen 2014; Morse et al. 2016). The most prominent of these versions is Charmaz' constructivist Grounded Theory. This moves Grounded Theory from its location within a positivist/postpositivist perspective into a constructive/interpretive one. This was a seismic shift in the philosophical location of Grounded Theory, with it now able to inhabit the full spectrum of paradigms considered earlier in the chapter.

The epistemology and ontology underpinning constructivist Grounded Theory denies the objective reality of Glaser and Strauss, perceiving theory instead as a relativist interpretation of human interaction (Mills et al. 2006b; Charmaz 2014). Multiple and even competing realities are possible, and the role of the researcher in reflexively constructing theory is of key importance (Charmaz 2017a). This was resonant with the researcher's philosophical matured belief of knowledge as relative, and positionality as a knowledgeable involved professional. Interpreting meaning through interaction felt compatible with research aims of gaining understanding and enabled use of researcher knowledge and insight.

Charmaz (2017b) describes the goal of constructivist Grounded Theory as moving away from its positivist roots which sought to explain and predict, towards a goal of greater abstracted understanding anchored in a specific context and intimate knowledge of topic, participants and settings. The theory is located in a unique historical setting of interactions and generalisations can be only partial (Charmaz 2014). Although desiring the wider application of theory, of primary importance are the research aims and the question which seek as full and broad an understanding as possible of the emergence of the phenomenon, which constructivist Ground Theory makes possible.

The role of the researcher shifts radically from being a conduit to theorise what already exists, to actively co-creating knowledge which emerges from interaction with data and participants. Resultant theory is an interpretation of reality, not an exact portrayal of it (Charmaz 2014; Denscombe 2014). Reflexivity, optional in objectivist Grounded Theory, becomes crucial in constructivist Grounded Theory as the researcher actively engages in analysis and knowledge construction (Charmaz 2017a; Singh and Estefan 2018). Preconceptions of the researcher, rather than being erased to form a *tabula rasa*, are instead examined and used to shape the analysis (Charmaz 2014). This was resonant with the positionality of the researcher in the field and considered an achievable, logical, and appropriate use of the researcher's knowledge and experience.

Theory building in constructive Grounded Theory adds abduction to induction and deduction, in which the researcher enriches theory by intuitively and creatively engaging with ideas to explain puzzling observations (Charmaz 2014). These ideas may originate with the researcher's knowledge and experience, or from exploring the literature, and enable the researcher to go back to the data with new questions and greater insight, and this is aligned with the desire to include professional knowledge and insight of the researcher into theory building.

Charmaz's departure from Glaser's classic Grounded Theory has, in common with evolved Grounded Theory, received scathing criticism from him. He considers Charmaz's version not to be Grounded Theory at all. Co-construction of meaning is seen as researcher intrusion into the data, with the risk of data being forced in lengthy interviews in which the researcher can introduce bias (Glaser 2002). Glaser's discounting of constructivist Grounded Theory is not upheld by most, and the methodology is well positioned to meet research aims and to answer the question, fits with personal beliefs, and meets the need for researcher knowledge and experience to be integrated into the research.

Glaser's warnings of the risk of forcing the data and researcher bias are however important to consider. A tension in co-construction of theory is remaining open-minded in selecting what is observed and reported, and in being permitted to pursue lines of inquiry of interest to the researcher (Wood and Brink 1998; Charmaz 2014; Denscombe 2014). The risk of following paths of subjective interest rather than emergent ones and forcing data into preconceived beliefs and ideas is mitigated by reflexive exploration and acknowledgment of researcher preconceptions to ensure quality and rigour (Mills et al. 2006a). Measures taken to reduce risk of these are considered in discussion of Methods.

Exploring potential paradigms was a fruitful journey in developing understanding of how methodology needs to be in harmony with the position of the author. Denzin and Lincoln (2008) state that one cannot easily move between paradigms, as they represent belief systems attached to a worldview. This researcher would suggest that *understanding* of one's own worldview can change through studying and reflecting on it, as has been described here. The initial assumption of being able to discover a realist objective social process to explain the observed phenomenon, amenable to quantitative measurement, stemmed from assumptions of the researcher as a clinician trained and working within a system of medical management of health. This grew into a relativist perspective which sought subjective understanding as the clinician-cum-researcher reflected on personal beliefs and awakened to the position of perceiving knowledge as subjective and relative, with the research area being perceived more widely than within a medical management model.

The methodology chosen is one which can meet research aims and answer the research question by exploring subjective understanding and interpreting meaning individuals give to their choices related to bowel management. The shift through paradigms which occurred demonstrates the importance of considering the theoretical framework before starting research, in order that research methodology and design fit with the research question and can produce theory which makes sense both to researcher and researched.

Of particular importance is Charmaz' concept of the role of the researcher as an active coconstructor of meaning. This researcher's role as a professional working with the participant population means they bring knowledge, experience, and subjective opinions about the research area, which would be difficult to wholly set aside to approach the study with neutrality, even with the use of reflexivity. Professional knowledge and experience, together with insider understanding of the organisational context within which the phenomenon is occurring, are considered to bring valuable insights into the area being studied.

3.14 Chapter conclusion

This chapter has discussed how the understanding of personal beliefs and research aims and the question developed, and has explained the position of the researcher as an involved professional with expertise in the area being studied. These, together with deepened understanding of the Wider Landscape in which the phenomenon of interest has arisen, have informed a journey in which different potential methodologies have been perused and appraised for their usefulness and fit.

The desire for understanding, together with the lack of existing knowledge, and positionality of the researcher as an involved expert, have all led to the conclusion that constructivist Grounded Theory is the most congruent methodology to accommodate these and shape research which is meaningful and will produce answers which make sense of the phenomenon.

Having reached this point, the methods and steps used within the approach to achieve the research aims and answer the question will now be discussed. The next chapter will also demonstrate efforts made to avoid the potential pitfalls of the methodology which have been identified as including the risk of researcher bias in the selection of data and construction of theory. This occurs as part of wider consideration of quality and rigour in the approach.

Chapter Four: Methods

4.1 Chapter introduction

The Methodology chapter has described the journey to deciding and stated the research aims and the question as seeking understanding of insider experiences of the choice for colostomy formation following SCI. With the researcher an involved professional, the most appropriate methodology has been decided as constructivist Grounded Theory. This methodological approach will facilitate co-construction of knowledge between participants and the researcher, allow abductive theory to emerge which is inductively grounded in data, and will increase understanding of insider experiences in an area where knowledge is lacking. Constructivist Grounded Theory fits with the personal philosophy of the researcher and allows their knowledge to be integrated with and shape the emergent theory.

This chapter will detail the research process and methods. It is helpful to the novice researcher that constructivist Grounded Theory methodology comprises a well described process. Key elements of this are simultaneous data collection and analysis, creation of analytical codes and categories from the data, use of constant comparison, inductive theory generation, use of memo-writing, theoretical sampling, and performing a literature review after data analysis, if at all (Glaser and Strauss 1967; Glaser 1978; Corbin and Strauss 2008; Charmaz 2014). The systematic way in which data is analysed and compared leads to inductively produced unforced theory, abstracted from the situation being studied but closely tied into the data (Higginbottom and Lauridsen 2014). Activities are performed in an iterative process in which new information is compared with previous data, codes, and categories, going back and forth, and refining and developing the emergent theory. This process is summarised in Figure 5.

Research methods will be described in three sections in this chapter. These are data collection, data analysis, and theory building, although as the three are interwoven and iterative, it is not in reality a completely linear process.



Figure 5: Grounded Theory process (Tweed and Charmaz 2012)

In the first section, data collection is discussed with reference to operational definitions created and used, and the recruitment and sampling of the target population. Methods of data collection are then explained as primarily through interviews, but also to include documentary sources of data (often referred to as extant literature), memo writing and use of a reflective diary. Data analysis comprised stages of initial and focused coding, use of sensitising concepts and constant comparison, theoretical sampling, and saturation. The final theory building section will explain how this occurred in stages and will also include discussion of the use of extant literature in this research. Following this, ethical considerations are discussed, and then a final section will consider quality and rigour in the approach, and will include discussion of power, positionality, and researcher bias, as well as credibility, originality, usefulness, and resonance of the research.
4.2 Data collection

The desire to understand insider experiences guided the decision for the primary method of data collection to be interviews. Data collection was not however limited to this one method. Grounded theory permits eclecticism and diversity of methods with Denzin and Lincoln (2008, p.5) describing qualitative researchers as bricoleurs, using whatever bits and pieces are available to assemble an interpretation, a bricolage, and Glaser (2007) asserting that *'all is data'*. Walter (2006) considers that without freedom to employ mixed methods, the depth and richness of a research project will be unnecessarily limited. This freedom allowed the theoretical sampling of other data, informed by early analysis, as it became pertinent to the enquiry.

In early exploration of the observed phenomena of earlier colostomy, differences were observed between those who chose colostomy formation at an early point following injury, and those who chose to have the procedure later. It was desirable to understand the differing experiences and motivations of both. To guide interview sampling, at an early point a distinction was made between these two participant groups, and an operational definition was created to guide the sampling process.

4.2.1 Operational definitions

A definition was sought for the two groups in terms of passage of time post injury, stage in rehabilitation, and use of traditional bowel management. This was necessary for consistency and reliability in the research, to guide the sampling process, and to aid analysis. 'Early' colostomy is therefore defined as one requested within the first year following SCI, whilst the individual is undergoing inpatient rehabilitation. 'Later colostomy' is defined as the decision to have the colostomy formed made more than a year after SCI, after first utilising traditional bowel management methods at home. Figure 6 provides a fuller definition.

These operational definitions have not been used prior to commencement of this research and are not based on evidence, as no one prior to this author has described the phenomenon of colostomy being performed as a choice so early following SCI (Boucher et al. 2019). As no definitions were available it was necessary for the author to put forward clinically driven working definitions of early and later colostomy, which may change as work progresses, to guide purposive sampling.

Early Colostomy:	Later Colostomy:
Decision to have colostomy made:	Decision to have colostomy made:
during acute inpatient	after discharge from acute hospital
rehabilitation period	rehabilitation
• prior to continuing traditional	after first utilising other methods of
bowel care management at home	bowel management at home
• within first year following SCI	• more than a year after SCI

Figure 6: Operational definitions of early and later colostomy

4.2.2 Purposive sampling and inclusion and exclusion criteria

Purposive sampling can be defined as choosing participants who can help with the purpose of the research, and is a helpful sampling strategy when informed by theoretical understanding of the topic being studied (Robinson 2014; Morse et al. 2016). In this case the purpose was to understand more about the experience and timing of colostomy following SCI and this was informed by the observation that some are choosing it early post-injury in contradiction to traditional guidance. It was therefore desirable to interview both those who had made this choice early and those who had followed the accepted model and chosen it later after trialling other bowel management methods for a longer period at home.

This phenomenon is not documented as occurring in other units. It was therefore appropriate to purposively sample participants from this one spinal unit where the change had been observed. Focusing on one spinal unit allowed the depth of detail required for theory development. In addition, opportunities for greater depth of context are possible from insider knowledge of the organisation and working relationships with professionals within it, which were useful in later development of theory.

Permission was given, and is discussed in section 4.6, for relevant hospital databases and records to be searched. This revealed that between 2005 and the research commencing in

2016, sixty individuals with SCI had chosen to have a colostomy for bowel management. A division into two groups was made using the operational definitions of early and later colostomy. Twenty had chosen to have an early colostomy (the first time this happened was thought to have been in 2013, although subsequent investigation into records revealed two outlying individuals who chose it in 2009), and the rest had chosen it later.

Inclusion criteria were participants with an existing spinal injury from any cause who went on to choose a colostomy for bowel management either early or later. Exclusions were having the colostomy immediately in relation to sustaining the spinal injury or having no choice about it (e.g., it was necessary for wound healing). Purposive sampling was employed to ensure similar numbers of both groups were interviewed. As there is a gender imbalance in those sustaining SCI, with approximately four times as many men as women sustaining SCI, it was appropriate to interview men and women in approximately this ratio (Winter et al. 2014). No attempt was made to purposively sample any further characteristics such as age or ethnicity, mainly due to the small target population available for study. If this had become pertinent or of interest as analysis developed, this could have been considered in further theoretical and purposive sampling.

The catchment area for the researcher's target population is considerable, with many living several hours journey from the spinal injury unit. As those with SCI receive life-long followup review appointments in the unit, the most practicable method of interviewing participants was to do so on the same day they were attending the hospital for another appointment. Permission was granted by the hospital for the researcher to access the computerised appointment system, and purposive sampling was performed by examining this and the stoma care database. It could be discovered who with a SCI and a colostomy had an upcoming appointment, whether they had chosen to have the colostomy, and whether they had chosen it earlier or later. From this purposive sampling, convenience sampling was employed by inviting for interview those who met the inclusion criteria and had an appointment in the hospital within the next month. This allowed the individual time to read information related to the study and decide whether to participate. Sample size was not known at the commencement of the study, as this is dependent on achieving theoretical saturation, discussed in section 4.3.8. As analysis progressed, observations and questions

emerged, and theoretical sampling was also employed. This is explained and examples given in section 4.3.7.

Interviews were performed over a period of approximately eighteen months. There is no way of knowing whether participants knew each other or discussed amongst themselves participating in this research. Two of the twelve participants were known to the researcher in a previous nurse-patient relationship at the time that they underwent colostomy formation. The potential influence of this prior relationship, power and positionality are discussed and reflected on in later sections of this chapter.

4.2.3 Interviews

Interviews were held in a convenient and wheelchair accessible room on hospital premises either within the spinal unit or the stoma department, depending on room availability. Interviewing participants on a day and in a location where they already had an appointment minimised inconvenience and increased the likelihood of participants agreeing to be interviewed. Minimising inconvenience was an important consideration. For the person with SCI everyday tasks of washing, dressing and travel arrangements can be lengthy affairs requiring a great deal of planning. Interviewing participants in their homes would have been considered if it proved difficult to recruit those attending the hospital but was not proposed initially due to practical difficulties relating to the time away from work travelling would have entailed for the researcher, and the requirement of additional risk assessments. Virtual interviews were not considered at the time but could be a method employed in future research as the Covid-19 pandemic has increased availability and familiarity with this method.

Interviews were planned to ensure participants felt as relaxed as possible. Relatives or carers could be present if desired. The presence of another person may have influenced what information was disclosed or withheld, but it was felt on balance that the choice to have or not have someone present should be offered. This decision led to a later unanticipated dilemma relating to consent to use the relative/carer's contribution to the interview conversation, and is discussed in section 4.6.

A semi-structured approach was taken with broad questions and a general framework, but the researcher remained open to following the direction taken by the participant, to avoid narrowing the topic and to remain open to important new concepts which may arise (Charmaz 2013). An interview guide was written to comply with ethical approval processes (Appendix 1). During each interview it was checked that all elements within the guide had been introduced for consistency. The researcher respected the depth and level of information which the participant was comfortable giving. Interview transcripts were checked against the audio recording of each interview by the researcher.

4.2.4 Reflexive writing and memoing

Charmaz (2013) suggests the use of memos when researching, which are thoughts about codes, category development, links, musings, and things to check. Memos were hand-written immediately after interviews to document impressions and reflections. Thoughts and observations when critiquing literature were recorded on electronic documents, and the researcher maintained a hand-written reflective journal throughout the research journey. All of these were treated as data and grappled with analytically as part of the process of analysing and theorising.

4.2.5 Documentary data

As questions arose during interview data analysis and theory development, additional naturally occurring data which became of relevance was gathered in further purposive sampling. This came from healthcare records, demographic information about participants, and stoma care department records. The theoretical question which arose at an early point of what differences in experiences might there be between individuals who could perform their own bowel management and those who required help, led to gathering this information from health records.

As codes emerged and divergences were observed, a further theoretical question developed concerning the relevance of the time period in which the SCI was sustained. To explore this, hospital medical records were searched to establish the dates each participant sustained

their spinal injury. This led to the creation of the participant timeline given in Chapter Five which served to illuminate codes and categories.

Extant literature, discussed in Section 4.5, was treated as secondary data, as was the reflexive research journal of the researcher. These additional sources of documentary data added context and enriched the developing theory.

4.3 Data analysis

Data analysis started once the first participant interview was completed, after which data collection and analysis became an interwoven iterative process rather than a linear one. Charmaz (2014) describes several strategies for data analysis in constructivist Grounded Theory. These include coding, focused coding, category development, constant comparison, free-writing and memoing, and diagramming. These are now considered, and examples given to illustrate use of these strategies in this research.

4.3.1 Initial coding

Each interview was transcribed verbatim and checked for accuracy against the recording by the researcher. Transcripts were then manually subjected to systematic line by line coding. Computer programmes to aid coding were considered but had to be ruled out due to the researcher's IT department not permitting the downloading of these programmes onto their laptops. A hospital laptop was favoured for use because of the additional data protection this afforded. The difference to data analysis from the choice to use manual or computer assisted coding is not known, but manual coding became an enjoyable and stimulating part of analysis which spurred creative thought and was applied consistently to all data.

Codes, which are labels given to segments of data, were assigned to the transcripts and efforts were made to use action labels, or gerunds, to focus on actions and processes as advocated by Glaser (1978). Charmaz (2006, p.118) advocates using *"speed and spontaneity"* when performing initial coding to spark thinking and keep the intensity and impact of the data. Doing this enables the researcher to engage actively and kinaesthetically with the data

(Charmaz 2013). Phrases felt to be of special importance were kept as *in vivo* codes, e.g., *'Being Alive Again'*.

From initial coding of the first interview, 186 different codes were identified, many of which appeared several times. Figure 7 shows an excerpt of coded transcript from this interview.

Interview data	Code
24 I don't recall any options being discussed. In the	Being excluded from decisions
25 earlier part of it there was no other real answer because as I	Having no choice
26 say initially I couldn't be moved. Later on as time progressed	Being excluded from decisions
27 again no discussion was made about what options might be available.	Being kept in the dark

Figure 7: Initial codes on a section of interview one transcript

The ability to analytically code data segments was a skill which developed over time. The researcher's reflective diary after coding the first interview demonstrated this journey:

"The first thing I recognised was how weak some of [the codes] were! Looked at together I could see some were purely descriptive, others were analytical and one or two resonated loudly as important emergent themes." (Reflective diary 11/11/2018)

Conscious of the need to be analytical and not descriptive, the interview codes were reconsidered and with practice this became easier and led to satisfying moments of insight:

"I feel I'm starting to understand more about some things he's said. I had a moment of insight where I realised, he's 'trying to keep his body whole'. This I hadn't seen initially as a code, but it suddenly seemed to explain a lot of what had initially appeared to me as mundane things about managing a pressure sore." (Reflective diary 21/11/2018)

4.3.2 Focused coding

The initial codes from the first interview were examined to create focused codes. These are codes which appear more often, have more significance, or make the most analytical sense (Charmaz 2006). The 186 codes were grouped according to similarity, and codes within each

group studied and their meaning reflected on. From this, 23 focused codes were developed from the first interview, and it was checked that these fitted the data the initial codes came from. Figure 8 gives examples of initial codes grouped to form focused codes from interview one:

Focused code:	Battling with my body	Being empowered
Initial codes:	Body restricting me	Wanting independence
	Struggling to manage my body	Being a means to an end
	Beating my body into submission	Informed decision making
	Battling with my body	Having choice
	Mastering my body	Regaining control
	Managing my body	Being empowered

Figure 8: Initial codes grouped into focused codes from interview one

Codes and focused codes were held lightly, and through constant comparison were reshaped and moulded as new data from subsequent interviews became available. Some were not fully comprehended at this point, such as *'being a means to an end'* in the example above. At a later stage, this code was moved as insight grew and it became important in illuminating a group of focused codes labelled for a time as *'professional misunderstanding'*.

Related focused codes were grouped together into five areas, with some appearing in more than one area at this stage, and tentative working labels given to the groups which would later inform the development of categories (also called themes). Figure 9 gives an example.

The Inner Battle Defending my body Battling with my body My body letting me down Playing Russian Roulette	Loss Loss of self Being powerless Loss of control Loss of self-image Loss of time Loss of dignity	Suffering My body letting me down Playing Russian Roulette Bodily decline Being subject to interference Suffering Pain as inevitable Being powerless
Regaining self/being alive again Being empowered Regaining self/being alive again Regaining control Regaining dignity	Professional misunderstanding Professional misunderstanding Wanting an easier option	

Figure 9: Groups of focused codes after interview one

Three of these codes stood out and seemed particularly telling at this point: 'pain as inevitable', 'playing Russian Roulette', and 'Being Alive Again'. These in vivo codes felt important and were of particular interest.

At this stage, some focused codes felt problematic and not fully understood, particularly those relating to *'professional misunderstanding'*. Analysis of subsequent interviews, reflexivity, and the use of sensitizing concepts would later aid insight and development of codes, but for now they were left fallow in their unfinished state.

4.3.3 Constant comparison

The process of initial and focused coding was repeated following each subsequent interview, with data collection and analysis occurring simultaneously. Codes from a fresh interview were compared with those of every earlier interview, and any novel codes would be searched for in previously analysed interview data. This method is termed constant comparison (Charmaz 2014). Focused codes, codes, and data were all subjected to this throughout data collection and analysis. Constant comparison led to the discovery of codes in earlier interviews not previously noticed:

"Wanting independence' I'd only identified in a couple of the later colostomates, but it was now obviously a major element of what the independent earlies had wanted, for some reason I'd missed it. I guess this is because some people made things much more explicit, so I picked up on that code more quickly in some. And then recognised through constant comparison that that is what someone else was also saying." (Reflective diary 09/03/2019)

As data collection and analysis continued, focused codes were placed on an electronic spreadsheet which grew and developed. New groups of codes emerged, and constant comparison led to addition and refinement of codes within and between groups.

"I'm now working through comparing each code with interview data to make sure I've got the meaning right, and to condense and crystallise that meaning. E.g., in my initial category of 'bound by tradition', I've removed 'mistrust of professionals' as checking through where this occurs, it's actually about 'information being withheld'." (Reflective diary 05/12/2018) Having the codes displayed on the spreadsheet facilitated visual comparison of the distribution of codes for each person interviewed. It was observed with interest that focused codes grouped together under the heading *'suffering'* appeared frequently in those who chose colostomy later, and infrequently in those who chose it early, and these differences became important in theory development.

4.3.4 Sensitizing concepts

Sensitizing concepts are broad terms to spark thinking about a topic, and are used as a tool to guide inquiry, raise questions, and develop ideas (Charmaz 2014, p.30). They emerged from terms found in interview data, prior knowledge, and from intentionally searching the literature to learn more about extant theory. Sensitizing concepts from extant literature included Todres et al's (2009) humanising care concept, Johnson & Morse's (1990) work on regaining control, Gullick & Stanton's (2008) term *'shrinking life world'*, and Charmaz' (Charmaz 1983) *'living a restricted life'* code. Sensitizing concepts were taken and used in constant comparison to question and explore the data. They illuminated findings, deepened understanding, broadened the context of experiences, and demonstrated areas of convergence, divergence, and extension of existing theory.

4.3.5 Free writing, memoing, and reflexivity

Free writing and memoing are tools which facilitate reflexivity and can lead to deeper understanding of data (Charmaz 2014). Experimenting with these and allowing thoughts and words to run freely helped with understanding and led to moments of insight and illumination. In these streams of thought flowing from head through to fingertips the words and inflections of the participants voices were recalled and mused upon.

Free writing was used to grapple with the inadequately comprehended 'professional misunderstanding' group of codes. Understanding developed that this was related to a lack of agency and choice and 'Failure of Care', which later became key aspects of the theory:

"Later colostomates: They're being subject to a regime that isn't right for them. They're suffering, it's unacceptable, they're not being given choice. Care is

ritualised and info is being withheld. In a role of being passively subjected to care that doesn't work. The resources aren't there to provide properly that care. It's a loss of control, power, agency...Having to conform. Being forced into something that doesn't fit. Lack of individual based care. Production line. Homogeneity of care. Ritualised care. Being misunderstood. Not having rights. De-personalisation. Stripping of self." (Memo: Trying to make sense of professional misunderstanding category 14/08/2019)

These musings evoked prior knowledge of Todres et al's (2009) concept of humanising care and led to further examination of the data with this model used as a sensitising concept.

4.3.6 Diagramming

Diagramming was a valuable tool in consolidating understanding of data. Its benefits are described as giving visual representation of categories and their relationships and teasing out relationships during analysis (Charmaz 2014). Diagrams were constructed throughout data analysis to clarify thought and convey concepts, processes, and connections diagrammatically. These were frequently beneficial in increasing understanding in an area.

Diagramming helped explore the observed differing experiences of early and later colostomates (see Figure 10). It was perceived that being given information and choice facilitated the movement from the categories 'suffering' and 'loss', into that of 'regaining self'. The positive benefit of colostomy as a means of regaining self was universal, but those choosing it later who lacked information and choice, first plumbed a greater depth of suffering which the early colostomates avoided experiencing.



Figure 10: Comparing early and later colostomate experiences

Experimentally exploring this through diagramming increased understanding of how key the availability of choice and information were and led to the earliest version of the theoretical framework (see Figure 11).



Figure 11: Earliest theoretical framework

Diagramming also developed insight into the shifting balance of power over time between patients and professionals and this was related to the availability of information and choice (see Figure 12). This in turn led to theoretically sampling both literature and NHS policy documents, demonstrating the use of simultaneous collection and analysis of data.

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Figure 12: Changing balance of power over time

4.3.7 Theoretical sampling

Theoretical sampling was a strategy employed to gather further data as theoretical questions or new concepts emerged as important or of interest. The first way in which this occurred was following analysis of several interviews which revealed differences in experiences related to whether participants were independent or dependent on others to perform bowel management. Interviews with those who required the help of a caregiver had codes relating to this which were not present in those who were independent. This difference had not been considered prior to commencing the research and led to purposive theoretical sampling from that point to ensure inclusion of similar numbers of participants who were dependent and independent. Details of this were added to a table of participant data and this ensured participants from all domains were sampled.

Theory development guided a second indication for theoretical sampling at a point when *'control'* and the provision of information emerged as important themes in data analysis. A theoretical question emerged of whether these were themes for all those dealing with bowel management following SCI, or just those who went on to choose the option of colostomy. To examine this question, it became desirable to interview participants who had not chosen to have a colostomy. Robinson (2014) states that sample size can be increased if analysis makes the researcher thinks an important group has been omitted, to enhance validity or transferability of findings or theory. Interviewing those without a colostomy was a deviation from the original target population and required an amendment be approved by the Research Ethics Committee (REC). If data analysis from this new target sample confirmed control and information as important themes it may extend the validity and transferability of theory, but the primary motivation was to understand more about the emerging theme.

A third instance of theoretical sampling demonstrates its use to gain greater understanding of data and codes. An interesting code found in analysis of two participant interviews was *'pain as inevitable'*. Intrigued by this code and wanting to understand more, one of these participants was interviewed for a second time. This provided additional information in relation to the code and led to new information as he related the belief of *'pain as inevitable'* to the period in time he sustained his injury. This information led to a new theme developing of *'changes over time'*.

4.3.8 Theoretical saturation

Data collection and analysis continued until saturation point had been reached, and no new information was being yielded. There is an important distinction to be made between saturation of data and saturation of theoretical concepts which is what is meant here by theoretical saturation (Charmaz 2013). In asking similar questions about bowel management, interviews yielded similar data about for example how it could be embarrassing or became increasingly difficult over time. This is not what is meant by theoretical saturation of a concept. Instead, this occurs when it is felt that all dimensions and variations and the extent and range of the concept have been discovered. Gathering further data beyond this point does not bring incremental benefit to the theory development process (Strauss and Corbin 1998). When theoretical saturation was considered to have been reached, data collection stopped.

In the example above, analysis of difficulties relating to bowel management led to the creation of codes including '*Failure of Care*' and '*Suffering*', and these conceptual codes were explored in further data collection. Simultaneous analysis of data and constant comparison meant real time judgement could be made about whether these concepts had been fully explored and understood, and whether fresh data was adding anything further.

A further example is data collection concerning the amount of choice and information participants were given when analysis revealed variation in this related to the participant timeline of injuries. Theoretical sampling was performed through literature searches to discern societal changes over the length of the timeline, such as the rise of consumerism. NHS documents were traced to explore strategic aims of making information and choice more available and the limitations of these aims. These data collection strategies with simultaneous analysis furnished dimensions of theory, relating observed changes in availability of choice and information to concepts of humanization theory and contextualising these in time. The point was reached where it was felt further data collection revealed no new information relating to the concept, and so theoretical saturation was reached and investigation in this area ceased.

4.4 Theory development

The development of final categories and construction of the theoretical framework is now considered. Categories are codes of special significance or themes which are developed into abstract analytical concepts to inform theory (Charmaz 2014). The provisional groupings of focused codes were the start of category (or theme) formation. As data collection and analysis proceeded iteratively and with constant comparison, the groups were modified, dismantled, and re-assembled several times, and only became firm categories at the end of analysis which included further data from extant literature. The researcher's reflective journal charted reflection on categories as seen in the example below, (pseudonyms are always used for all participants):

"I feel Terry is fighting with and against his body. He fights against interference to keep it whole and defend it, and at the same time has to fight against his body as it lets him down and holds him back from doing what he wants to do. I wonder if this 'inner battle' Terry is fighting will emerge as significant." (Reflective diary 24/11/2018)

During analysis of interview three the category 'time' emerged transiently, and constant comparison revealed related codes in earlier interviews. Musings within the reflective diary demonstrate how understanding of the dimensions of 'time' grew and led to it being dismantled as a category and developed into differing focused codes as understanding of differences clarified:

"Jim talks a lot about making the most of time – for Terry 'loss of time' is part of a category called 'loss'...Jim's time issues aren't about loss, they're about time being precious, having things to do, wanting to make the most of time..." (Reflective diary 22/12/2018)

Understanding these differences was important. Both participant interviews initially contained *'loss of time'* as a code, but constant comparison revealed that Terry's loss of time was a loss of months of his life whilst suffering bowel related complications. In contrast, Jim was anticipating losing time to bowel management once he was discharged home from inpatient rehabilitation when he had other priorities, such as seeing his grandchildren. Constant comparison with other categories, codes and data led to the decision that these

variations in *'time'* belonged in different categories. Terry's loss of time became part of *'suffering'*, and Jim's *'having things to do'* became part of *'regaining self'*.

The spreadsheet of codes continued to be useful in showing visually the variation of codes within a category, how many interviews a code appeared in (which gave an indication of its strength) and making it possible to see differences in the population of codes between the early and later colostomates. Examples are found in Appendix 2. The gaps in codes were telling areas about the differences in experiences between the two groups. Variation was evident in the lack of codes for early colostomates in categories of *'pain and suffering', 'loss of agency'*, and *'battling with the body'*. The later colostomates had less codes relating to empowerment, choice, and independence. These gaps and differences provided clues in developing answers to the research question and aims and developing theory.

When all interviews had been coded and constant comparison had been performed, there were eight categories. Some categories and codes were stronger, had greater interconnectedness, and seemed more pertinent to the research aims. These were raised as major categories for development of abstract theoretical concepts (Charmaz 2014). Categories set aside at this time were those which were weakest, contained fewest codes, were identified in fewest participant interviews, and which had less interconnectedness with the other categories. Felt to offer little insight into research aims and questions, these were set aside and not discarded, and were available to be drawn back into the theory if new knowledge or analysis suggested this. It is acknowledged that the direction of the theory once interview analysis was complete reflected the researcher's interpretation of what was most significant and interesting.

The theoretical framework went through several stages of development and modification, more detail of which will be given in Chapter Five. An initial model was created after analysis of interview data, and this changed and evolved after further data was gathered from extant literature. The final framework was completed after exploration of the wider context of participant experiences in relation to the theme *'Failure of Care'*. The use of literature in theory development and presentation of findings marks a departure from many forms of research and format of thesis and is of key importance. This is now discussed.

4.5 The disputed use of literature in Grounded Theory

Grounded Theory differs from other methodologies in its approach to reviewing and use of literature. In non-grounded theory research, a linear process is followed where the review of literature occurs early and is the foundation on which new research is built. In doctoral studies the resulting thesis can logically be presented in the traditional *'Literature Review* \rightarrow *Findings* \rightarrow *Discussion'* format (Dunne 2011, p.120). This presents difficulties however, when using Grounded Theory methodology, where existing knowledge from the literature is held differently.

Analysis of primary data leads to theory emerging inductively from it, and all grounded theorists emphasise the importance of not forcing a Grounded Theory to fit into pre-existing categories, which might hinder the development of rich new knowledge (Glaser and Strauss 1967; Strauss and Corbin 1990; Dey 2007; Dunne 2011; Charmaz 2014). Knowledge from previous research is therefore not the foundation on which research is built, but something to be held at a distance until the framework of the new theory has emerged. Once this occurs, grounded theorists then in varying ways apprehend the literature as a source of comparison and further analysis to be integrated into thinking as the theoretical framework stabilizes (Locke 2001; Charmaz 2014). It is also used to demonstrate how the study is located within the field and develops existing knowledge (Dunne 2011; Morse et al. 2016). This integration of extant knowledge in a non-linear manner means it is woven into the fabric of the theory, presenting a challenge if writing a thesis in a traditional format where discussion of literature comprises a discrete and early chapter.

From this common ground in ideological understanding of the purpose and positioning of extant knowledge, grounded theorists further agree that a literature review *should* be performed, but it is disputed amongst them *when* and *how extensive* it should be (Cutcliffe 2000; Bryant and Charmaz 2007; McGhee et al. 2007; Dunne 2011). At its inception Glaser and Strauss advised literature reviewing to be delayed until a late stage after data analysis was complete, to prevent forcing of data (Glaser and Strauss 1967; Glaser 1978). This is a position Glaser maintains:

"When the grounded theory is nearly completed during the sorting and writing up, then the literature search in the substantive area can be accomplished and woven into the theory as more data for constant comparison." (Glaser 1998, p.67)

This position is logical as the unpredictable nature of Grounded Theory research means it is not known at the start what literature may be relevant, and time-consuming and extensive reviews of publications in a particular area may be wasteful and inefficient (Glaser 1998; Locke 2001; Dick 2007; Dunne 2011). Charmaz (2006) tends to agree with Glaser in advising delaying the literature review to avoid importing and imposing ideas on work, and to allow the researcher's ideas to emerge. In this research Glaser's point about not knowing at the start what literature may be relevant is a pertinent one. The starting point of the research journey sought understanding of a clinically observed deviation from accepted bowel management practices, and the unanticipated destination was theory relating to control and failure of care.

A pragmatic difficulty arises if wishing to avoid early interaction with the literature, as prior to starting research a research proposal is often required which will necessarily include writing a review of the literature (Charmaz 2014). It is unavoidable therefore to investigate and review the present state of knowledge in the field of interest, and this is how the researcher identifies a gap in knowledge worthy of investigation. Grounded Theory is proposed as a useful methodology when relatively little is known about an area, but this is a conundrum if wishing to delay a literature review, as how else can such areas be identified? The solution to this proposed by Charmaz (2014) is that if a literature review is required for a research proposal, the researcher should engage critically with the literature, and then allow it to lie fallow until categories and analytic relationships have been developed, remaining alert to how and when prior knowledge is informing thinking.

Other grounded theorists advocate an early literature review, with Dunne (2011) describing advantages of this as providing a rationale for a study, justifying the research approach, identifying gaps in knowledge, contextualising the study, developing sensitizing concepts, becoming aware of preconceptions, and promoting clarity of thinking. All are important but it could be argued that only the first three or four necessarily occur at an early stage in the Grounded Theory research process. The remainder are benefits which a later literature review can bring during data analysis and theory development.

Still other grounded theorists take the position that the literature should be consulted throughout the research process. Lempert (2007) describes using the literature extensively whilst collecting, coding and memoing and writing. She considers the literature review necessary to understand and define parameters of a current conversation she hopes to enter, but which will not define or restrict her research. In consulting the literature to define the context of bowel management following SCI prior to commencing research, the parameters of this conversation were understood, but as Lempert (2007) describes this did not then restrict the flow of conversation into other areas which emerged as important.

These varying stances are consistent with Grounded Theory's assertion that data must not be forced into pre-existing categories and demonstrate a range of permissible interaction with the literature which a researcher may choose to adopt. It was the choice of this researcher to perform a preliminary literature search at the outset to provide the context and Wider Landscape of the starting position. It was from this that the research proposal was written, the gap in knowledge in the clinical context was located, and research aims and the question were identified.

This knowledge was then set aside as the research journey started. During data analysis new points of interest emerged, and at these waypoints relevant literature was searched and used as a secondary data source as it became relevant. This new data was woven into the theoretical framework. As the destination came into view, final questions were asked of extant literature which located the theory within the New Wider Landscape the research journey had led to.

This treatment of the literature, whilst permissible, appropriate, and consistent with the methodology used, became problematic as writing up commenced and the expectations of the report, in this case a doctoral thesis, were considered. The traditional accepted format has been described at the start of this section as *'Literature Review* \rightarrow *Findings* \rightarrow *Discussion'*

(Dunne 2011, p.120). This works well in non-grounded theories which start with a literature review and build upon and incrementally add to an existing body of knowledge. This Grounded Theory, however, had emerged in unplanned, non-linear, and unanticipated ways, with literature consulted at several points and then woven into the fabric of the theory.

Most literature was searched during theory development and treated as a secondary data source. It became part of the theoretical framework as it was modelled and remodelled, and the traditional formatting structure felt incompatible with and a non-logical way of portraying the research journey and writing the final thesis. Extracting elements of the theory originating in extant literature and forcing them into a separate chapter would not make theoretical or logical sense and would undermine the coherency of the theoretical framework. For this thesis, the most appropriate and logical structure is to interweave findings from literature searches with findings from primary data analysis. This is necessary to present a cohesive theory, rather than fragmenting it to produce a separate literature review discourse chapter. Further detail is now provided about the treatment and use of extant literature in this research.

4.5.1 Use of literature to furnish the Wider Landscape

Extant literature was used firstly in an exploratory search to give the rationale for the study, justify the research approach, identify the gap in knowledge, and give context to the starting point of the study. This enabled the research question and aims to be framed, and the results of this literature search form the basis of the contextual information given in the Wider Landscape chapter. Its purpose was to inform factually, and critically consider current bowel management practices following spinal injury. It was not perceived or constructed as a traditional literature review which serves as a setting to critically locate later findings.

Questions being asked of the literature at this time concerned the nature of SCI and bowel management, the professional guidance being given, and the current role and timing of colostomy. These were questions which located this research in its starting position of the *clinical* field, prior to data collection or analysis. To have more extensively consulted and interrogated this literature would have proved as Glaser (1998) states to be wasteful, as it

was not until concepts and theory had been abstracted that it was known what the substantive areas to search for in the literature were.

4.5.2 Initial literature search strategy

The initial literature review of the clinical context was performed at the start of the research prior to data collection. Search terms used were 'spinal cord injury' OR 'SCI' OR 'spinal injury' AND 'colostomy' OR 'stoma'.

All searches were performed using the university electronic library advanced search tool, which searches Medline, Complementary Index, APA PsychInfo, Academic Search Ultimate, CINAHL Complete, SocINDEX, SPORTDiscus, ScienceDirect, Regional Business News, Directory of Open Access Journals, SwePub, Networked Digital Library of Theses & Dissertations, ERIC, APA PsychArticles, Art & Architecture Complete, British Library Document Supply Centre Inside Serials & Conference Proceedings, Government Printing Office Catalogue, Supplemental Index, British Library ETHOS, Gale OneFile: News, and JSTOR Journal and Education Source.

For inclusion results had to:

- Include the key terms
- Be peer reviewed

Articles were excluded which:

- Were not in English
- On screening abstracts did not identify the key terms and demonstrate relevance

After screening of abstracts this initial search yielded 29 results. From these results, relevant citations were also explored. This search informed the background and discussion of colostomy following SCI found in the Wider Landscape chapter. This literature search was repeated towards the end of the writing up process to check for recent publications. More recent publications found included the updated MASCIP (2021a) guidance, and those written

by Cooper et al (2019) and Johns et al (2021), and new information from these was woven into the thesis. Further searches were performed to set the scene and increase knowledge relating to spinal injuries, bowel management strategies, and clinical outcomes related to alternative management options. Sources of this type of information were critiqued and interrogated for reliability as detailed in sections 2.3.1 and 2.3.2.

4.5.3 The literature as a secondary data source

The second stage of engagement with literature was delayed to avoid forcing data into preconceived categories and to allow theory to emerge inductively. As codes and categories and a tentative theoretical framework started to emerge, pertinent questions were asked of the literature as it was engaged with critically and comparatively (Charmaz 2006). This produced sensitizing concepts which were taken back to the primary interview data in further constant comparison, and this informed and developed data analysis. This iterative use of the literature helped build and contextualise the theory.

The purpose of the later engagement with and searching of literature can be summarised as to:

- Explore emergent themes
- Provide secondary data
- Identify sensitizing concepts
- Further develop and contextualise the emerging theory
- Add quality and rigour to the research by comparing it with existing theory
- Develop and explore themes and ideas from data analysis using theoretical sampling

4.5.4 Methods of analysing and integrating secondary documentary data

Secondary documentary data sampled included data relating to participant demographics, statistical information about numbers of 'spinal colostomies' performed, government policy documents, national and international guidelines, as well as books and articles. To achieve the purposes of gathering secondary data discussed in the previous section and in consistency with how primary interview data was treated, extant literature and documents

were analysed using grounded theory techniques of coding, use of sensitising concepts and constant comparison, theoretical sampling, and saturation.

With a large quantity of secondary data sampled, and many documents being electronic ones, it was not possible to employ line by line coding as was done with primary interview transcripts. Instead, as each item was read and critiqued, notes were made in a table in an electronic document. This table detailed the nature of the document, information about the authors, participants, setting, and notes from critiquing the document, as well as new and existing codes as they occurred. Pertinent quotations, reflections, and musings were also recorded. New codes from the literature illuminated similar codes not previously identified in primary data analysis and added to understanding of interview data and concepts. Examples of this are described in the Findings and Theoretical Discussion chapters. Adjustment and refining of codes within all themes occurred as understanding grew.

There was a reciprocity in the process of constant comparison of interview and secondary documentary data: codes from the latter explained and illuminated interview data, and interview codes extended understanding of findings in literature data. Secondary data analysis thus informed and was woven into the fabric of the developing theory.

4.5.5 Methods of sampling and critiquing the literature

Literature used both in consideration of the Wider Landscape and that used as a secondary data source, was examined critically using the Critical Appraisal Skills Programme (CASP) (2018) tools to assess quality and rigour, and an electronic spreadsheet was created to aid review and analysis, and in which memos were written. For Grounded Theory studies, an additional tool developed by Berthelsen et al (2018) was used to further assess quality and rigour. These tools were helpful in critiquing literature and ensured consistency when interrogating it.

Interestingly, and not anticipated, the critical appraisal and memoing yielded further data, as stated and unstated ideologies, perspectives, and other political and organisational factors were revealed. Discerning these through critical examination of literature led to additional

codes and further development of the theory. An example of this was an article by Cooper et al (2019) which on first reading affirmed this researcher's emerging findings of the benefits of offering colostomy at an early point following SCI, and was an exciting indication of the phenomenon of early colostomy occurring in other spinal injury units. Critical analysis however revealed the authors in their professional roles to be acting as gatekeepers of information and paternalistically deciding who would benefit from early colostomy and who would not. This was a useful finding from the critique and added to the developing theory.

Inclusion and exclusion criteria were applied when searching the literature for secondary data similar to those applied to the initial literature searches relating to the clinical context of the Wider Landscape chapter. For inclusion results had to:

- Include key terms related to codes or the question being explored
- Be written about events within the timeline of participants

Articles were excluded which:

- Were not in English
- On screening abstracts did not identify the key terms and demonstrate relevance

When searching the literature later to gather secondary data, successive searches were performed using key codes and to ask theoretical questions which had emerged from analysis of primary interview data in a process of theoretical sampling described earlier. An excerpt from the list of key codes and questions can be found in Appendix 3. Where extant data was limited, searches were widened to include literature related to chronic conditions, as SCI can occur due to injury or disease or degenerative processes (WHO 2013). Widening searches in this way identified resonant themes including Gullick and Stainton's (2008) *'shrinking life world'*, which was taken back to the interview data as a sensitizing concept.

Other areas explored by searching the literature which became important in theory development included:

- Changes over time in health policy and provision
- Todres et al's (2009) framework of humanization
- Kuhn's (1996) work on scientific revolutions and paradigm shifts
- Theories of control

Successive searches continued until it was felt the literature had been explored to a point of theoretical saturation and no new insights were being added to the theory. Constant comparison of literature search findings with codes, categories and raw interview data refined the theoretical framework.

4.5.6 Reflection on the literature search and 'forcing' categories

Even delaying the literature searches until concepts and the framework were developing, it was possible to fall into the trap of forcing data into pre-conceived ideas which felt resonant. This was recognised and reflected on, and making this explicit is useful in demonstrating robustness of the research:

"I did initially get caught in the trap of seizing on ideas of others I liked and started to unconsciously 'force' my categories a little. This brought me to a point during writing up of getting 'stuck'. In talking about 'reconstructing identity' I tried to find where in my data I had found this, to give quotes to support this finding and realised I didn't have any. I had been caught in the mistake of recognising the truth of what the literature said about how struggling with bowel management following spinal cord injury led to loss of identity, and knew I had read elsewhere in my literature search about examples of this happening, and had come to believe my participants had talked about this too. Reading through the transcript data and early codes I realised this was not the case. I had a moment of honestly recognising my mistake in trying to force my data into the theories and categories of others which had resonated with what I found. The theories and categories of other researchers give context, are in general agreement, inform, resonate with my findings. But I had to go back to my own data and categories, some of which were similar to others (shrinking life world); some added new dimensions (playing Russian Roulette); some weren't in my data at all (reconstructing identity). This was a key moment in my research activity, this recognition of where I had stumbled into error. I put aside my nice tidy 4Rs findings chapters and went back to my own data and my earlier categories of loss, suffering, expanding self and changes over time. This was what my data and analysis had shown. Some were supported, enhanced, challenged by what I had read, and this was how literature needed to form part of my theory." (Reflective diary 08/08/2020)

Reflecting in this way added to the robustness of the Grounded Theory, with consideration of rigour and quality being important in theory development. This is further considered shortly, after first discussing ethical considerations which were made at the start and throughout the research process.

4.6 Ethical considerations

Ethical approval was gained from the sponsoring university, and the REC (Appendix 4), and permission granted by the participating hospital to be the research site. The amendment to include participants who had not undergone colostomy was approved by the REC (Appendix 5). A detailed participant information sheet was written (Appendix 6) and sent at the same time as an invitation letter and a consent form (Appendix 7 and 8). Further opportunity was given once participants attended the interview to ask questions. Understanding of the research was checked and consent confirmed and documented prior to the interview starting.

In planning the research ethical issues such as preventing harm, avoiding exploitation, use of findings, and confidentiality were early considerations. Planning for the physical and psychological safety of participants is important, and there is an obligation to ensure that participants are portrayed sensitively, research is useful, and data is handled and findings disseminated appropriately (Leavy 2014). All participant interview data was treated in the same methodical process of analysis.

Participants were made aware that they could withdraw at any time from the research, without giving a reason, and at no detriment to their future or ongoing care. It was, however explained that at a point in the data analysis process it would be impossible to extract their data from the theory which was being constructed. As many of the participants were unable to sign a consent form due to limited or absent hand function, and in line with hospital policy, it was acceptable for a representative to sign on their behalf in the presence of the participant and a witness, or for an electronic signature to be given via email. The location of the interviews were rooms within the hospital assessed as safe and accessible for those using a wheelchair to aid mobility. It was planned that an interview would be suspended if a

participant became distressed and appropriate intervention and comfort given. The interview would be continued later if the participant wished.

Learning about the participant's world is an important part of interview preparation (Charmaz 2013), and here there was an advantage that the researcher had professional knowledge about bowel management following SCI, and it was hoped this would reduce embarrassment and make participants feel more comfortable in discussing this personal domain. A potential disadvantage was that assumptions of shared understanding by either researcher or participant could lead to potentially useful information not being discussed. In the interview situation it is important to develop rapport quickly, to facilitate trust and openness (Ashton 2014). The fact that the researcher was already known to some (but not all) of the participants was helpful in this. An ethical concern was not to misuse trust and it was fully explained that in the interview situation the role was one of researcher, not their nurse. The risk existed that participants would feel pressured to be involved in the research because of the prior relationship. This was mitigated as far as possible by only approaching potential participants formally by letter.

The Data Protection Act 1998 and GDPR regulations were complied with concerning the collection, storage, processing, and disclosure of personal information (UK Research and Innovation 2020). All participants were given pseudonyms which have been used throughout, with only the researcher having access to the single record of patient identities. Where real names are used in the Dedication at the start of the thesis, specific permission was sought and confirmed to do this with the participants' next of kin. Only anonymised data was shared with research supervisors. Publications and reports will not contain patient identifiable information. Permission was sought and gained from the Trust to use hospital databases for research purposes. Computer records were only accessed within the Trust and information not copied or shared. The research was subject to ongoing review and monitoring by the named university research supervisors and has been subjected to independent academic review within the university.

Two ethical issues not considered arose during the interviews. The first occurred when two participants related problems they were experiencing with their stomas, seeking advice from the researcher as their stoma nurse. Morse (2000) warns of the skill needed in navigating ethical

and caregiver dilemmas during research. Discussing these issues during the interview would have interrupted the flow of the interview and risked sensitive information being unnecessarily recorded. Not to have addressed their problems would have been neglectful for the researcher as a suitably qualified professional. It was therefore agreed with the participants that after the interview had been concluded time would be made immediately available to discuss and assist with the issues raised, and this was agreeable to both participants with whom this situation emerged.

The second dilemma occurred whilst interviewing the two participants who had not chosen to have colostomies. During these interviews bowel related issues were disclosed, and it became apparent that both participants had little or no knowledge of the option of a colostomy, which researcher knowledge indicated may be a beneficial option for them to explore. From analysis of previous interviews, the researcher knew that lack of information was an important finding, with later colostomates stating they wished they had known of the option of colostomy earlier. This felt somewhat of an ethical dilemma as to whether it was right to impart or withhold information which may be of benefit to the individuals being interviewed.

During in-the-moment thinking and reflection as this dilemma arose, there was awareness of the importance of not promoting a personal agenda, and knowledge that the investigation was not yet complete, and findings not fully known. It was decided that the correct thing was not to give information relating to colostomy unless it was asked for (which it was not). All participants being interviewed were attending the hospital to see a health professional to discuss their health status, and this provided reassurance that there would be opportunity for any health issues to be appropriately managed on that same day.

A further ethical dilemma arose at a late stage of writing up, when it was realised that permission had not been explicitly sought to use comments made by the participants' companions during the interview. Companions, when present, had included close relatives or partners and employed caregivers. Some of these had, of their own volution, contributed to the interview discussion, at times with great strength of feeling. All companions were present prior to the start of the interview when it was checked that the participant had read

and understood the participant information sheet, and the consent form was explained and signed. Companions were therefore aware of the purpose of the research and the consent process and had spontaneously contributed to the discussion in the context of this knowledge. On deliberation it was felt that their consent could not be assumed on this basis, and all were contacted and permission to use their contribution confirmed.

4.7 Ensuring quality and rigour in the approach

Having discussed methods, the use of literature, and ethical considerations, the final section of this chapter will describe measures taken to ensure quality and rigour in the research. In the methodology chapter, criticisms of constructivist Grounded Theory were highlighted as the risk of forcing data into pre-conceived categories and the risk of researcher bias in selection of data and construction of theory. This chapter has demonstrated how methods and reflexivity have reduced these risks as far as possible. Further considerations relating to ensuring quality and rigour in the research are now discussed.

4.7.1 Positionality

Consideration of the ethical questions which arose during interviews illustrates the tension which can arise when a professional acts as a researcher in their area of work, especially when there has been a nurse-patient relationship prior to the researcher-participant one. Much has been written about the concept of insider/outsider researchers, with positives and negatives inherent in both positions. Some consider positionality a more helpful term, which is concerned with where one stands in relation to another, and the acknowledgement that these positions can shift (Merriam et al. 2001). Both concepts were helpful in reflexively considering the relationship between researcher and participants, what impact this may have on data collection and analysis, and in striving to ensure a balance of power in the interview and research relationship.

In this situation, the researcher felt both an insider due to professional knowledge and experience related to the area being studied, and an outsider due to not being part of the participant population. As an insider in the interview situation, there were shared understandings, cultural nuances, and use of terminology and concepts related to SCI and bowel management which were advantageous (Johnson-Bailey 1999; Charmaz 2014; Kelly 2014). Being a partial insider can however also be a disadvantage as assumed knowledge from years of immersion in the field may not be a correct understanding of how true insiders experience it. This brings with it the danger, as Merriam et al (2001) state, of assumptions leading to lost opportunities for gaining richer information. Constructivist Grounded Theory acknowledges that theory is a unique co-construction of knowledge from one interaction between participants and researcher, and a non-insider researcher (or another insider researcher, or the same researcher at a different time) would have likely discovered different data and formulated an alternative theory.

The research environment and the participant population were ones which the insider researcher was familiar with and comfortable relating to, but Morse (2000) warns that this can create difficulties of seeing beyond the professional role and seeing participants and not patients. There was awareness of this, and as described if participants appeared to be seeking professional advice this was agreed to be discussed after the interview.

4.7.2 Power

Consideration of the power relationship between researcher and participants was important in relation to the interview situation, and in later data analysis and theory construction. Reflexively grappling with personal world view, status, prestige and power is necessary as these will influence what is perceived and how research is performed (Charmaz 2013). Research has been described as an inherently hierarchical process, with potential inequities of power shaped by e.g., culture, gender, and education (Merriam et al. 2001; Vanner 2015). As a nurse-researcher, there is a privileged relationship due to familiarity from a shared understanding of health, illness and the body (Gardner 1996). These areas were reflected on, preconceptions and knowledge from the prior nurse-patient relationship (if there had been one) set aside, and efforts were made to overcome any perceived imbalance of power by making both explicit and implicit that the participant could express whatever they felt was relevant and important to them in confidence.

The trust which existed from any previous interaction or from the researcher being known to be a nurse was an advantage that was used with integrity to encourage the participant to relax and speak freely, and participants were able to take the interview in the direction they wanted to. There was awareness that participants could use their power to promote their own agenda, which may have been what happened with the two individuals who used the interview situation to ask about their own health issues. It is also possible that important or pertinent information may be withheld entirely or described differently than it would to an unknown or outsider observer, or to the same observer on a different day or when any number of factors affecting a participant's personal situations differed. Reflexive awareness of potential power differentials was used to minimise them as far as possible.

4.7.3 Researcher bias

A further area reflexively considered throughout the research process was the potential for researcher bias, and this is the second area where there may be a power imbalance as it is usually the case that the researcher and not the participant writes the theory. Here the researcher, whilst developing the theory, consulted further with one participant to check understanding and meaning of emerging concepts. This gave opportunity for this participant to shape theory development. More could have been done to involve a greater number of participants in this way, but it was not felt practicable as others were not due to return to the hospital as the one who was consulted with did, and sadly three participants passed away before the research was complete. Simultaneous data analysis and collection did allow for emerging concepts to be checked in future interviews, and in this way codes and concepts were refined and either raised or set aside through participant responses. Participants were therefore co-constructors of theory whilst not actually writing it.

Researcher bias in analysis and theory development is further considered in the conscious or unconscious use of pre-existing knowledge of the researcher. Here, co-construction of knowledge is the chosen methodology, and this contains the risk of researcher bias overly influencing the selection of data and development of theory. Reflexive thinking and writing have been used extensively throughout the research process to eliminate this as far as possible, with examples given throughout this chapter.

4.7.4 Reflexive consideration of researcher position

The professional position of the researcher has been stated in Section 1.5 as being a Stoma Care Clinical Nurse Specialist, having extensive professional knowledge and experience in the area being studied. Personal beliefs from this knowledge and experience were reflexively considered to reduce the risk of researcher bias and are made explicit here to ensure transparency.

It has been an overwhelmingly repeated professional observation that undergoing a colostomy for those with SCI is transformative in liberating individuals from difficult and lengthy bowel management practices. It has also been observed that despite many encountering problems related to their colostomy, these individuals continue to state that they are still pleased with having a colostomy, and seldom has anyone in the researcher's professional experience expressed any regret at having it performed.

Efforts were made to set professional knowledge and personal feelings aside, and this is seen in the author's reflective diary, and in the use of a sensitizing concept termed 'the negative case' discussed in Section 8.10 of the Findings chapters. 'The negative case' describes data that demonstrates sharp contrast to major patterns in the developing theory (Charmaz 2014). During interview data analysis, it was realised that there were no codes relating to negative experiences of having a colostomy, and it was reflectively considered this may be due to researcher bias. The 'negative case' sensitizing concept was a useful tool to intentionally search for data which unconscious researcher bias may have overlooked, and this led to further theory development.

In searching for negative cases, an instance was found in one interview transcript where a participant mentioned a problem related to the colostomy, and no follow up questions or exploration of this was performed. An unconscious professional judgment at the time had categorized what was revealed as a minor problem. This was recognised in analysis as researcher bias in the interview situation and a lost opportunity to elicit further information. This highlighted the importance of in-the-moment attentive and objective listening. It demonstrates the difficulties of being both professional and researcher, and reflexive

awareness was raised that a professional judgment had been made during an interview. This awareness reduced the risk of repeating the error in future interviews.

During data analysis, openness was maintained to all emergent codes and categories, although some areas were of less personal interest. The reflective diary demonstrates awareness of this and provides evidence of measures to ensure researcher bias did not influence category development:

"Perhaps my own interests/objectives in researching this are coming too strongly into play...at this stage I still need to be open to all emerging codes and not deliberately close off possibly important themes." (Reflective diary 28/01/2019)

The importance of avoiding pre-conceptions is a known element of Grounded Theory, but Charmaz (2014) goes further in saying that awareness of these can lead to moments of discovery and enrich theory. This occurred related to the author's pre-conception of colostomy as being just a simpler method of bowel management than manual bowel care. There was an arresting moment of illumination during data analysis as a participant stated of bowel care that:

"It's all about freeing you up to do what you want." DE258

It was realised that the researcher had pre-conceived bowel care as being only concerned with physiological management. In fact, for participants bowel management was perceived in relation to desires and hopes for their wider lives, and the actual way in which bowel care was performed was of less importance. This was revelatory in researcher perception of the purpose and meaning participants gave to bowel care and was a turning point in progressing thinking.

4.7.5 Judging quality and rigour in the approach

Awareness of power, positionality and researcher bias meant these could be reduced as far as possible. Further considerations were important to ensure quality and rigour, and there has been much debate about how to judge the quality of qualitative research (Holloway 2005; Pope and Mays 2006). With its eclectic methodology and variety of versions, it is important in Grounded Theory to make explicit methods and theory generation to ensure rigour, which some systematic reviews have found lacking (Chiovitti and Piran 2003; Dan and Nikola 2012; da Silva Barreto et al. 2018). Rigorous quantitative verification methods cannot be applied to grounded theory due to its flexibility and use of mixed methods (Glaser and Strauss 1967). Debate has ensued concerning how then should Grounded Theory be assessed for quality and rigour?

An essential element is provision of detailed explanations of the actual strategies used for collecting, coding, analysing, and presenting data when generating theory (Glaser and Strauss 1967). Bluff (2005) describes assessing quality and rigour by judging the theory, the process used to develop it, and the appropriateness of the methodology, stressing the importance of an audit trail for every stage of the research. Holloway (2005) states that truthful representation of the reality of participants, thick description, detailed description of the audit trail, reflexivity, triangulation, peer reviewing, and the search for alternative cases to be essential.

Consideration of all these measurements to ensure quality and rigour has been provided, and this chapter has made methods explicit and therefore replicable. Examples have been given of the use of methods and efforts to redress potential power imbalances and researcher bias. Charmaz (2006) further describes quality of research as being measured by its credibility, originality, resonance and usefulness. These four concepts are now explored in relation to this research.

4.7.6 Credibility

Credibility is described by Charmaz (2006) as meaning the data is sufficient to merit the claims being made of it. Suggested ways of ensuring this include letting participants guide the enquiry process, using participant's actual words in the theory, articulating the researcher's personal views and position, and ensuring systematic comparison of data and categories (Glaser and Strauss 1967; Strauss and Corbin 1988; Strauss and Corbin 1998;

Chiovitti and Piran 2003; Charmaz 2006). Credibility in this research is demonstrated in several ways.

The open nature of interviews allowed participants to take interviews in the direction they felt to be important. Openness was continued throughout data collection and analysis. This was seen, for example when 'control' emerged as an important concept, by asking participants further questions about this and theoretically sampling the literature to find out more. In vivo codes were kept such as 'Being Alive Again' and 'playing Russian Roulette', and theory, codes and concepts are illustrated using segments of interview data in the Findings chapters. Checks were made to clarify understanding by asking patients to explain what was meant, and one participant was interviewed a second time to explore especially pertinent themes raised in his first interview.

Credibility is provided in making explicit the researcher's professional connection with the research subject and personal opinions prior to starting the research. These have been stated critically. Reflexivity was a key part of the research process, demonstrated in the use of a reflexive diary, excerpts of which have been used as illustrations. The Methods chapter has demonstrated the credibility of the research by making methods clear and describing a trail amenable to audit and replicability.

4.7.7 Originality

Originality of research is another key element of quality, and it should be demonstrable that research, particularly doctoral research, contributes to extending knowledge or challenging existing practices (Charmaz 2006). The initial exploration of literature to contextualise the research and write the research proposal demonstrated a gap in knowledge relating to the colostomy formation following SCI. This research both extends knowledge and challenges existing practices. How it does this will be reported in Chapter Twelve, after findings have been discussed.

4.7.8 Resonance

For research to be resonant, the findings need to make sense to those affected by them (Charmaz 2006). During interviews, further questions were asked to check understanding, and one participant was interviewed a second time. From this, clarity was enhanced about emerging themes, and their resonance confirmed. In communication with relatives of participants who had died at the conclusion of the study, an area of resonance was further confirmed by one relative when they spontaneously described a theme present in the theoretical framework. As concepts of *'control'* and *'being freed up'* emerged as important, these were further explored in theoretical sampling in subsequent interviews and were found to be concepts which resonated with participants.

In the researcher's simultaneous professional role, knowledge gained from the research is repeatedly affirmed in ongoing encounters with new patients wanting to know more about and undergo colostomy formation following SCI. The lack of information identified in the interviews of later colostomates resonates time and again in those injured many years ago who have never been told of alternatives to traditional bowel management. The experience of *'Being Alive Again'* is observed to resonate in the experiences of the continuing flow of patients who have had a colostomy after years of suffering and loss as these research participants have. Numbers of newly injured patients seeking a method of bowel management that fits into their desired lives after discharge from hospital continue to grow. Although anecdotal evidence at this stage, these continued professional interactions with new members of the population being studied demonstrate the findings from this research to be resonant with the experiences of many.

4.7.9 Usefulness

Usefulness rests on whether research informs practice and contributes to knowledge (Charmaz 2006). The contribution of this research and Grounded Theory to practice is discussed in the Further Discussion chapter. Changes have already been instigated in response to research findings. These include practical changes in the local hospital setting, and early indications of a shift in thinking related to bowel management found in recent publications. The research is also useful in pointing to further areas requiring future study.
4.8 Chapter conclusion

This chapter has led the reader through a detailed examination of the research methods employed. Although divided into discussion of data collection, data analysis, and theory building, it has been demonstrated that these occurred in a simultaneous, interwoven, and iterative process.

Data collection has comprised primary data gathered from interviewing a purposively defined sample of the population being studied, with this being informed by later theoretical sampling. Secondary data has been gathered from documentary data, memoing, and theoretically sampling by the extant literature in relation to emergent themes and concepts. Data analysis comprised initial and focused coding, constant comparison, theoretical sampling, use of sensitizing concepts, memo writing, diagramming, and reflexivity. Examples have been given throughout. Theory building was explained as a process of building, shaping, and re-shaping of categories and codes to construct a final coherent theoretical framework. Making methods explicit and providing examples has left a clear audit trail of the research process.

The use of the literature in theory construction and the research overall has been discussed in a separate section, as this is an important area and has been approached in a non-standard way in this research. Demonstrated as being congruent with the methodology used, it has been explained that an early exploration of the literature was performed to contextualise the research, and at a later stage literature was consulted as a secondary data source during data analysis and theory construction.

Ethical considerations have been discussed in this chapter, including dilemmas which occurred during the research. Quality and rigour in the research approach have been explained, with reference to positionality, power, and researcher bias. The credibility, resonance, originality, and usefulness of the research have been discussed.

Having journeyed from the starting point outlined in the Wider Landscape, travelled through consideration of methodological approaches, and explored methods used, the stage is now

set to describe and explore the research findings. Section Two of this thesis will now present six Findings and Theoretical Discussion chapters followed by Further Discussion and Concluding Remarks. **Section Two:**

Findings

Chapter Five: Introductory findings and the theoretical framework

5.1 Chapter introduction

The research journey started with consideration of the Wider Landscape of SCI and bowel management, finding that the novel phenomenon of the increasing choice for early colostomy is arising in the context of guidelines based on weak evidence which have allowed deviations from widely accepted practice to occur. Consideration of research aims and a question which seek understanding of experiences, the developed philosophical stance of the researcher, and their professional knowledge in the area being studied, led to the choice to use constructivist Grounded Theory to research this. Interviews with those with SCI who have chosen a colostomy for bowel management were the primary method of data collection, but secondary data sources have also been used including extant literature and theory. Theoretical questioning of the literature and constant comparison led to findings from primary and secondary data becoming interwoven. This led to the logical decision to present Findings and Theoretical Discussion together to maintain coherency of the theoretical framework.

This chapter will introduce findings by restating research aims and the question, furnishing details of relevant contextual findings, and explaining the stages of development of the theoretical framework. The final theoretical framework will then be presented. The stages of development are explained to delineate findings from primary data analysis and demonstrate where the framework was developed from secondary data analysis. This interplay of primary and secondary data will be made clear throughout the Findings and Theoretical Discussion chapters to:

"...show where and how their [other researchers'] ideas illuminate your theoretical categories and how your theory extends, transcends, or challenges dominant ideas in your field." (Charmaz 2014, p.305)

This Introductory Findings chapter will be followed by six 'Findings and Theoretical Discussion' chapters, with a final Further Discussion chapter reflecting on, pulling together, and further developing these.

5.2 Setting the scene for the Findings

In setting the scene for the Findings chapters, it is helpful to firstly recount the research aims and the question. The aims have been stated to:

- Explore choices made related to bowel care management
- Explore reasons for the decision to have an early colostomy
- Discover differences in experiences between those who have early or later colostomy

The research question is:

'What are the experiences of those living with SCI in relation to choices about bowel management?'

Twelve participants took part in this research. Five were 'early colostomates' who chose a colostomy in the early weeks and months following SCI whilst still undergoing inpatient rehabilitation, and five were 'later colostomates' who chose it years after their injuries. Two further participants were sampled from the population with SCI who do not have a colostomy at the point when this became theoretically pertinent.

Colour coding is used in diagrams of the theoretical framework to ease recognition of participants groupings, as shown in Figure 13. The early colostomates will appear in purple, the later colostomates in green, and findings for all those with a colostomy in blue. As further detail of the development of this model is given, red will be used to indicate findings which have originated from extant literature rather than primary data.



Figure 13, Colour coding explained

A summary of relevant participant demographics is given in Figure 14 with pseudonyms used consistently to preserve anonymity for all participants. For ease of reference, each time a participant is now mentioned a parenthesis will follow the pseudonym to indicate their age at injury, age at colostomy, and the year they had their colostomy. E.g., Graham who was 21 when injured, and 71 when he had his colostomy in 2012, will be described as Graham (21:71:2012). Those who did not have a colostomy will have their age at injury in parenthesis after their pseudonym e.g., Leon (15).

Pseudonym	Age at injury	Year of injury	Age at colostomy	Year of colostomy	Independence with bowel management
Later colostomy					
Graham	21	1962	71	2012	Independent
Terry	28	1992	51	2015	Dependent
Steve	26	1995	41	2010	Independent
Alice	55	2002	63	2010	Independent
Monty	69	2010	70	2011	Dependent
Early colostomy					
Sophie	48	2013	48	2013	Dependent to independent*
Andy	66	2014	66	2014	Dependent
Dan	52	2015	52	2015	Dependent
Emily	49	2016	49	2016	Dependent to independent
Jim	62	2016	62	2016	Dependent to independent
No colostomy					
Leon	15	1994			Independent
Brian	38	2009			Independent

Figure 14: Table showing participant demographics

*'Dependent to independent' means that prior to the colostomy an individual was dependent on others to manage their bowels, but the colostomy enabled them to become independent.

As findings developed, it became pertinent to create a timeline of when participants sustained their injuries, and this is given in Figure 15.



Figure 15: Timeline of participant injuries

Apart from two outliers in 2009, the phenomenon of early colostomy being requested in this spinal unit started in 2013 and there has been an increase in numbers of those with long standing spinal injury also requesting a colostomy, as seen on the graph below.



Figure 16: Numbers of individuals with SCI having colostomy formation (graph includes those performed by choice or necessity).

It must be noted that the Covid-19 pandemic meant a considerable reduction in the number of all operations which the colorectal surgeons were able to perform in 2020 and 2021. Operation lists were greatly reduced with at times only the most urgent cancer and emergency operations able to go ahead. This makes the number of spinal colostomies which were performed remarkably high in this context.

5.3 Evolution of the theoretical framework

The theoretical framework developed in three stages. The initial theoretical framework was created from interview data analysis alone. A second reconstructed framework came from sampling literature to develop this initial theory. The final theoretical framework emerged after further interaction with literature to gain understanding of the wider context of participant experiences.



Stage One

The stage one theoretical framework developed at the culmination of analysis of primary interview data alone, with further detail of this described in the Methods chapter. The framework in Figure 17 summarises themes and processes, shows how loss resulting from bowel function management was transformed into an expanded self through colostomy formation, with the availability of information and choice being key in this process. Differences in experiences between early and later colostomates were observed and are illustrated with colour coding.

Stage Two

Once this initial framework had been constructed from primary interview data, secondary documentary data was gathered from the extant literature to develop this, in congruence with the methodology used and as detailed in the Methods chapter. This led to a new theoretical framework being created as understanding deepened and findings crystallised, shown in Figure 18.



Figure 18: Stage Two theoretical framework

The second framework contained final categories of '*Experiences of Loss*', '*Progression into Suffering*', and '*Being Alive Again*', with processes and differences in experiences between early and later colostomates indicated. '*Expanded self*' changed from the stage one model into '*Being Alive Again*'. This was not a change which resulted from interacting with the

literature, but rather a final decision after wavering between how best to describe this category, with the final decision being to use the interview *in vivo* code.

Stage Three

The fourth major category which first appeared during early data analysis was 'Failure of Care'. This is not included on the stage one and two diagrams, as at these stages it comprised concepts and ideas which were seen or sensed to be influencing findings but were not yet understood. The category was conceived as the part of an iceberg below the surface of the water, with visible findings suspected to be contingent on partially discerned but hidden and unknown wider contextual factors. This is illustrated in Figure 19.



Known findings: Experiences of Loss, Progression into Suffering, Being Alive Again, Failure of Care

Unknown findings: The wider context of participant experiences contributing to Failure of Care

Figure 19: Known and unknown findings represented as an iceberg

In the third and final stage of theory development these unknown areas of interest were investigated by further consulting the literature to consider questions which emerged and will be outlined in the first three Findings and Theoretical Discussion chapters. This exploration led to *'Failure of Care'* being constructed as containing elements of the Ideological, Professional, and Institutional context of participant experiences, and these comprise the final three Findings and Theoretical Discussion chapters. These are not thought to be the only three areas which are influencing participant experiences and findings, but were indicative avenues to explore from the questions which arose during theory development. Investigating other areas of potential relevance will be an interesting direction for future research.

5.4 The final theoretical framework

The final theoretical framework is shown in Figure 20. This completes the framework by demonstrating the presence of elements of the wider context influencing participant experiences. These are described as *'Failures of Care'*.



Figure 20: The final theoretical framework

5.5 Chapter conclusion

This chapter has restated research aims and the research question, and introduced the twelve participants. The participant timeline of injuries has been given, which will be important in understanding of later findings. A graph showing the number of spinal colostomy operations performed in this hospital has been provided. Stages leading to the development of the final theoretical framework have been given.

Having set the scene for the findings, these will now be presented combined with theoretical discussion. The first three chapters detail key categories within the theoretical framework of *'Experiences of Loss'*, *'Progression into Suffering'*, and *'Being Alive Again'*. These are followed by a further three chapters presenting findings and theoretical discussion in relation to the Ideological, Professional, and Institutional contexts which have contributed to the fourth key category of experiences of *'Failure of Care'*.

Chapter Six: Experiences of Loss

6.1 Chapter Introduction

This chapter will present the theme of '*Experiences of Loss*' in relation to the research aims and the question. Key focused codes from primary data analysis within the theme are '*loss* of control over the body', 'playing Russian Roulette', 'loss of self-determination', 'decisionmaking and information variability', 'disempowerment', and 'loss of dignity'. How these relate to and were better understood through interaction with secondary data from the literature will be explained, with reference to extant theories relating to control, dignity, and dehumanisation.

Areas of confluence and divergence between this research and existing knowledge will be considered, and areas in which this research extends theory demonstrated. Differences between the early and later colostomates start to emerge through exploration of their differing reactions to *'Experiences of Loss'*. A final section will relate findings to the research aims and the question.

The final theoretical framework was given at the end of the Introductory Findings chapter. The first part relating to *'Experiences of Loss'* is amplified, and further detail given in the theoretical model in Figure 21. Boxes outlined in red show where secondary data from extant literature has been introduced and woven into theory through constant comparison



Figure 21: Experiences of Loss

6.2 Loss of control over bowel function

'Loss of control' over bowel function was a key theme which emerged from interview analysis. This comprised both a physical loss of control over bowel function, and a loss of self-determination over how this would be managed (discussed in section 6.4). Unpredictability of continence and bowel function related problems were a universal experience for both early and later colostomates, and those who had not had a colostomy. Following SCI there comes the realisation that physical control over the previously taken for granted function of bowel emptying is lost and cannot be regained by effort and will. Leon (15) described realising this at age 15:

Leon (15): "I thought if you try hard enough and put that much effort into something you will overcome it... that's what I assumed I would do really, a few months in here, which didn't turn out to be the case." LN14

With regaining physical control over the body not possible, participants became recipients of the bowel management interventions detailed in the Wider Landscape chapter as professionals instigated the 'least invasive' routines and practices which are the first steps suggested in guidelines. These are centred on physiological aims of establishing regular bowel emptying and maintaining continence during inpatient rehabilitation and afterwards at home. When these routines failed in these aims, participants experienced a loss of physical control which was unpredictable and led to feelings of devastation:

Sophie (48:48:2013): "Sometimes they would have to do it more than that because I wouldn't cooperate and it [bowel emptying] wouldn't go into a pattern. It just did it when it felt like it." SE45. "It just did what it did when it wanted to." SE52

Andy (66:66:2014): "I was devastated, devastated about it [being incontinent]." AE140

Consulting the literature to gain further understanding of experiences of loss of control over the body, insight was gained into how failure to control the body, for example by having a bowel accident, leads to mortification, loss of trust in the body, and a diminished sense of self (Goffman 1963; Charmaz and Rosenfeld 2006). These elements of loss were all present in participant descriptions as they described the effect incontinence had on them. Murchison and Adler (1930) further suggest that the need to exert control over one's body and life is fundamental and inherent to life itself. Taking this back to interview data, evidence confirming this extant theory is seen in Steve's (26:41:2010) words as continued incontinence became so untenable, he felt he could no longer continue living:

Steve (26:41:2010): "The last thing you want to do when you're in a wheelchair is have an accident. Cos that's a lot of things to deal with. You can't stand up and get away from it. So whatever you do you will be sat in it." SL83. "I don't think I'd be here now if I didn't have the [colostomy] operation. Because I think there comes a point where you can't handle cleaning up after yourself, day in and day out." SL186

For these participants, utilisation of the 'least invasive' lower-level interventions for bowel management failed to meet their aim of predictability and reliability of bowel function, and this in turn led to a greater failure to meet the fundamental need to control the body and have trust in it. With their strong focus on physiological management of bowel function, guidelines may be failing to comprehend this fundamental psychological need, and the failure of guidelines will become of progressive importance as findings develop.

6.3 Playing Russian Roulette and Living with Luck and Chance

An extension to theory relating to loss of control and unpredictability of the body was observed in interview data and is termed *'playing Russian Roulette'*. This is an *in vivo* code which arose in Terry's (28:51:2015) description of unpredictable symptoms of autonomic dysreflexia he experienced related to his bowel function:

Terry (28:51:2015): "It got to the stage where I would be worried...I do talks in schools and it would be Russian Roulette as to whether I was going to have to go through a session of talk in a lot of discomfort, mild dysreflexia, red, perspiring and try not to show it." TL177

Reflecting on experiences of '*playing Russian Roulette*', this was compared with the code of '*unpredictability*' found in sampling the literature for loss of control over the body (Johnson and Morse 1990). '*Playing Russian Roulette*' was felt to better account for the experiences of participants as it suggests danger and tension, with the phrase evocative of the serious and chance consequences of being let down by the body. This code represents an extension of theory relating to the unpredictability of the body. Daring to engage in desired activities such as Terry's (28:51:2015) work in schools, or even Jim's (62:62:2016) necessary activity of moving from bed to shower to wheelchair became a gauntlet which had to be run:

Jim (62:62:2016): "I looked at the colostomy option because I was having bowel problems and it was that, to get out of bed and into the shower chair, to go for a shower, I would leak and have a mishap and sometimes I had got into the chair and had the mishap. Then other times I would have a mishap on the shower floor, and also if I got through that I then would get dressed and have a mishap getting from the bed into the wheelchair." JE16

Incontinence and bowel related symptoms were random, unpredictable experiences, which led to uncertainty concerning how planned activities would go, and a fatalism about the likely success of trying to do anything as Dan (52:52:2015) described:

Dan (52:52:2015): *"If you don't have the evacuation in the morning and you decide to go out, you can have an accident anytime of the day, you probably will though during the course of the day."* DE189

In helping to understand the 'playing Russian Roulette' code and assess its explanatory power, a related code of 'living with luck and chance' discovered in sampling the literature was weighed for fit with participant experiences. Cooper et al (2010), exploring the experiences of those suffering from Inflammatory Bowel Disease (IBD), describe 'living with luck and chance' as an adaptive means of individuals accepting a lack of personal control over their bodies. Although some of Cooper et al's (2010, p.1503) participants found the lack of control to be distressing, they describe the majority to view it as "...an acceptable part of the chronic illness experience." They evidence the code using the following interview quotation:

"I think the tablets I'm on must help, because when I was really ill I could go to the toilet twenty or more times a day. Being on the medication it's now down to about eight to ten times a day, so I presume they must do something." (Cooper et al. 2010, p.1505)

The wider data set may suggest 'living with luck and chance', but this single quote provides weak evidence for it, and alternative explanatory codes could be given to this data segment by another researcher. The concept was, however, felt to be an interesting potential explanation of how individuals manage unpredictability of bowel function, and together with 'playing Russian Roulette' was used as a sensitising concept to further explore the interview data.

Both convey bodies as unpredictable and beyond individual control, with Cooper et al's (2010) statement of living with luck and chance as a means of accepting the loss of personal control offering a potential explanation of how participants continue to engage in desired and necessary activities. The two codes differ however in the depth, severity, and consequences of loss of control over bodies they evoke. *'Living with luck and chance'* does not convey the devastating nature of the consequences of losing control of the body described by participants here and in other sections of data highlighted later. Given the potential serious and mortifying consequences of bowel incontinence, *'playing Russian Roulette'* is felt to better account for the experiences participants endured.

In considering how the two codes may account for how individuals *adapt* to a loss of control, there is a divergence observed in this research between participants who have chosen to

have a colostomy and those who have not. This provides insight into the theoretical question posed in the Section 4.3.7 which asked whether control was an important theme for all dealing with bowel management following spinal injury, or just those who went on to choose the option of colostomy. Like Cooper at al's (2010) participants, the two in this research without a colostomy appear to have accepted lack of control over their bodies at times, and can *'live with luck and chance'* as seen in Brian's (38) words:

Brian (38): "I had no control [over bowel function]. It's more of a feeling – I just get on with things. There's other stuff I don't dwell on either. You've just got to move on – stuff happens in life." BN81

In comparison, participants who later went on to have a colostomy experienced greater and more devastating loss of control in their experiences of *'playing Russian Roulette'* and reached a point where they could not accept and live with them. It appears that some with SCI can adapt to the loss of control over their bodies by *'living with luck and chance'*, but those experiencing greater levels of devastation and disruption cannot adapt to the loss of personal control in this way. Although presented using a questionable quotation, Cooper et al's (2010) *'living with luck and chance'* proved a useful sensitising concept to expose differences between those who have and do not have a colostomy.

6.4 Loss of self-determination

Findings so far have discussed the lack of physical control over bodies which participants experienced. After data analysis had established this as a broad theme, the extant literature was sampled to increase understanding of this. Pertinent insight was gained from Johnson and Morse's (1990) grounded theory study of 14 individuals adjusting to life following a heart attack. They describe the sense of control as including self-determination. Control has been found by Boschen et al (2013) to be important in adjusting to SCI, and the importance of self-determination is confirmed in Hammell's (2007) meta-synthesis of seven qualitative studies which examined SCI and Quality of Life (QOL). Hammell (2007) examines original data from studies and identifies that being able to direct others and having the ability to make decisions and choices is more important than having the physical ability to carry these out in achieving a sense of control.

This new data from sampling the literature resonated with participant experiences, and Hammell's (2007) insight was considered of potential importance in increasing understanding of how control can be experienced without physical ability to perform a task. This concept is explored further in the *'Being Alive Again'* chapter. Loss of self-determination was used as a sensitizing concept and was found to account well for several codes already found but which were inadequately organised and understood. These related to choice and decision-making. Many participants described a lack of control over how bowel function would be managed:

Dan (52:52:2015): "It's more, once you go in its going to be manual. They don't talk about other systems really." DE87

Terry (28:51:2015) : "We weren't told, 'These are options, these are things you can do." TTL26

Andy (66:66:2014): "That was the usual thing where they give you a tablet and then they sort of ... they take it out manually." AE7

From use of this sensitising concept, a wider dimension of loss of control through loss of selfdetermination was better understood, and a key discovery was made. This was the variability with which participants were included in decision-making about how their bowel function would be managed, both during inpatient rehabilitation and in later years following their injury. Studying this variation, it was found to be related to the timeline of when participants sustained their injuries given in the Introductory Findings chapter on page 113. Loss of selfdetermination is now discussed more fully in relation to how involvement in decision-making has changed over the length of the participant timeline.

6.5 Changes over time in decision-making involvement

Those injured longest ago describe no involvement in decision-making during their initial rehabilitation, with Graham (21:71:2012) likening his experiences in the 1960s to imprisonment:

Graham (21:71:2012): "Well, we used to call [the ward sister] the commandant. In fact when I used to write I would put 'this is Stalag 22' which was a sort of prisoner of war camp." GL190

Exploring the literature to trace changes in the culture of healthcare provision, Graham's (21:71:2012) experience of being subjected to dictatorial inpatient care occurred during a period when healthcare was dominated by the power of professionals, and fits with Bradshaw's (2008) description of how historically health service users were in a position of subservience and their views inconsequential. Users (patients and service users) were given what producers (policy makers, managers, and clinicians) believed they needed. During this time, as Goffman (1963, p.19) states of institutions such as hospitals, *"Characteristically, the inmate is excluded from knowledge of the decisions taken regarding his fate."* Graham (21:71:2012) does not discuss inclusion in decision making, and throughout his interview he does not appear even more recently to have expected to do so. Rather, a product of the time of his early interaction with healthcare institutions, he submits to the bladder and bowel management routines which formed part of the daily routines of the hospital ward, more detail of which is given in the next chapter.

No information was given in this period in time about possible alternatives to manual bowel management. As introduced in the earlier Wider Landscape chapter, guidelines for bowel management are physiologically focused and have been created with little involvement of those for whom they are designed. Those injured earlier on the timeline felt it would have been beneficial to have had more information earlier. Shaped by their prior experiences of largely professionally determined health care provision at the time of their injuries, they did not however actively seek out information on alternative bowel management strategies when first injured or for some time afterwards.

Moving along the timeline, changes towards greater involvement in decision making can be perceived. In the historical cultural context of healthcare provision discussed in the literature, DeJong (1979) considers the rise of consumerism in health care provision important in challenging the dominant professional power portrayed through Graham's (21:71:2012) recollections. The influence of these external factors on participant experiences are considered more fully in Chapters Nine to Eleven. Despite policy changes

these later chapters discuss which aimed to increase service user involvement in shaping health service provision, there is little evidence of greater inclusion in decision-making in Terry's (28:51:2015) experiences of inpatient care in 1992. He describes being permitted limited choice in desiring bowel care be performed in the bathroom rather than on the bed, but no real involvement in decision making:

Terry (28:51:2015): "I don't recall anyone discussing [colostomy] with me or with any of the other people I was in here with." TL31. "It must be a hangover from back in the nineties. Such things weren't discussed – the way forward was manual and suppositories and that was fine for everybody." TL196

As the timeline continues, information continued to be scarce, with individuals finding out about alternatives not necessarily from health care professionals, and often feeling the information came too late as Steve (26:41:2010) described:

Steve (26:41:2010): "I can't remember the exact way I found out, but I thought 'there is an answer' and obviously someone explained it to me. When it was explained to me, whoever explained it, I thought 'Why didn't I get this done years ago?'" SL97

The period between 2010 and 2016 when all participants chose to have their colostomies maps an interesting period of change in the degree of active involvement in decision-making and in the relative power between professionals and the participants as service users within that process, both for those deciding it as newly injured inpatients or for those with longer standing spinal injuries.

Graham's (21:71:2012) involvement in deciding to have a colostomy at this time continued to be shaped by his earlier institutional experiences of the power to determine body management residing with professionals. Although desiring a colostomy, he does not request a change in the method of bowel management until it is suggested by healthcare professionals: Graham (21:71:2012): "So when [the consultant] mentioned it; I had been thinking about a possible stoma operation although I didn't know whether it would be possible, whether it was an option, but he mentioned it and I said, 'Yes please, that would be great.'" GL30. "He made the suggestion and I said yes I would like to do that." GL280

Relative power in this encounter continues to reside with healthcare professionals. The doctor suggests an alternative option at a point when their professional judgement considers it physiologically appropriate, and Graham (21:71:2012) agrees to the suggestion rather than actively requesting it.

In contrast Andy (66:66:2014), during inpatient rehabilitation in 2014, pro-actively asked healthcare professionals for the option he had decided on: *"I just mentioned it to [the consultant] and she seemed to be quite keen once I mentioned it."* AE19. The contrast is stark between Graham's (21:71:2012) inpatient experiences and the imbalance of power perceived in his statements, and those of Andy (66:66:2014) who was able to decide for himself on a desired method of body management and felt empowered to suggest it to the professionals involved. The potential wider issues influencing the changing involvement in decision making are considered in later findings chapters.

6.6 Variability of information

Making decisions is contingent on information being available, and analysis demonstrated an inadequate provision of information concerning alternative options of bowel management. Participants agreed they would have liked to have had more information about possible alternative bowel management strategies at an earlier point following their injury, with those who had a later colostomy feeling strongly they were not given sufficient information at the time:

Terry (28:51:2015): "Yes. I think to be offered [colostomy] at the time I was in, but also to have known it was a possibility for thereafter. I may well have tried." TL358

Steve (26:41:2010): "Like I say if I'd found out I would have had the colostomy earlier. Probably much nearer to the beginning." SL190.

Returning to existing knowledge used to contextualise the research in the Wider Landscape chapter, participant experiences here confirm previous findings that those with SCI frequently wish they had a colostomy sooner after injury and feel they are not made aware of the option early enough (Kelly et al. 1999; Rosito et al. 2002; Branagan et al. 2003; Bølling-Hansen et al. 2016). Following participant interviews in this research as the desire for earlier and more organised information was repeatedly stated, this researcher responded by introducing a regular Colostomy Information session for inpatients of this spinal unit, and it continues to be an option which is discussed and a choice which individuals can make (subject to organisational limitations discussed later) at an early point during inpatient rehabilitation.

It is not known whether information is provided in an organised manner in other spinal injury units, or the option similarly made available at this early point, with no evidence found that it is when this research commenced. Although a range of options are described for managing bowel function following SCI, historical reliance by professionals on the progressive stepped model means individuals may not be fully informed of all alternatives and not be able to make adequately informed or fully participate in decisions made about their bowel management method. Sampling the literature, a similar lack of consistent information producing unnecessary suffering is found in other areas of healthcare, with Charmaz (1983) describing:

"Not all patients are given sufficient information and treatment to reduce their suffering losses of self. When they rely on information from one practitioner or one perspective, they may remain unaware of possibilities that could increase their participation in life. A man whose medical treatment for myasthenia gravis and peripheral neuropathy failed to include rehabilitation measures exclaimed: 'I lost three years and just became immobilized at home because I thought that's what you should do if you wanted to live at all with something like this. If I had just known what a few gadgets and a little exercise therapy could do for a person like me.'" (Charmaz 1983, p.173)

This finding is quoted as it is resonant with the experiences of the later colostomates who endured years of difficulties through not knowing of the alternative option of colostomy. Researcher insider professional experience gives evidence of many others with SCI only learning of the option of colostomy after years lost through enslavement to and perseverance with traditional manual bowel management. The loss of years of people's lives that Charmaz (1983) describes is an area of great concern to this researcher, as there continue to be unknown numbers of individuals with SCI similarly losing years of their lives due to not being aware of alternative methods of bowel management.

Returning to the provision of information for these participants, although bowel management practices continued more recently to be performed in a homogenous way, as Emily (49:49:2016) states: *"So it's manual extraction,"* EE27, a difference is observed related to the timeline which demonstrates an increasing *desire* for information. Dan's (52:52:2015) words illustrate this thirst for information about alternatives, and his suspicion that information was deliberately being withheld for reasons not related to the best interest of spinal unit inpatients:

Dan (52:52:2015): "They don't talk about other systems really. If you knew about it and spoke to one of the nurses or whatever, they would know about it. They know how to change them, they know what the stoma is all about. But until you ask the question, they don't seem to talk about it. Like I was saying, somehow the patients seem to find out." DE88

Dan's (52:52:2015) suspicion was that the reason for the perceived secrecy about potential alternatives may be a financial one:

Dan (52:52:2015): "I have the feeling the hospital didn't want to necessarily do the stoma operation from an expense point of view, but that's only because nobody had spoken about it." DE123. "It just wasn't a topic of conversation so therefore I had to enquire about it and then gradually we found out ... Otherwise in hospital these days you have to almost ask for things to be done, it's not volunteered. I'm sure that's to do with the National Health Service and cutbacks. If the patients don't ask for it, it's not volunteered with operations, procedures and surgery." DE130

His words may contain elements of truth. The publicly funded NHS with its finite resources is not able to fund all operations, procedures and surgeries which may be desired by or beneficial to all individuals. It is not known what factors influence clinical decisions made on this spinal unit relating to bowel management or other aspects of body management. Reflection on this led to gathering further data from the literature. Themes which emerged relating to how clinical rationing and professional power contribute to the category *'Failure of Care'* are explored in later chapters.

At the time of Dan's (52:52:2015) interview, the availability of information relating to the option of colostomy is known by this researcher to have been disorganised, but capacity to perform what is termed by professionals within this organisation as a 'spinal colostomy' was not a particular problem with most performed within a few weeks or months of being requested and before inpatients were discharged home. It is in more recent times that difficulties of organisational capacity have emerged in this setting due to increasing demand for spinal colostomies, compounded by the backlog of operations delayed due to the Covid-19 pandemic. This organisational contribution *to 'Failure of Care'* is discussed in Chapter Eleven.

Further sampling of the literature related to information availability revealed a novel dimension to exist in this research. This is illustrated by constant comparison with findings of a study by Ogilvie et al (2015) which researched experiences of young adults in an Australian spinal injury unit with traumatic injuries similar to those of participants here. They too describe a lack of adequate information on treatment and injuries, and inconsistent disorganised information which resulted in feelings of loss of control:

"Every time a doctor comes in and says 'Hey, this week we might get you up' another doctor might come in and say 'No, we need to advance with caution'. It's like false hope you know. It's like nothing comes of it. Everything is stalled, and you know, I think [health care professionals] ignore you too. It's as if they have you on a leash and what you want is just right there and they keep pulling you back. Saying 'No', just like a dog." (Ogilvie et al. 2015, p.1845)

This participant quote used by Ogilvie et al (2015) demonstrates inconsistent and changing management plans and differs to the type of information being sought by participants in this research. Ogilvie et al's (2015) participants wanted organised and consistent information about the management plans professionals have decided upon, and desire empowerment

related to this. The participants of this research go further in questioning the professionally imposed body management plans and seeking information about alternative strategies.

The key difference observed is a fundamental difference in the nature of information the participants in this research desired. Participants here are questioning accepted body management guidelines and professional practices. This extends theory as information is desired about options which professionals are not making readily available, and choices are being made which do not conform to the stepped direction of the generally accepted and widely utilised bowel management guidelines. This is explored further in consideration of patient and public involvement in healthcare in Chapter Eleven.

6.7 Experiences of disempowerment

The lack of information and mistrust of staff described by Dan (52:52:2015) and in the work of Ogilvie et al (2015), together with hospital routines contributed to *'Experiences of Loss'* through disempowerment:

Dan (52:52:2015): "Having to wait around all morning for someone to come." DE34. "The patient is lying around for several hours in the morning if they are not getting a response [bowel movement] because normally you are not allowed out of bed until you've had a response." DE149

Such experiences produced by an organisational culture of adherence to available bowel management protocols and institutionalised routines, are further observed by this insider researcher to stem from organisational factors such as availability of nursing staff and facilities such as the number of bathrooms on the spinal inpatient unit. To what extent these resource issues contribute to Dan's (52:52:2015) experiences of waiting for someone to come is not known and may merit further investigation.

Experiences of disempowerment are not confined to hospital inpatient institutions but are seen in this research to extend to community-based care provision. Care providers can effectively imprison people through inadequate service provision or by being organised to suit the needs of the organisation rather than the needs of the individuals they provide care for, as Monty (69:70:2011) and his wife found:

Monty's (69:70:2011) wife: "He couldn't get up. I would put the suppositories in, sometimes [the nurses] would come within the hour and sometimes they would come within a couple of hours, and the carers couldn't get him up until the nurses had been, and then you would get a phone call saying they weren't coming until the afternoon." ML129

Monty's (69:70:2011) wife found she was powerless to try and change things: "I tried talking to their manager about it but we didn't get very far there." ML143. This finding of how the organisation of care provision and power differentials leads to disempowerment of health service users, came to be understood as part of the 'Failure of Care' category, and is considered further in later chapters.

These disempowering experiences suggest that both in hospital and community settings, bowel management comprises a physiological task which professionals perform in times and places which suit theirs and their organisation's needs, and which fail to account for the wider lifeworlds of those on whom they are performed.

6.8 Loss of dignity

Use of the lower-level bowel management interventions have been shown for these participants to fail to achieve continence and predictability over bowel function. Participant insider experiences of bowel management practices themselves are now considered and how these can be experienced as a loss of dignity.

The Wider Landscape chapter introduced how socialization processes and societal norms produce unconscious beliefs concerning the fundamental need to be 'clean', i.e. continent, with bowel emptying a function to be carried out autonomously and privately (Kira 1974; Jackson 1993). During hospitalisation following SCI these functional and societal norms are broken, at least in the early weeks and months.

Bowel emptying is no longer achieved by voluntary control and in private, but instead involves another person being present and performing a daily procedure to facilitate the removal of stool by putting a gloved finger inside the person's rectum. This procedure, at least initially, is performed with the individual lying on a bed, and has been observed by the researcher to occur in ward areas with several other patients and possibly staff members present in the same room, with conversations and the bustle of activity, separated from this by only a screen or curtain. Having no alternative but to submit to this procedure, participants described it as:

Sophie (48:48:2013): "It was embarrassing." SE24

Andy (66:66:2014): "They take it out manually, which I thought was terrible." AE6. "I couldn't...just didn't want to think about going through life with that [manual bowel care]." AE9

In Emily's (49:49:2016) description of how it felt to have this procedure performed she stated: *"Having to worry about it all going, right, OK, assume the position shall we say."* EE68. Her words conjured an experience of having to brace herself for a bodily intrusion and trespass, which participants describing the same procedure in other research have gone so far as to describe as rape (Dickson et al. 2008). The procedure was described by Terry (28:51:2015) as being performed with scarce consent whilst not fully awake:

Terry (28:51:2015): "Having to go [have bowels emptied] on the bed. I don't really remember much about it as they used to come round in the early hours about four o'clock/five o'clock in the morning, they would just come in, I would still be dozing. The whole operation took place without you really knowing a great deal." TL47

Manual bowel care interventions are experienced by participants to be embarrassing at best, and an assault at worst, and led to a loss of dignity as Terry (28:51:2015) states: *"For me it was really important for my own dignity to go over the toilet, so that was my goal."* TL54. To understand participant experiences more fully, concepts of dignity and humanisation were explored in the literature. Dignity was found to be a debated concept which can have multiple meanings in a variety of situations. Useful in providing insight was Galvin and Todres' (2014) exploration where dignity is described as a conjunction of vulnerability and value, which can be ruptured or restored, and which as well as being an insider experience has a relational dimension.

In the relational activity between nurses and patients as bowel care is performed, 'embodied dignity' is risked, the element of dignity which comprises a person's bodily connection in the world, described by Galvin and Todres as:

"Experientially the body 'screams out' in painful awareness when one's bodily privacy is invaded, or when one's bodily presence in the face of others is shamed." (Galvin and Todres 2014, p.413)

This description of embodied dignity was resonant with how participants described their experiences of manual bowel interventions. Participant vulnerability is evident from the nature of this relational activity, but it could not be discerned from interview data whether or in what way value might be lacking, which from Galvin and Todres' (2014) theory could have restored rather than ruptured the perception of dignity. Terry's (28:51:2015) stated goal for bowel care to be performed in a bathroom may indicate the environment to be lacking, or may reflect a desire to have greater privacy, or to return bowel management to as close to the previous norm as possible.

It is not known in what ways nurses sought to bring the value required for dignity to be maintained in this situation, and they likely endeavoured to do so. It is possible that the sensitising concept of Galvin and Todres' (2014) definition is revealing this to be an activity where imparting 'value' is insufficient to restore dignity, and their theory is not able to fully explain experiences. There may be unknown modifications to the activity which could have imparted value and restored dignity, or it may be that this is an act which is inherently undignified. Further research is required to understood this more fully.

With loss of dignity not fully accounted for, the literature was explored further and humanisation theory considered (Todres et al. 2009). Dehumanization is stated to occur when one or more humanising 'dimensions' are obscured to a significant degree.

Dehumanization moves experiences along a continuum towards objectification, passivity, homogenisation, isolation, loss of meaning, loss of personal journey, dislocation, and reductionist views of the body. Appraising participant experiences using these as sensitizing concepts it could be perceived from interview data that several humanizing dimensions were obscured in both inpatient and outpatient experiences of bowel management interactions, and in the wider way in which these activities were organised. These included being objectified through the requirement to fit into hospital routines, individuals rendered passive recipients of the procedure, and homogenisation in the way individuals become 'patients' and occupy as Parsons (1939) would describe a sick role in accepting and submitting to professional procedures. The potential was seen for individuals to feel they were being treated in a reductionist manner with attention focused on interventions to meet physiological needs and which may neglect insider feelings during procedures.

In their theory, Todres et al (2009) consider dehumanizing procedures as being at times necessary, giving the example of life-threatening intensive care situations when it is essential to focus on meeting physiological needs for life to continue. The experiences participants here describe do not however fall into this category. Bowel emptying is necessary to continued health but is not generally performed as an emergency procedure. It may therefore represent an extension of procedures which are unavoidably dehumanizing, and this fits with the observed divergence from theory which states dignity can be restored through imparting value in relational activities which create vulnerability. Manual bowel management, which is the mainstay of present bowel management guidelines, may inherently produce a loss of dignity, with guidelines failing to fully consider this insider experience.

6.9 'Getting used to it' versus 'Rejecting professional guidelines'

Although bowel care was described by many participants as involving loss of dignity and was observed to create feelings of dehumanization, use of the spreadsheet of codes and the timeline of injuries illustrated differences related to this. This important discovery of divergent responses to loss of dignity increased understanding of the differing experiences of the early and later colostomates.

The later colostomates described loss of dignity less frequently and only when prompted to recall early memories. It appears that over time and once at home rather than in the hospital, individuals adjust to the new norm of bowel emptying and embarrassment lessens. Leon (15), injured in 1994 recalled:

Leon (15): "Yeah of course it was horrible – but I suppose maybe I see it now differently to how I did then. I would have been scared and nervous and ashamed and a bit disgusted having my bowels emptied manually, but the nurses were taking care of me. It was definitely not something I wanted to shout out about, I wanted to keep it hidden." LN81

Graham (21:71:2012) when asked about his early experiences of bowel care in the 1960s described it as:

Graham (21:71:2012): "Dreadful. Dreadful. Yeah, it was an awful experience. It is probably the worst part of becoming a paraplegic." GL89

Afterwards the researcher reflected:

"Graham (21:71:2012) doesn't give detail about why bowel care is the worst part of becoming paraplegic. It's so terrible. His words hung in the air and I didn't press him further because I could see the terrible chasm his words opened up; the horrible place/memories he doesn't want to look at and revisit. I respected that and allowed him to move the conversation away from the chasm." (Reflective diary 28/02/2019)

A similar 'getting used to' unpleasant procedures is described by Dickson et al (2008) who found that dependency on others to perform bowel management becomes easier over time, with individuals accepting it as part of their everyday lives. Steve (26:41:2010) in this research described how he forced himself into following the regime, unaware for many years that there was any alternative:

Steve (26:41:2010): "It's a matter of just psyching yourself up...if you're going to make it a problem...you either get on with it or you don't. If you put barriers up

front then you're not going to get on with it. It's something you have to do so you've got to learn and get on with it. As horrible as it is you've got to just carry on with it." SL16

'Getting used to it' appears to be a means of learning to live with and endure the ongoing unpleasant bowel regime necessary for many following SCI. Given time it is possible that the early colostomates would have also learnt this adaptive strategy. Historically this has been what is required with no alternative offered during inpatient rehabilitation in the immediate aftermath of SCI in this spinal unit. Individuals had no choice but to find a way of accepting and assimilating this as part of the fallout of sustaining a spinal injury. The extent to which 'getting used to it' should be an accepted means of enduring dehumanizing bowel management practices when alternatives are available may be contentious and open to future debate. An extension of this code is observed in how some participants came to the belief of 'pain as inevitable', discussed in a later chapter.

In sharp contrast to the later colostomates who had no alternative option available to them and who adapted by *'getting used to'* dehumanizing bowel procedures, the early colostomates responded by *'rejecting professional guidelines'*. As they anticipated lifeworlds shrinking due to loss of time with traditional bowel management regimes, they fought against this by rejecting the accepted model and practices of bowel management. Jim (62:62:2016) and Dan (52:52:2015) described the reasoning behind their decision-making:

Jim (62:62:2016): "I thought well hang on a minute; if I end up doing my own bowels in the morning there is quite a severe time element involved in this. I worked the average out to be half an hour flat, then if I need to attend to that in the day then that's another huge issue because if you go into somewhere that doesn't have a place for you to deal with it you are sort of stumped, it would restrict my lifestyle." JE33

Dan (52:52:2015): "Even in the mornings it still takes minimum two hours in the morning to go through the procedure of eating breakfast, washing, dressing, exercise. Two hours minimum and then if we do some physio stuff, two and a half maybe three hours. You're not getting up and out until late morning. That is a big chunk of the day gone. If you then had to wait for the bowels, you wouldn't be doing much in life would you." DE263

The restrictions which traditional bowel management created were considered unacceptable and were rejected:

Jim (62:62:2016): "But once a day once again your day would be dictated by toileting so the three hours then becomes six hours. So I was not prepared to spend that number of hours a day in my life. I'm not going to do that." JE125

Reductionist bowel management guidelines are apprehended differently by the early colostomates and rejected rather than adapted to as the later colostomates did. This was discerned as potentially related to the changed culture of society and healthcare provision in relation to the timeline of injuries and is explored further in the *'Failure of Care'* chapters. With more information available to them and in an evolved healthcare culture which permitted patients greater power and involvement in decision-making, they rejected the physiologically based progressively stepped bowel management model which fails to account for the needs of their wider lifeworlds. This led to them using colostomy as a *'means to an end'*, a code returned to in Chapter Eight.

6.10 Confluence, divergence, and extension of theory in relation to extant literature

Having discussed findings within the '*Experiences of Loss*' category, the relationship between findings from primary interview data and those from secondary data are now reflected on in a quality measure to ensure the origin of findings is explicit. The gathering of secondary data from and interaction with the literature revealed areas of convergence and divergence from the research findings of others, and areas in which this research extends theory.

Findings related to 'Experiences of Loss' in interview data were found to fit and be resonant with secondary data sampled from the literature. Understanding increased of how the unpredictability of the body threatens the fundamental human need to control it, and interaction with literature developed understanding of the finding of loss of self-determination. An important finding was how for these participants, failure of the professionally determined bowel management model led to experiences of 'playing Russian Roulette'. This differed from and was more devastating than the body merely being 'unpredictable' as others describing similar experiences have suggested.

'Living with luck and chance' was found to have explanatory power for how participants who have not had a colostomy adapt to unpredictability and illustrates that, in contrast, the relentless experiences of those who go on to have a colostomy means they cannot adapt in this way.

Loss of self-determination through lack of involvement in decision making, which changed over the course of the participant timeline, was better understood through engagement with the literature. This contextualised experiences in relation to the historical culture and power differentials within healthcare provision. Experiences of disempowerment through hospital routines and lack of information were echoed in the literature.

Exploring research in similar areas of healthcare confirmed participant experiences of the loss of dignity and feelings of assault which manual bowel management interventions following SCI can produce. The concept of and dimensions to *'loss of dignity'* were better understood by exploring related theory. It was found that existing theories do not fully account for participant experiences, with not enough information presently available to understand how and whether value could be imparted during bowel management to restore dignity, or whether in fact it is an innately undignified procedure.

An important divergence from and extension of extant theory is the difference in the type of information being sought by these participants. In other studies participants wanted greater information related to management pathways made available by professionals, whereas here participants questioned those pathways and sought information about alternatives not being readily suggested or made available. The emergence of the phenomenon of early colostomy may therefore arise from a revolutionary patient movement in which the accepted and professionally dictated regimes are questioned, and alternatives sought.

The early rejection of the professional model and choice for colostomy had not been described in the literature at the commencement of this research other than by this researcher and is a novel phenomenon for which there is presently no existing theory.

6.11 Relating findings to research aims and question

Considering findings of 'Experiences of Loss' in the context of the research aims and the question, it has been seen that participants have endured incontinence, inadequate bowel management, loss of dignity, and disempowerment through professionally instigated reliance on 'least invasive' bowel management methods. Differences related to the timeline of injuries and the choice for early or later colostomy have been observed concerning the availability of information, institutional experiences, and in the power differential between participants as patients and professionals.

Colostomy has been a choice made due to the failure of traditional regimes to provide control over their bodies, and to redress the unpredictability of them. Early colostomates have been able to make this choice at an early point because unlike the later colostomates, they have had information available to them about alternative bowel management strategies. Those injured longest ago were able to adapt to the loss of dignity by *'getting used to it'*. In contrast, the early colostomates did not reach this point but instead made an early rejection of practices which were unreliable and created a loss of dignity.

6.12 Chapter conclusion

This chapter has explored the finding of participant *'Experiences of Loss'*. These comprise loss of control over the body, playing Russian Roulette, a variable loss of self-determination through lack of involvement in decision-making which is related to the timeline of injuries, loss of dignity, and experiences of disempowerment. Research from extant literature has fitted with and informed development of theory in these areas, and areas of confluence and divergence from extant theory have been discussed.

Extensions of theory have been observed in how those without a colostomy can adapt to the loss of physical control by *'living with luck and chance'*, with those who go on to choose a colostomy not able to do this, possibly related to their danger-laden experiences of *'playing Russian Roulette'*. An important area of divergence between participants has been discovered in how loss of dignity in the later colostomates led to them developing the adaptive mechanism of *'getting used to it'*, whereas the early colostomates have been

observed to seek a different level of information than those injured longer ago and have responded by rejecting the professional regime.

A golden strand is starting to emerge of the ways in which professional guidelines for bowel management following SCI are failing. This failure has so far been seen to comprise failure to meet their aim of predictability and continence, and failure from their physiological focus which fails to account for the wider lifeworlds of participants. The phenomenon of early colostomy is potentially the start of a patient-led revolution which rejects this model.

The next chapter progresses the theoretical model in discussing the category of '*Progression into Suffering*'. This is a finding in which some participants, notably the later colostomates, descend from '*Experiences of Loss*' into experiences of suffering.

Chapter Seven: Progression into Suffering

7.1 Chapter introduction

The first findings and theoretical discussion chapter discussed '*Experiences of Loss*' including loss of physical control and self-determination, lack of information, loss of dignity, and disempowerment. Differences have started to emerge between the experiences of early and later colostomates, with the later colostomates adapting to losses by 'getting used to' the indignities, unpredictability, and time-consuming norms of bowel management, and the early colostomates rejecting the professional guidelines which necessitate this adaptive strategy. Lack of involvement in decision-making and information variability have been observed to be related to the timeline of when spinal injuries were sustained. A golden thread has started to emerge relating to the failure of professional guidelines to meet physiological aims or to comprehend the lifeworlds of those they are written for.

'Experiences of Loss' were universal. For some, a progression was observed of further and greater losses, which became more appropriate to describe as suffering. Analysis revealed these experiences to be almost exclusively found in the later colostomate group. This chapter will examine the category 'Progression into Suffering', which comprises 'bodily suffering', 'battling with the body', 'reaching the end of the road', and 'colostomy as a continued lack of choice' and is shown in the amplified section of the final theoretical model in Figure 22.

As in the previous chapter, findings from primary data will be described and related to extant theory found in secondary data, areas of confluence and divergence will be considered, extension to theory demonstrated, and findings related to the research aims and question.


Figure 22: Progression into Suffering

7.2 Bodily suffering and planning ahead

'Experiences of Loss' discussed in the previous chapter included the failure of bowel management guidelines in their aim to maintain predictability over bowel function, with participants describing a loss of control which led to incontinence. In an extension of these experiences, some participants revealed that prior to the colostomy they experienced pain and damage to their bodies as a direct result of bowel management function and practices. These included autonomic dysreflexia, haemorrhoids, pressure sores and other localised damage to their bodies. These are consistent with complications of manual bowel care which other researchers have described and have been discussed in the Wider Landscape chapter (Luther et al. 2005; Coggrave et al. 2009). This was mostly limited to the later colostomates, with Jim (62:62:2016) being the only early colostomate to describe bodily damage in the form of a large haemorrhoid which developed from time spent sitting on the shower chair during bowel care which caused *"extreme discomfort to the point where I had to go to bed."* JE490. Although not the reason for having a colostomy, he reflected that:

Jim (62:62:2016): "All those things were not things I considered at the start of the whole process but by the time the operation came round I thought thank God I'm having this, you know because it was causing me a lot of problems." JE493

Jim (62:62:2016) had good reason to be thankful, as the continued and prolonged use of a shower chair while bowel care was performed resulted in Terry (28:51:2015) developing a pressure mark on his skin which led to many years of investigation and bed rest. Only after Terry (28:51:2015) had the colostomy did he realise the cause was the length of time spent in the shower chair. He described how the bowel management regime led to a downward spiral of damage to his body over the years:

Terry (28:51:2015): "I don't recall necessarily problems in the beginning. I just remember it was never a comfortable affair and it was always quite drawn out. It got to the stage where what was happening was obviously, as time went on, the dreaded haemorrhoids came in. They began to proliferate, quite a number, until in the end you're reminiscent of a baboon more than anything else and the discomfort was quite noticeable." TL75

Terry's (28:51:2015) symptoms were present since sustaining his injury, but progressed in severity over time:

Terry (28:51:2015): "I think that happened over a period of time, but it was always uncomfortable; it always set off a certain level of dysreflexia, discomfort. In the latter years that got significant and ended up with tremendous perspiration from the level of the injury up especially down one half of my body. You could literally wring the t-shirt out over the sink. Dysreflexia, where do you start?" TL85

As well as having damaged and declining bodies, participants perceived a trajectory of further decline, and the decision to have a colostomy was in part *'planning ahead'* for the continued failure of the body:

Graham (21:71:2012): "As I got older I got heavier and weaker and I was finding that my bowels weren't working very well and I could be off and on the toilet for five or six hours through the night." GL23. "This was happening more and more frequently. Sometimes incontinent, sometimes having to change the bed two or three times a night." GL28. "So, you know, life was becoming more difficult. I was getting older and weaker." GL58 'Planning ahead' is an observed response to bodily deterioration in the later colostomates. Colostomy is used as a means of planning for and mitigating further deterioration, maintaining valued independence, and to manage ageing bodies. The experience of the later colostomates of deteriorating bodies is in concordance with literature discussed earlier which found that as people with SCI age their bowel function worsens (Savic et al. 2010). Historically this has been the reason for having a colostomy at a later stage following injury as a last resort, as discussed in the Wider Landscape chapter.

The early colostomates also used colostomy as a means of 'planning ahead', but for differing reasons. For them it reduced reliance on healthcare professionals and avoided potential problems of dealing with episodes of incontinence once at home. This is a novel finding and extends knowledge by demonstrating that the early colostomates are making a choice based on planning ahead for a lifestyle that maximises their lifeworld aspirations and potential. In doing so they reject accepted bowel management guidelines which do not accommodate this.

7.3 Battling with the body

The bodily suffering of the later colostomates, together with lack of control over bodies which let them down with unpredictable incontinence, led to them living in a state of ongoing *'battle with their bodies'*. Data analysis revealed that at times participants protect the body, care for it, are let down by it, manipulate it, force into submission, and push it to the limit. At other times their bodies launch unprovoked and unanticipated attacks which became progressively wearying to deal with as Terry (28:51:2015) describes:

Terry (28:51:2015): "I could suddenly end up with a dysreflexia attack and you wouldn't know why and we would be leaning me forward and putting me back on the bed, and the bed would alleviate it." TL160. "Having to try and deal with that in time." TL94

Graham's (21:71:2012) wife talks of the ongoing battle he had with trying to force his body to function and experiences of it letting him down:

Graham's (21:71:2012) wife: "I mean the nights were not funny were they when you were incontinent? You'd be on the toilet for about three hours and then come to bed thinking you'd been to the toilet enough and then half an hour or one hour later I was hearing 'Oh no! No!' and I was like 'No? What?' And that was it we'd have to strip the bed, it was just awful. Just horrendous!" DL412

Secondary data was gathered from the literature to better understand the battle the later colostomates were having with their bodies, and similar battling experiences were found in those living with chronic health conditions. Exploring these enhanced understanding of the experiences of participants prior to having a colostomy, particularly those choosing it many years after injury.

Charmaz (1995a) perceives those with chronic conditions to both battle *with* their condition to keep their bodies functioning and lives as normal as possible, and *against* their condition as an enemy to be battled as they try to regain a past identity and restore their sense of self. Comparing this with interview data, participants here appear to be similarly engaged in battling both with and against their bodies. They battle *with* them as they utilise the tools of body management given to them by professionals to try and maintain bowel emptying and continence, and *against* them as they seek to maintain their identity through engagement in desired activities discussed shortly.

A further sensitizing concept from secondary literature data demonstrates participants to engage in what Gullick and Stainton (2008) describe in those undergoing lung surgery as *'conscious body management'*. This comprises consciously planning for the needs of body, pushing it to the limits, being aware of the limits, and consciously managing the body's environment. In constant comparison this sensitizing concept revealed conscious body management being deployed to maintain control over the body. Terry (28:51:2015) described the diligence this requires:

Terry (28:51:2015): "Even just a catheter being slightly out of place can cause you a lot of discomfort so you have to think about things, making sure your bowels are regular so you don't end up constipated and all the problems associated with that." TTL66

'Conscious body management' was deployed by other participants. Prior to the colostomy Steve (26:41:2010) 'picked his battles' by deciding when he could deal with the fallout of alcohol affecting his bowel function, and Brian (38) manipulated his diet to reduce incontinence. Weighing the concept for fit with interview data, it fitted well particularly for Brian (38) and Leon (15) who have not gone on to have a colostomy. It felt however inadequate in conveying the depth of suffering experienced by some in trying to manage their bodies. 'Battling with the body' is a better fit for the experiences of those including Graham (21:71:2012), on and off the toilet through the night, and Terry (28:51:2015) spending prolonged periods resting in bed recovering from the assault of bowel care. The sensitizing concept of 'conscious body management' therefore served well in exposing differences between those for whom this was a successful strategy for maintaining bowel function and continence and did not go on to have a colostomy, and those for whom it failed in this aim.

Tactics deployed in conscious body management included adherence to the routines and management tools given to individuals by professionals based on available guidelines. These have been seen in the previous chapter to fail in their aim of providing regular bowel function and maintaining continence for these participants. Perhaps this is unsurprising, given the weak evidence on which guidelines are based and the apparent lack of user involvement in their development, as discussed in the Wider Landscape chapter. Other researchers have found a similar failure of suggested strategies to adequately manage bodies, and Charmaz (1983) suggests that professional practices can set in motion restricted lives. This led to development of the theme *'professional practices restricting lives'*, discussed further in Chapter Ten.

7.4 Shrinking lifeworld and living restricted lives

Bodily suffering and decline, together with relentless battling with their bodies, have been observed in the data from the later colostomates. Bowel management and its failure consumed lives and resulted in a significant loss of time and energy to engage in activities. Monty's (69:70:2011) wife recalled that prior to the colostomy:

Monty's (69:70:2011) wife: "As soon as the carers got him into the chair to take him through to the shower, it was everywhere. And then usually the whole of the morning was taken up cleaning him up because it hadn't been done properly. It just took over your life, didn't it?" ML50

The experience of lives being dominated by body management was sampled in the literature. This revealed theory that some exist in a *'shrinking lifeworld'* with *'lifeworld'* being understood as Husserl (1913) describes, as a person's experience of the world as shaped by their personal concerns and relationships. This phenomenological concern with people's lived experiences offers the potential for future research to gain more understanding in this area. Knowledge from alternative philosophical approaches could enrich understanding of the effect that bowel management following SCI has on the individual and build greater understanding. This is considered further in the Further Discussion chapter.

Returning to the sensitizing concept, Gullick & Stainton (2008) in their research with individuals with Chronic Obstructive Pulmonary Disease (COPD) use rich illustrations from interview data to describe a *'shrinking lifeworld'* as:

"Progressive failing and unpredictability of the body led to a shrinking scope for physical effectiveness and therefore for effectiveness as a person...[and].. shrinking social networks and a perceived loss of usefulness to others...loss of mobility, hobbies and social networks...their worlds became contracted to the realms of the home." (Gullick and Stainton 2008, p.609)

In Bury's (1982) study of chronic illness scant methodological and analytical detail are given, but participant quotes provide further evidence of shrinking lifeworlds as Bury describes:

"Maintaining normal activities...have to become deliberately conscious activities, and thus frustrating and tiring. In the end the effort simply does not seem worth it...the simplest outing becomes a major occasion of planning and expedition... individuals begin to restrict their terrain to local and familiar territory." (Bury 1982, pp.175-176)

Bury's (1982) participants restrict their activities outside the home, and similarly Charmaz found many of her participants to be *'living restricted lives'*, with some quitting work, limiting

social engagements, and avoiding activity. Some even restricted their lives more than was necessary: *"Living a restricted life fosters an all-consuming retreat into illness"* (Charmaz 1983, p.175). Reflecting on the two codes *'shrinking lifeworld'* and *'living a restricted life'* to better understand participant experiences, the latter implies a static state of being (although Charmaz' later concepts of identity and bodily hierarchies describe movement along continuums), and the former suggests progressive deterioration over time.

In constant comparison, *'shrinking lifeworld'* better accounts for later colostomates' experiences of progressive bodily suffering and deteriorating bodily function, which culminated in the decision to undergo colostomy formation:

Monty's (69:70:2011) wife: "Then we decided to go for it [the colostomy] because it just got stupid." ML99

Lives shrunk to the point of *'reaching the end of the road'*, a focused code considered shortly. Early colostomates' interviews did not yield evidence of shrunken lifeworlds, due to their bowel management experiences prior to the colostomy occurring whilst still hospital inpatients. They referred as Jim (62:62:2016) did in the previous chapter to anticipating restricted lives, but did not get to the point of experiencing this. In the two participants without a colostomy, there is no suggestion that Brian (38) is experiencing progressive body management problems, whereas Leon (15) appears to be aware of and yet in denial about deterioration in his body, carrying on with existing methods of body management for as long as possible:

Leon (15): "I use a suprapubic catheter which has a time period on it and I'm getting near the end of that time period and my bladders got small so much so it will end up causing me problems, so we've been looking into the bladder options there. I looked ten years ago but the options weren't really good." LN99

With these differing experiences there is insufficient data from these two participants to fully explore experiences of those who do not have a colostomy with those who do, in terms of restricted or shrinking lifeworlds. Theoretical saturation was not reached in this area, and it would require interviewing more participants without a colostomy to achieve this. With the focus of this study on the timing of colostomy formation and other areas of investigation felt to be of more central importance, the decision was made to leave this for investigation in further research.

7.5 Fighting a shrinking lifeworld and determination through suffering

Further constant comparison between interview data and findings in the literature revealed an important difference in how individuals in this research react to a shrinking lifeworld. In the literature discussed in the previous section many restrict their lives, even more than might be necessary. In contrast, the later colostomates continued desired activities despite this being a struggle with several describing holidays, work, and social activities:

Monty's (69:70:2011) wife: "When we went on holiday I used to do [his bowel care] myself." ML72

Graham (21:71:2012): "I have ended up on the floor a few times, not at home, we had a holiday caravan." GL59. "We've been to America, Canada, and Australia, so we've had some nice holidays." GL341

It appears that some with chronic health conditions like those described by Charmaz (1983) choose to accept a shrinking lifeworld and the limitations imposed by their bodies. Others, like the later colostomates, fight against this. This discovery led to the development of extensions to extant theory. Where lifeworlds of the later colostomates had shrunk due to bodily decline and ineffective bowel function and management, a reaction against this was observed and labelled as *'fighting a shrinking lifeworld'*.

In a further extension of extant theory, later colostomates who had experienced suffering and the shrinking existences the early colostomates only anticipated, struck out against this, and displayed a *'determination through suffering'*. They doggedly persisted with traditional regimes, unaware of alternative options, and willed their bodies to conform to achieve their desired lifestyle goals and aspirations. Terry (28:51:2015) displayed determination to continue travelling, pushing his body to comply with what he wanted to do despite the likelihood of having to endure subsequent suffering: Terry (28:51:2015): "I used to quite like travelling and I'd have to force myself to go to the loo, get showered and get back in the chair, get back on the road and carry on. And sort of feel the consequences whilst travelling." TL122

This 'determination through suffering' is a complementary expansion of Charmaz' (1980) theory that in struggling against the body people refuse to accept lesser or restricted lives (Charmaz 1980, 1994). Analysis of these participants experiences gives additional dimensions of the nature and purpose of the struggle that those with chronic conditions engage in against their bodies. They do so with purpose to achieve wider life goals and have a determination in doing this despite the suffering it entails.

A further dimension is observed in Dickson et al's (2008) participants, for whom fear of incontinence was a major factor, but they did not let this prevent them from socialising. Rather, like the participants of this research they lost independence and spontaneity, with extensive planning for activities required. In this research Terry's (28:51:2015) early wakening to allow sufficient time for body management concurs with this but goes further in demonstrating a determination to participate in desired activities.

The fighting and determination of these participants contrasts with those of Charmaz (1983) who retreated and restricted their lives sometimes more than was necessary, and Gullick and Stainton's (2008) who felt a loss of effectiveness, social networks, and usefulness. This may represent a difference in experiences of those with differing health conditions, or it may be that the similarity exists but was not uncovered by the interviews or found in sampling the work of other researchers.

'Determination through suffering' and 'fighting a shrinking lifeworld' are codes which demonstrate the importance of overcoming bodily restrictions to achieve life goals for these participants. Bowel management guidelines do not adequately address these concerns and focus almost exclusively on how best to physiologically manage the body. Contained within their wording is the expectation that lifeworlds will need to change to accommodate body management. This expectation has been rejected by the early colostomates, and these codes demonstrate the later colostomates striking out against it.

7.6 Reaching the end of the road

Participants who chose to have a later colostomy are observed in a culmination of suffering, bodily decline and shrinking lifeworlds to arrive at a point of *'reaching the end of the road'*. Here, their situations had deteriorated to the extent they felt they had no choice but to pursue what seemed to them the radical route of undergoing colostomy formation. Radical, because colostomy is considered the final and most invasive option in the pyramid of interventions within the perspective in which they had been indoctrinated. Participants described:

Terry (28:51:2015): "Year in and year out, it gets tiring. In the end I think I was almost pushed into the situation. I pushed myself into the situation. I got to the point and thought, you need to look at alternatives." TL95

Steve (26:41:2010): "I was getting up in the day and having a bowel leak before I'd even started. So then you've got to clean your bed sheets, get in the bath, take your clothes off, get new sheets on, and then you find that it's happened again. So after putting up with it for ooh how many years, fifteen years? Yeah, after fifteen years I decided enough was enough." SL64

Reflection and diagramming led to the discovery that colostomy for them was a continuation of the lack of choice in how their bodies would be managed, and this contrasts with the experiences of early colostomates for whom it was an active choice. The lack of choice was described by Alice (55:63:2010) and her husband, and Graham (21:71:2012):

Alice's (55:63:2010) husband: "I think it was a fait accompli. We were in a position where she was struggling so much, and because of the spinal injury it was difficult to get up and down. This was another additional stress." AL63

Alice (55:63:2010): "I couldn't have done anything else." AL96

Graham (21:71:2012): "I think it was a psychological thing really. I would rather have managed without it, put it that way. And whilst I did manage it wasn't always easy, but you know it came to a point where I think it was necessary as opposed to just wanting to do it, I think it became necessary." DL289 This is in contrast with the early colostomates who instead made an active choice about bowel management in the context of their wider lifeworlds, their aspirations for continuing with desired activities, and regaining control over their lives:

Emily (49:49:2016): "Having to wait in for somebody to come round because it's not always reliable on the time and I like to get up and do what I've got to do." EE64. "By the time you have had your bowels done and then got cleared up, had your shower and whatever, most of the day is gone." EE137

Sophie (48:48:2013): "Well it's the time commitment as well as the inconvenience [of traditional bowel management]." SE266

The newly injured participants, still adjusting to their injury, glimpsed what the later colostomates had already experienced, how their days and lives would be shaped and dominated by lengthy bowel care regimes and waiting for carers, and their lifeworlds would shrink as a result.

A stark difference and change over the timeline are thus observed between the two participant groups. The later colostomates who were given no alternative to traditional bowel management, 'got used to' the associated indignity and unreliability, and eventually had the colostomy as a 'continued lack of choice' as they 'reached the end of the road' in a place of last resort. In contrast the early colostomates who were able to challenge the status quo, had more readily available information, 'rejected' professional practices which were undignified and restrictive, and were able to make an 'active choice' for an alternative method of body management.

7.7 Confluence, divergence, and extension of theory in relation to extant literature

Findings of *'Progression into Suffering'* which stem from primary and secondary data are now summarised. The *'bodily suffering'*, *'battling with bodies'*, and progressive decline which participants endured were echoed in findings of researchers exploring other areas of chronic health conditions. Notions of struggling both with and against bodies from the literature fitted with participant experiences, and the concept of *'conscious body management'* was

seen in how participants planned for and managed the needs of their body to try and maintain control. *'Conscious body management'* was a useful concept which distinguished between participant groups. Those without a colostomy had less severe symptoms and were able to successfully employ this, whilst those who went on to have a colostomy experienced more profound battles with their bodies and reached a point of being unable to do so.

The sensitizing concepts of 'shrinking lifeworld' and 'living restricted lives' were resonant and valuable in illuminating the struggles which the later colostomates were engaged in and exposing differences between extant theory and this research. The literature described individuals able to accept and live restricted lives, whilst participants in this research differ by rejecting this. In an extension to theory, the later colostomates react by 'fighting against shrinking lifeworlds' and display a 'determination through suffering'. The early colostomates reject the guidance which requires their lifeworlds to be restricted.

7.8 Relating findings to research aims and question

Findings of '*Progression into Suffering*' have revealed further differences between the experiences and choices of the early and later colostomates. Suffering, bodily decline and shrinking lifeworlds led to the later colostomates undergoing colostomy as a culmination of their lack of choice over how their bowel function would be managed. In contrast the early colostomates made an active choice for it in the context of their wider lifeworlds, to maximise their freedom and independence after leaving hospital.

Differences are seen in those who could achieve acceptable bowel function and continence from use of professional guidelines and didn't go on to have a colostomy, and those who could not achieve this and instead were engaged in an ongoing battle with the body. Of those who did have a colostomy, further differences are observed in differing uses of the concept of 'planning ahead'. The later colostomates did so in relation to bodily deterioration, and the early colostomates to reduce carer reliance and in relation to their wider lifeworld aspirations. A final important difference in the experiences of early and later colostomates is the observation that the later colostomates arrived at the point of having a colostomy as a *'continued lack of choice'* when they *'reached the end of the road'* and there was no other option available to them. This is in congruence with traditional models and accepted professional practices where colostomy is used as a last resort. In contrast, the early colostomates *'rejected'* these and made an *'active choice'* for colostomy based on their lifeworlds.

7.9 Chapter conclusion

This chapter has explored the '*Progression into Suffering*' which some participants, mostly the later colostomates, experienced as an extension of themes of the unpredictability of the body and the failure of the model described in the '*Experiences of Loss*' chapter. Experiences of 'bodily suffering' and 'battling with the body' were greater understood through engagement with sensitizing concepts from extant literature, and this led to the development of extensions to theory in codes of 'fighting a shrinking lifeworld' and 'determination through suffering'.

Further differences between the early and later colostomates, and those who do not have a colostomy have emerged in both experiences of depth of suffering and decision-making related to bowel management options. The early colostomates '*plan ahead*' by anticipating the restrictions on their lifeworlds which manual bowel management will entail and therefore make an 'active choice' to have a colostomy. The later colostomates '*plan ahead*' to mitigate for the trajectory of their declining bodies, or find themselves at the point of '*reaching the end of the road*' and undergoing colostomy formation as a '*continued lack of choice*'.

In 'Experiences of Loss', a golden strand started to emerge of the failure of professional guidelines to meet their own aims of predictability and continence, and a further failure to account for the wider lifeworlds of participants. In adapting to the losses by 'getting used to it', greater detail of the impact of these failures is observed in how the later colostomates 'Progress into Suffering' through perseverance with traditional guidelines. The 'rejection of guidelines' by the early colostomates has been reinforced in this chapter as being a decision

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made in relation to their wider lifeworlds, and this differs to the physiological framework of the guidelines.

Having explored participant experiences which led up to them having a colostomy formed, attention is now turned to what happened afterwards, through exploration of the category *'Being Alive Again'*.

Chapter Eight: Being Alive Again

8.1 Chapter introduction

The first two findings and theoretical discussion chapters have traced a golden thread of the failure of bowel management guidelines to meet their aim of maintaining continence and to account for the wider lifeworlds of those with SCI. It has been described how bowel management following SCI leads to *'Experiences of Loss'* through *'unpredictability', 'loss of self-determination'*, and *'loss of dignity'*. These experiences led to the early colostomates *'rejecting professional guidelines'*, and the later ones to adapt by *'getting used to it'*. In a *'Progression into Suffering'*, the later colostomates have been observed to go on to endure *'bodily suffering', 'battling with the body'*, before finally *'reaching the end of the road'*. The later colostomates then chose to have a colostomy as a *'continued lack of choice'*, whereas the early colostomates made an *'active choice'* to have it.

Despite the early and later colostomates approaching the colostomy from these differing positions, there was a universal finding of *'Being Alive Again'* afterwards, as experiences of *'Loss'* and *'Suffering'* are reversed. These will be explored in this chapter through examining how *'control is regained'*, *'suffering relieved'*, and *'dignity regained'*. Next are discussed transformational and expansive experiences of *'living with confidence'*, *'having a day'*, and *'care becoming easier'*. Regaining of control is returned to later in the chapter to explore more of its nature, and consideration is given to how this can be defined to best account for participant experiences. A tentative new construct of control is proposed.

A section later in the chapter describes the intentional search of interview data for contrary or negative findings. This was performed to increase quality and rigour and reduce the risk of researcher bias, but also led to the discovery of new codes and further theory development. As complications from the colostomy are examined, a theme of *'still glad to have it'* emerges. Changes to self and bodily concepts and how relationship status impacts on decision making are considered. Finally, the use of colostomy as a *'means to an end'* is explored, and the notion developed of how this is used in relation to a hierarchy of need.

As in the two previous chapters, findings from primary data analysis were developed through interaction with extant literature. The amplified theoretical model in Figure 23 demonstrates this interaction. Ways in which this research fits with and diverges from and extends existing theory will be discussed, and a final section will consider how the findings in this chapter contribute to answering the research aims and the question.



Colostomy

Interaction

Colostomy

Colostomy

Figure 23: Being Alive Again

8.2 Regaining control

The 'Experiences of Loss' chapter described how following SCI participants lost control of their bodies through unpredictable bowel function and mortifying incontinence. This led to engagement in necessary or desired activities becoming danger-laden experiences of 'playing Russian Roulette', and experiences of 'shrinking lifeworlds'. Professionally instigated bowel management programmes created dependency on health professionals leading to a further loss of control as some participants were unable to be independent with their body management. Particularly for the later colostomates, choice was not often given over how the body should be managed.

Following the colostomy there is a universal benefit of regaining control over bowel function, with bowel emptying no longer resulting in incontinence. Further dimensions of control are

regained in varying ways according to whether participants required the help of a caregiver, and whether colostomy was chosen early or later.

Those who chose it later and could manage their bodies independently regained control through achieving continence and time not being consumed by bowel management:

Steve (26:41:2010): "It's been the best decision...I didn't have to worry about cleaning up after myself. No sheet changes. No constant bathing. Not having to get out of the wheelchair and sort everything out, clean everything." SL125

Monty (69:70:2011), a later colostomate who was seen in previous chapters to be disempowered, receiving ineffective care, and experiencing a shrinking lifeworld, was liberated from problems created by his previous dependency on healthcare professionals. With his wife now able to change the colostomy pouch for him and not having to wait for nurses, they regained control over their wider lives:

Monty's (69:70:2011) wife: "Well we don't see the nurses at all now. He's got a suprapubic catheter and I change that as well. So we don't see them at all now." ML193. "I took over, I have done the colostomy right from the start. His catheter I've been doing for about four years now. So we don't see anybody." ML218

Early colostomates experienced regained control from the self-determination of exerting choice in how their bodies would be managed. Those with higher injuries and no alternative but to be reliant on healthcare professionals, became able to instruct others more easily how care should be performed. Having a colostomy pouch changed on their abdomen was simpler and more visible than receiving manual bowel care, which they were unable to see and was more complex. Andy (66:66:2014), with a high spinal injury and very limited movement described his feelings of control:

Andy (66:66:2014): "I've got a mirror like that up on the wall, opposite the bed and from there I can see what they're doing. It's been a godsend really. If you lie there [with manual bowel care] you're trying to tell people, it might be a fresh person and it's quite hard to know if they are doing it as you want it, because you can't really say 'do this,' I can't really feel anything. [With the colostomy] I can look up at the mirror and I can see what's happening." AE384

The early colostomates with lower-level injuries regained self-determination as they moved from dependence on others to perform manual bowel management, to being independent, as the accessibility of the stoma on the abdomen meant they were now able to manage this themselves. Independence after leaving hospital was important to this group, and Emily (49:49:2016) demonstrated using colostomy as *'a means to an end'* of regaining control in this way:

Emily (49:49:2016): "Because it is that sense of independence and control that you've got back in your life, at least over something. You know, paralysis you can't do an awful lot about it, you've got to live with it. But you know, how your bowels are emptied, and your bladder, but how your bowels are emptied especially, it is something you can have a choice in, and an informed choice as well." EE251

These nuanced differences demonstrate there to be several dimensions to *'regaining control'* and that it is experienced differently by those with differing injury levels and when performed at differing times post injury. These different dimensions are displayed in Figure 24.

	Independent	Require caregiver help
Later colostomates	Regain control over body	Dependency reduced
	Regain lost time	Regain lost time
Early colostomates	Regain independence	Able to direct others
	Can self-manage body	Can observe interventions
	Exercise choice	Exercise choice



Previous research into how bowel management is experienced by those requiring it and the impact it has on their lives, has affirmed control as of great importance. Hammell's (2007) meta-synthesis of qualitative findings relating to QOL after SCI describes the importance of control, and Waddell et al's (2020) systematic review of colostomy and QOL found the

majority of those with SCI ranked loss of bowel control as the greatest functional loss after mobility. Evidence of this research demonstrates colostomy to increase control not only over their bodies but over their wider lives. The importance of control does not appear to have been appreciated and incorporated into the development of clinical guidelines. With regaining control of particular importance to the early colostomates, this indicates why they might reject guidance which creates dependency in favour of an option which facilitates independence.

Extant theory about control was found to comprise a large body of existing knowledge. Consideration of the dimensions of control is returned to later in the chapter and how theory relating to this was further developed. For now, the main findings from primary data continue to be presented.

8.3 Bodily healing and relief from suffering

Manual bowel management has been found for these participants and in discussion of the Wider Landscape as leading to physical problems including incontinence, haemorrhoids, bleeding, autonomic dysreflexia and pressure marks. Following the colostomy, the physical suffering and damage sustained related to manual bowel methods was healed. E.g., Jim (62:62:2016) experienced healing from the haemorrhoid he developed from prolonged periods spent in the shower chair having bowel care performed.

Healing of localised complications directly related to manual bowel care could perhaps be expected, but bodies also healed in other unanticipated areas. In addition to relief from the pain and bleeding from haemorrhoids, Terry (28:51:2015) experienced healing of a persistent pressure mark and relief from disabling episodes of dysreflexia:

Terry (28:51:2015): "The cause of the mark was the time spent in the shower chair [having bowel care]...because it's cleared up since, resulted in this ongoing pressure mark that went on for years and years...that was the most, over and above the pain and discomfort of having the suppository, was the most wonderful thing [pressure mark to disappear]." TL224. "I don't have all the aggro I had before, I don't really notice it, and it's kind of gone. My people, family,

friends, say you look better, you don't look red anymore, you don't go through those red phases [dysreflexia symptoms]." TL377

Terry (28:51:2015) had not previously associated the pressure mark with time spent in the shower chair. The finding from this research that having a colostomy heals pressure marks created from manual bowel management methods, demonstrates these to be another complication of traditional bowel care methods. The incidence and impact of these may not be known or appreciated if, like Terry (28:51:2015), they are not recognised as associated with length of time sitting in a shower chair during bowel care.

Sampling the literature using search terms of 'body healing' and 'relieving suffering', it was difficult to find research which described a similar relief of suffering through choosing a body management option. Most relate to suffering being alleviated in a palliative setting. Older research by Carter (1994) and then Morse & Carter (1996) was found to be of most relevance. They used a bank of interviews performed with individuals (and their relatives) who had suffered illness or accident and spent time in a rehabilitation hospital. They describe how when suffering ceases, individuals report feeling renewed, living more fully and being richer from the experience, which they describe as a reformulated self.

In constant comparison with interview data, their described concepts of 'feeling renewed' and 'living more fully' could be seen in participant data. Beyond this, divergence is seen, as the suffering of Morse and Carter's (1996) participants was relieved by them adapting to their changed health status. In contrast, the later choice for colostomy resulted in an actual improvement to their health status, and benefits were related to this and not to a psychological adaptation. This relief enabled individuals to be renewed and live more fully, rather than achieve this through reformulating themselves through use of an adaptive strategy to deal with suffering. The adaptive strategy described in Morse and Carter's (1996) research did however add to understanding of the 'getting used to it' strategy described in Section 6.9. Their theory suggests 'getting used to it' to be a strategy used not just to accept loss of dignity, but which also enables individuals to move forward and 'live more fully' and 'reformulate themselves' through acceptance of changed health status. This information used as a sensitizing concept adds to what is known about 'getting used to it'.

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It is not suggested that colostomy is the only body management choice in chronic illness or injury which can relieve suffering and heal the body. Numerous searches using a variety of terms failed however to yield pertinent data relating to this. This may be a limitation of using codes as search terms and represents an area for further future exploration to furnish the dimensions of this code.

8.4 Regaining dignity

In a further reversal of '*Experiences of Loss*', having a colostomy was found to restore dignity. Dignity was discovered in the Experiences of Loss chapter to be a concept described in the literature as a conjunction of vulnerability and value which can be ruptured or restored, and which as well as being an insider experience has a relational dimension (Galvin and Todres 2014). The relational activity between nurses and patients during bowel management was found to risk '*embodied dignity*', and to include dehumanizing elements of objectivity, passivity, homogenisation, and reductionism.

These dehumanizing and undignified experiences ceased following colostomy formation. Emily (49:49:2016) described her relief at no longer having to go through manual bowel management following the colostomy:

Emily (49:49:2016): *"To have my day without having to worry about it all going...right ok...assume the position, shall we say."* EE68. *"I was happy to have it [the colostomy] because it was less intrusive."* EE97

Dignity is an aspect of bowel management given scant attention in existing guidelines, and despite the best efforts of care providers, it has been observed and can be imagined, to be a procedure which can easily lead to a loss of dignity. It was speculated in the earlier discussion of dignity that manual bowel management may be an inherently undignified procedure. The importance placed on regaining dignity by participants suggests professionals need continued awareness of this, and it should perhaps be afforded greater consideration in the development of bowel management guidelines and methods.

It was seen in Section 6.9 that over time the later colostomates developed an adaptive strategy of 'getting used to' the indignity of manual bowel care. Other researchers have found embarrassment to lessen over time, and it is a strategy which the early colostomates may have eventually learnt (Dickson et al. 2008) The question emerges of whether 'getting used to' an undignified procedure which can fail to achieve continence and can impose considerable restrictions on lifestyle should continue to be the professionally accepted expectation for all with SCI, when there is a body management option available which removes the need for this? With new knowledge from this research, the time may be right for professionals to reassess their assumptions about bowel management. This is an area which needs further investigation to build understanding.

8.5 Living with confidence

'Experiences of Loss' and 'Suffering' have been demonstrated so far in this chapter as being reversed following the colostomy, but participant data demonstrated much more to be gained beyond this. The confidence and joy with which participants moved forward in their lives led to findings described as 'living with confidence'. This section is unashamedly littered with participant quotes which illustrate the enrichment of lives after choosing to have a colostomy.

A previously discussed finding was how bowel leaks and other problems related to bowel management created difficulties in pursuing desired activities. This was described in Section 7.5 as producing an adaptive response of *'determination through suffering'* to engage in desired activities despite suffering these would entail. Following the colostomy, this strategy no longer had to be deployed.

Terry (28:51:2015): "This year in May/June we are off down through France/Spain. I think this will be a vast difference because of instead of having to dread an hour or two in the van whilst I get over what has just happened bowel wise in the morning, I feel I won't be doing that." TL338

Regained physical control over their bodies meant participants could enjoy activities with a new confidence that their bodies would not let them down. This is a further reversal of

experiences prior to the colostomy. Graham (21:71:2012) described this in relation to travelling:

Graham (21:71:2012): "I'm confident about where I go. Although we've been to Australia a few times before and with the odd mishap bowel wise, especially after a 27 hour flight. After having had the op in 2012 later that year we did fly to Australia without any problems, and I was confident that I could do that as well." GL328

The ease of managing a colostomy was considerable, and bowel function now fitted in with what participants wanted to do, rather than dominating their lives:

Terry (28:51:2015): "The sheer flexibility of it. Being able to change it when I want where I want." TL236. "When you are doing your colostomy you can do that on the bed, on the chair, you can do it wherever you like. Fundamentally you have no restrictions." TL215. "We just tilted my chair back and it was done in five minutes. All nice and clean and I'm confident and that had all been done. It's incredible." TTL157

Terry (28:51:2015) describes further the transformation in how he feels compared to before having the colostomy:

Terry (28:51:2015): "After a morning routine I would just have the covers pulled up, they would tuck me in and of course I became a dab hand at hiding what I was feeling, but actually inside it was uncomfortable and not pleasant. So to be warm and under your bed was a nice thing. But now I can spring out!" TL381

This vivid description of feeling that he can now spring out of bed is an experience beyond what is possible. His insider experience is that he now can spring out of bed; an outsider would observe he is unable to move from the chest down. Such insider experiences of the difference having a colostomy makes go unheard when service users are not included in the development of body management guidelines. This omission was found to have occurred in the bowel management guidelines discussed in the Wider Landscape and will be returned to in the Further Discussion chapter.

Andy (66:66:2014) compared his situation to that of others who don't have a colostomy and recognised the freedom it gave him:

Andy (66:66:2014): "I've heard people say they are afraid to go to weddings and things like that." AE48. "When you've got to disrupt your day because of it, or if you go anywhere, well really I haven't got concern myself with that." AE188

Jim (62:62:2016) and his daughter described the difference it made to his confidence in going out:

Jim's (62:62:2016) daughter: *"He can live his life without having to worry about say having an accident when he goes out; he doesn't have to worry about any of it now. It's really good."* JE436.

Jim (62:62:2016): "Oh my goodness me it [manual bowel management] would have restricted my life so much and now, I was at Twickenham rugby the weekend before last. I went to see Brit Floyd. I can do, I've just got no worries at all." JE502

These experiences illustrate the actual and insider transformative benefit which having the colostomy has wrought for these participants, and how they can now live with confidence in the knowledge that their bodies will not let them down or limit what they can do. As wider lifeworld aspirations become possible and easier, bowel management recedes from its previous domination of lives, and becomes an activity which fits in with the lifestyle of individuals rather than dictating it. The moral rightness that the potential for this is denied to some through lack of information and professional assumptions must be raised.

'Living with confidence' and a related term of 'expanded self' which was considered as a potential explanation for experiences, were used to search for further data from extant literature. Gullick and Stainton (2009) interviewed individuals with Chronic Obstructive Airways Disease (COAD) and their relatives, after patients had undergone Lung Volume Reduction Surgery (LVRS) or Endobrachial Valve (EBV) insertion. Participants found that the surgery, like colostomy for those with SCI, expanded their life choices. Evocative of Terry's (28:51:2015) words, participants described the procedure as being a 'miracle'. Further comparable data was found. Nelissen et al's (2019) participants commenced on invasive ventilation felt better, slept better, and had more strength and energy during the day, and Locker and Kaufert's (1988) found ventilation to lead to greater energy and zest for living.

Gullick and Stainton's (2009) description of their findings is given as it is resonant with those of this research:

"The decision to take a chance on a lung volume reduction procedure as a more extreme form of body management may be understood as an informed choosing for the possibility for an expanding life-world." (Gullick and Stainton 2009, p.302)

Colostomy, LVRS, EBV, and ventilation are similarly perceived by professionals as 'extreme' or 'invasive', but when insider experiences are explored, they are found to be choices made from lifeworld perspectives which value the chance to live to the full and achieve individual potential. The data from literature supports the finding that body management options considered by professionals to be extreme or invasive make sense and are justified by the lifeworld perspectives of those choosing them.

8.6 Having a day

An earlier finding discussed in Section 7.4 was the 'shrinking lifeworld' of participants. This was due to time spent performing bowel care, time lost waiting for carers to arrive, and time spent dealing with bowel accidents. A similar loss of time was found in other areas of healthcare management. Following the colostomy, this time was regained and is described using an *in vivo* code of 'having a day'.

For the early colostomates, time was a key consideration when deciding on a bowel management method which would best facilitate their freedom and ability to live as full a life as possible once discharged home from hospital. This demonstrates again that the decision to have a colostomy is not made from a purely physiological perspective. Dan (52:52:2015) stated about his decision: *"It's all about freeing you up to do what you want,"* DE259. Reflecting on the time element involved in manual bowel management and how that would

affect how he wanted to spend his day he said: *"If you then had to wait for the bowels, you wouldn't be doing much in life would you?"* DE268.

Jim (62:62:2016) described ways in which he thought manual bowel care would curtail his lifestyle choices and colostomy would maximise them:

Jim (62:62:2016): "If I need to attend to that in the day then that's another huge issue [with manual bowel care] because if you go into somewhere that doesn't have a place for you to deal with it, you are sort of stumped, it would restrict my lifestyle." JE35

Jim (62:62:2016) highlights the difficulty of finding public places to manage problems related to bowel management. This is a hidden difficulty faced by those with SCI needing to manage their bowels or deal with incontinence whilst not in their own home and was referred to by other participants. Interaction with the literature revealed theory relating to how society disables people rather than their bodies through inadequate provision of facilities, and this is a theme returned to and discussed more fully in the Institutional Failure of Care chapter.

Following the colostomy, bowel management became an activity lasting a few minutes rather than potentially a few hours, with no further time lost during the day from dealing with incontinence, as Andy (66:66:2014) stated: *"How it is now, it is only a few seconds, a few minutes."* AE135. For the later colostomates who had lived out the loss of time which the early colostomates only anticipated, the difference was considerable. Summarising the difference it made to them to regain lost time, Monty's (69:70:2011) wife describes how they now *'have a day'*:

Monty's (69:70:2011) wife: "We had time. We now have carers coming in just after eight o'clock in the morning and that started after his colostomy. They didn't have to wait around so by nine o'clock, he can't eat breakfast in bed because the swallowing reflex is affected. So we now have a day." ML176

Terry (28:51:2015) was released from the time it took undergoing bowel care, but in addition regained time previously lost recovering in bed from how this made him feel:

Terry (28:51:2015): "My time obviously in the shower chair was cut down from say two hours to twenty to thirty minutes if that." TTL111. "But then you're thinking I don't have to worry about that anymore [time recovering from bowel care]. So that makes a big difference." TL389

Participants were now able to follow pursuits and activities without being at the mercy of lengthy bowel management and unpredictable incontinence. Searching the literature for further data related to *'having a day'*, Charmaz (1995b) gives evidence of changes in body management allowing those with chronic illness or injury to entertain possibilities and try new ventures: *"People re-entered the worlds they left or embark on new pursuits"* (Charmaz 1995a, p.668). Locker & Kaufert's (1988) participants regained time due to a reversal of decline in respiratory function following periods of mechanical ventilation. Their participants described benefits of increased energy and zest for living, achieving more in the day, reduced fatigue, fewer respiratory infections, and improved disposition. These findings fit with those here and demonstrate the benefits of alternative methods of body management are not confined to one area of health care. Alternative body management can enable people to move on with their lives. The 'invasive' procedure of colostomy, like the invasive procedure of ventilation, led to lifeworlds expanding as lost time was regained and participants could now engage in desired activities, in a humanizing regaining of personal journeys.

Lifeworlds which had previously shrunk expanded and new possibilities emerged to the degree that Terry (28:51:2015) described life following colostomy as a resurrection experience of *'Being Alive Again'*, the code which has become a major and important theme in this theory. He used this to describe the feeling he experiences now that he can give talks in school without the threat of attacks of autonomic dysreflexia:

Terry (28:51:2015): "But I have done some [talks in schools] subsequently and they have all been wonderful, it's like being alive again. It was a massively important part to me." TL181

The importance of Terry's (28:51:2015) work in schools to him is evident. Ullah et al's (2018) research on returning to work following SCI suggests it to be a means of reinventing oneself, providing mental stimulation, purpose, self-satisfaction, and personal growth. This is

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confirmed in Hammell's (2007) rigorous meta-synthesis of seven qualitative studies looking at SCI and Quality of Life (QOL) which found a theme of *'activity as giving meaning to life'*, richly illustrated with participant quotes. Consideration of this adds to understanding of why individuals displayed a *'determination through suffering'* to continue activities prior to the colostomy. They do so because desired activities give meaning and purpose to lives.

This was an area not previously considered in data analysis, and sampling and comparing literature enriches findings here. It demonstrates the importance of utilising body management methods which facilitate maximum time and ease for desired activities, so that meaningful lives are lived, and greatest potential reached. Present bowel management guidelines are once again criticised as giving only lip service to this. Without making consideration of wider lifeworlds and aspirations of central importance, guidelines serve to restrict and diminish the potential of those who remain unaware of alternatives methods available. The next chapter will consider criticism that historically disabled people have been infantilised and not afforded full status in society. The possibility is raised that bowel management guidelines are an example of this, as they do not expect or accommodate the need for and ability that those with disabled bodies may have to engage in work and other meaningful activity.

8.7 Care becomes easier

Traditional bowel management methods following SCI were described in the Wider Landscape chapter as either straining if this is possible, or manual methods of removing stool which involve inserting a gloved finger into the rectum and either stimulating the bowel wall to promote evacuation and/or physically removing stool (MASCIP 2021a). This is not a skill which has historically been taught in general nurse training, but a specialized skill requiring additional training. Variation in the quality of care that participants received will be discussed in later chapters, with the finding that some care providers lack knowledge and expertise in performing bowel care.

Following the colostomy, variation in knowledge and expertise of care providers ceased to be a problem. Bowel management now consists of a simple easily taught procedure to change a colostomy pouch which does not require specialised skills. Those with higher injuries can easily observe this because bowel care takes place on the abdomen as Andy

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(66:66:2014) described earlier. It is simpler to instruct and direct a carer or PA in how to do this, as Terry (28:51:2015) describes:

Terry (28:51:2015): "I think also a really valid point that I think, it is infinitely easier to show someone say from an agency how to change a simple bag than it is to how to avoid haemorrhoids and be careful and what happens if you get a big bleed." TL265. "About anybody can do it – it's not rocket science or anything, whereas actually doing an internal invasive inspection is." TTL102

Dan (52:52:2015) and his PA both felt colostomy to be a much easier way of managing bowel function:

Dan (52:52:2015): "So this is a simpler system." DE36

Dan's (52:52:2015) PA: "Stoma bag [is better] because it is very easy how to keep the clients. Everything goes very quickly and I would say that everything is much cleaner." DE376

Those with lower injuries who were independent with bowel management also found the colostomy to be much easier than their previous methods, with Steve (26:41:2010) describing:

Steve (26:41:2010): "It [a colostomy] will make your life a lot easier. When you consider what does happen to your body sometimes, to be able to clean yourself from the front, to have access to your stomach which everybody can do whether you're tetra or paraplegic, you can clean yourself up. Whereas you can't really do that when it's underneath you." SL208

Colostomy is experienced as a simpler, easier system for managing bowel function which increases independence. Some with lower injuries who were previously dependent on healthcare professionals became independent, and others with higher injury no longer needed a trained specialist to perform bowel care. Although considered more invasive, it is assumed due to an operation being involved initially, the lifelong outcome is then a body management system which is easy, is not dependent on specialist care, and which it is more likely the individual can perform themselves.

Clear and consistent evidence confirming that colostomy is perceived by those with SCI as an easier method of managing bowel function than traditional methods was discussed in the Wider Landscape (Rosito et al. 2002; Coggrave et al. 2012). The question emerges of why professionals continue to be reluctant to suggest it, and why guidelines have not been challenged until this patient-led phenomenon of early colostomy.

8.8 Further consideration of regaining control

Having explored dimensions of 'Being alive again', the notion of regaining control is returned to, as this appeared to be an important theme with interesting insider experiences of control at times belying observable outward circumstances. The literature was sampled to further understand the dimensions of control discussed earlier in the chapter. This led to Skinner's extensively cited (1996) taxonomy of control which provided a helpful overview of what is a large area of theory. Control is summarised by her as the extent to which a person can intentionally produce desired outcomes, with 'experiences of control' being a person's feelings as they try to achieve a goal. The taxonomy was explored with summaries of listed theories weighed for fit with experiences of these participants, and constructs which felt most fitting used in constant comparison with interview data. As it became relevant, reflection on the researcher's insider information about the institution was also used to inform understanding of the nature of control being regained.

From sampling the literature came theory that *'experiences of control'* differ from *actual* objective control or *believed* subjective control, and as stated refers to a person's feelings as they try to produce a desired outcome. Skinner describes this as:

"...the one aspect of control that is unequivocally beneficial... No matter how bleak the objective conditions, the experience that one can improve them produces positive psychological consequences." (Skinner 1996, p.551)

For many of the later colostomates, they had very little *actual* choice in having the colostomy, and yet the described positive psychological consequence of an *experience of control* can be seen and has explanatory power:

Terry (28:51:2015): "When they [other people with SCI and a colostomy] told me the difference it had made to them, I knew I could make the same decision. I don't think I was really in a position of choice either because things were really, really difficult."

The early colostomates in contrast appeared to have a much greater degree of *actual* choice in methods of bowel management. The degree of *'actual control'* participants had over their choice of bowel management was reflected on, as there was a not yet developed sense of there being forces which may be impinging on this perceived control. Further sampling of theories of control started to advance understanding of this:

'The measure of actual control that subjects are given is directly tied to the amount of change the environment allows the subject to effect." (Chanowitz and Langer 1980, p.114)

"People may make choices but have little control to act on these choices. Control is dependent upon opportunities provided by the environment." (Hammell 2007, p.135)

These theory statements informed the stirring sense of wider contextual factors being at play and challenged the initial analysis of interview data which suggested the early colostomates experienced absolute choice in their method of bowel management. Taking notions of actual control back to the interview data as a sensitising concept, degrees of contradiction in the statements of participants were exposed relating to the actual control they had in exerting the choice to have a colostomy, which had not initially been noticed. Participants who spoke of making the decision to have a colostomy were observed to then counter this with statements which revealed awareness that power to proceed with this choice rested elsewhere:

Sophie (48:48:2013): "Wasn't that the thing? It wasn't actually guaranteed was it or something?" SE252

Added to this Dan's (52:52:2015) previously stated suspicion that the hospital did not want to do the colostomy operation for financial reasons, an awareness in participants could now be discerned of the existence of factors which may limit the degree of actual control they had, and their knowledge that having the colostomy operation was not guaranteed.

It became pertinent to reflect on researcher insider knowledge of organisational barriers affecting choices, and this was treated as further data. The newly injured inpatients have been observed to create a change in this spinal unit through the instigation of a new demand for early colostomy, which the hospital organisation initially stretched to accommodate. With the passage of time however, researcher insider observation has perceived the presence of constraining factors recoiling back and placing limits on the new demand. These include the organisation's capacity to facilitate increasing demand for this operation, the variability of professionals' ability to facilitate patient choices, the lack of clear pathways leading to inconsistencies in the management of individuals, and most recently the institution's response to the Covid-19 pandemic which led to a temporary halt to 'spinal colostomy' operations. Those receiving SCI management in this organisation are fortunate in being able to make the choice to have a colostomy at all. With referrals often received from outside the catchment area of the spinal unit and hospital trust, insider knowledge is that it is not made available in all geographical areas and is a choice which has been denied to some individuals by their more local healthcare providers.

Comparing this new insider knowledge data to interview data and extant theories of control, a sampled theory described as *'illusory control'* sounded as if it might help define experiences of regaining control in these participants in this environment (Langer 1975; Skinner 1996). On closer examination, however, the construct is described as control due to chance or luck, for example through feeling lucky at playing a game of cards (Langer 1975). Lefcourt (1973) describes the benefit of illusory control as:

"The sense of control, the illusion that one can exercise personal choice, has a definite and a positive role in sustaining life." (Lefcourt 1973, p.242)

Participant experiences of exerting control which are sensed by them to have unseen constraints, and the known constraints from insider knowledge, were considered in the context of these definitions of illusory control. The benefit to participants from perceived control and being presented with choice was definite and positive as Lefcourt (1973) states. The constraining environmental factors suspected by participants and known in part by the insider researcher are however more tangible than can be meaningfully likened to the random luck and chance of a game of cards. Although the label sounded resonant for this research, sampling it for fit with primary data and insider knowledge revealed illusory control does not account for what is being observed. With no single theory of control completely accounting for the nature of control which these participants experienced, a novel explanation was developed.

8.9 Superficial control

The literature has illuminated the positive benefits to participants of *'experiences of control'* even when situations are bleak and choices limited. Consideration of *'actual control'* and insider knowledge has revealed the presence of tangible environmental constraining factors. These constraining factors will be considered further in Chapter Eleven, but from interview data and researcher insider knowledge are known to include:

- Variability of available information about bowel management alternatives
- Inconsistency in the pathway of referral to consultation
- Limiting factors such as waiting lists and operational procedures

Reflection on primary data analysis, use of sensitizing concepts from the literature, and insider knowledge led to the emergence of the notion of *'superficial control'*, proposed as a potential fit for the nature of control being observed when participants make the decision to have a colostomy. Searching for academic references to *'superficial control'* yielded no results, suggesting that this is not a construct in use. In the absence of an academic definition, a dictionary definition was sought to provide a starting point for developing a more robust definition of superficial control. *'Superficial'* is described in the dictionary as:

- of or relating to the surface
- external or outward
- a superficial resemblance
- shallow
- not profound or thorough
- apparent rather than real

(Dictionary.com 2020)

Although a dictionary definition is a somewhat blunt tool to use to understand concepts, in the absence of an academic definition these descriptions provide a starting point for defining the nature of control individuals have in making and realising the choice to have a colostomy and fit well with what is being observed. A construct of control as surface, external, superficial, outward, shallow, and apparent, aids understanding of the nature of regaining control which these participants experienced by defining its limits. Participants have the positive benefit of the *'experience of control'* through exerting choice in what can be a limited and bleak situation, but their *'actual control'* is constrained by deeper, internal, and hidden factors within the wider context and organisation. From this, it became increasingly pertinent to explore these factors and this led to the development of the final three findings and theoretical discussion chapters which describe the *'Failure of Care'* in relation to these.

The novel theory of superficial control was taken back to interview data to explore its resonance with participant experiences. Supporting evidence was found where Sophie (48:48:2013) and her husband recognised the existence of unknown factors which may limit their choice:

Sophie (48:48:2013): "It wasn't an option that was… I think it was all down to [a particular doctor] that I got it, when I got it. Like you say without going home first…" SE255. "I thank [them] very much for the opportunity to get it when I did." SE273

In Andy's (66:66:2014) statement: *"They were very good and did it,"* AE33, awareness is implied of limitations to his power to proceed with the choice he had made.

Interview data appears confirmatory of superficial control as a potential explanation for the nature of control these individuals had in deciding to have a colostomy. There is an awareness that having made a choice there was no guarantee that this would be accommodated, and a power differential can be perceived between themselves and the professionals as gatekeepers. Superficial control can be defined as control which has the positive benefit of an *'experience of control'* through involvement in decision-making, but which is constrained or limited by sensed but hidden barriers.

A diagram (see Figure 25) was created to illustrate the construct showing five doorways as five hypothetical bowel management options. The third option is unseen as it is obstructed by information about it not being made available. Options one and five appear available but are obstructed by suggested potential barriers:



Front view - Apparent Choices

Bird's eye view - Actual Choices



Figure 25: Superficial control illustration

As the literature search for the term 'superficial control' did not yield any hits, it is presumed to be a novel description of control, encompassing elements and extending aspects of existing theory including the differences between actual and perceived control, and the importance of experiences of control. Further research is suggested to fully define superficial control and explore and test its usefulness as a construct.

8.10 The negative case and puzzling findings

Returning to the overwhelming evidence of the positive and transformative benefit of colostomy, it became important for quality and rigour to examine more closely interview data for contrary or negative findings, not found during initial analysis. Charmaz (2014) describes negative cases as including data which contrasts sharply with major patterns or which are puzzling, and states them as potentially beneficial in the refining of emerging theory. A further reason for intentionally searching for negative cases was to reduce the risk of researcher bias, a potential danger as the researcher is a clinical nurse specialist involved and having expertise in the area being studied. From doing this, evidence of physical complications following colostomy formation emerged, greater understanding of processes and concepts was achieved, and new codes emerged. Considered first is an important new code which was discovered and which led to further theory development. This was that despite any problems they may encounter related to the colostomy, individuals are *'still glad to have had it'*.

8.10.1 Still glad to have had it

Several participants disclosed they had experienced some form of complication related to the colostomy. Emily (49:49:2016) required further operations and experienced rectal discharge, Alice (55:63:2010) had a hernia requiring surgery, Sophie's (48:48:2013) stoma became retracted, and Graham (21:71:2012) experienced bleeding and a hernia. Steve (26:41:2010) described ongoing pain and difficulty related to eating and the stoma functioning, although it was not clear whether this was due to the stoma or something else – he described how numerous investigations had not found a cause for this.
In disclosing these problems, participants countered descriptions of these by stating they were *'still glad to have had it done'*. They appear to view problems with the colostomy as relatively minor when compared to previous or anticipated difficulties without it:

Emily (49:49:2016): "I'm still glad I had it done. Nobody could foresee that the first operation [would go] horribly wrong." EE178. "It is what it is and I'm glad I still went ahead to have it done. I wouldn't have changed my mind." EE363

Graham (21:71:2012): "One hundred percent better [life following the colostomy]. I don't regret doing it and it was the right thing for me to do at that time and possibly a few years before." GL458

Sophie (48:48:2013): "No regrets, I think everyone should be given the option." SE184

Steve (26:41:2010): "But definitely I would advise anyone who is worried about bowel accidents to seriously consider a colostomy. You get used to it very very quickly. It just becomes second nature. It's just part of your life and you forget it's any different." SL219

This code was found in both data from the later colostomates who could compare it with their struggles prior to colostomy, and data from the early colostomates who had not encountered the same depth of suffering but believed they would have faced worse problems if they had continued with manual bowel care. The number of participants experiencing complications related to their colostomy is relatively high and the theoretical question emerged of why participants were still glad to have had the colostomy despite this.

Searching the literature, the code of *'still glad to have it'* was found in other research. Waddell et al's (2020) systematic review found that despite common complications of rectal discharge, prolapse, wound healing issues, and skin irritation, individuals were still glad to have a colostomy because it led to an improved QOL. Coggrave (2012) similarly found that despite problems commonly being experienced, individuals were still glad to have a stoma. Research by Craven & Etchells (1998) suggests that complications are perceived as an inconvenience more than a problem. Potential explanations for 'still being glad to have' the colostomy were considered. It is possible that participants were influenced in what they said by the interviewer being known as a stoma care nurse and they may have voiced an alternative opinion or disclosed different information to another interviewer who was not an involved professional. This cannot be known and would require further investigation in future studies. Other explanations may be that participants are stating what they believe and perceive as true, or alternatively there may be more complicated processes at work. Further investigation to increase understanding was performed by theoretically sampling the literature, and this led to additional areas of extant theory being sampled and explored.

8.10.2 Changes to self and bodily concepts after colostomy

Theory consulted to increase understanding of why participants were still glad to have the colostomy despite encountering complications included Charmaz' concept of identity and bodily hierarchies (Charmaz 1987, 1995a). The hierarchies contain desired goals or objectives, with movement described along these continuums over the course of chronic illness. From this, interest widened to an area not previously considered of how the colostomy affects individuals' concepts of body and self (likened to Charmaz' 'identity'). Charmaz defines identity as including how individuals define, locate, and differentiate themselves from others, and describes the formation of identity goals which are the preferred identities people assume, desire, hope and plan for (Charmaz 1987). These descriptions of identity were comparable to notions of 'self' used by this author to incorporate aspects of participants' lives which have emerged as important to them, such as their identity from work, leisure, and in family relationships.

Taking identity and body hierarchy theory to interview data in constant comparison, evidence discussed so far of the positive and transformative effects of the colostomy can now be viewed as an elevation in identity hierarchies. This adds depth to the major theme of *'Being Alive Again'* through understanding from Charmaz' theory that an upward change in the body, such as from a successful treatment, can lead to people re-entering worlds they had left and having new possibilities or raised identity goals. Terry's (28:51:2015) joy at being able to perform talks in schools and travel with greater ease could now be perceived as elevating his identity and sense of self. Understanding this heightens the importance of

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listening to the experiences of and considering how different body management options affect people's wider lives and self-concepts.

The evidence is less clear of the effect on bodily hierarchies of having a colostomy, and whether this raises or lowers bodily concepts. Terry (28:51:2015) did not disclose the presence of any complications related to the colostomy, and after suffering a great deal prior to it he is the only participant to provide definite evidence of an elevation on his bodily hierarchy:

Terry (28:51:2015): "One of the big changes was getting rid of the toileting regime I was on because that made me think of my body in a different way as well. It made me sort of think life was not so bad after all because for many years it caused me a lot of problems and they all were associated with that." TTL69

Graham's (21:71:2012) perspective differed and he described the colostomy as something else to 'cope with'. It is unclear from the data whether he perceived it as lowering his bodily concept, but his words suggest it as one more in a succession of trials and tribulations since his injury:

Graham (21:71:2012): "It's just something else to cope with if you like. It's different to normal bowel movements, sitting on the toilet. But I'm fairly good at coping with that sort of thing." GL356

Only Dan (52:52:2015) referred to initially finding the colostomy a bit 'weird', but added "Once you get used to that, it's OK." DE50

With these differing perspectives, and mixed and unclear evidence of the overall effect on bodily concept, it was considered whether as Charmaz suggests that participants may be rewriting their experiences to accommodate a downward change in their bodies, and this could be why they were *'still glad to have'* the colostomy: "In order to handle their lives [people may] view identity loss as identity gain. In essence then, people can move up their identity hierarchy while they move down their bodily hierarchy." (Charmaz 1995a, p.671)

It was considered possible that to accept the presence of the colostomy at all or *'still be glad to have it'* in the face of complications developing, individuals may be internally rewriting their decisions and perspective so that their identity concept can still be raised even though in fact their bodily concepts have been lowered.

The extant literature suggests that a colostomy is more likely to lead to a lowered bodily concept. Researchers have described those having one as experiencing feelings of stigma, self-disgust, having lowered life satisfaction and deliberately self-isolating (MacDonald and Anderson 1984; Smith et al. 2007; Danielsen et al. 2013). These infer a descent down both identity and bodily hierarchies and are in stark contrast to the reactions of these participants, for whom careful searching revealed no evidence of them feeling similarly stigmatised, and to have mild or ambivalent perceptions of the effect on bodily concept.

Examining extant research findings more closely, the difference emerges as related to the reason for having the colostomy. The negative perceptions described in the literature are found in those having it due to cancer or other disease processes, whereas these participants form a distinct group who have it performed for reasons related to having a spinal injury.

Additional evidence relating to this comes from the repeated observation in the professional practice of this researcher that those having a stoma due to disease processes are more likely to struggle psychologically with or find a stoma stigmatising. In comparison, those choosing it following SCI have frequently been observed to display positive feelings related to it, and even joy from the transformation to their lives it effects, now known to be related to the elevation in identity hierarchy it brings as more becomes possible.

No clear evidence was found from interview data whether participants were re-writing an identity loss of having a colostomy so they could perceive it as an identity gain. Research

evidence of colostomy as a descent along bodily hierarchies is demonstrated as related to the reason for having it, with the group who have it due to having a SCI perceiving it differently to those having it due to disease processes. The concept of stigma related to colostomies will be further explored in the next chapter.

8.10.3 Body concept and intimate relationships

A finding related to self and bodily concepts was an additional consideration observed in some in the context of relationship status. Like Terry (28:51:2015), Jim (62:62:2016) felt more positive about his body following the colostomy, due to resolution of the haemorrhoid which was causing him problems. He appears not to have minded the appearance of the colostomy but considered it may have been a factor if he was in a relationship. When asked how he felt about the changed appearance of his abdomen he replied:

Jim (62:62:2016): *"I'm not in a relationship. I live on my own. I don't intend you know having a long-term relationship where that would be an issue."* JE315. *"Look clothes cover it. Nobody sees it, do they?"* JE322

Emily (49:49:2016) was mindful of the way her partner may perceive it:

Emily (49:49:2016): "My appearance does have an effect on my partner as well and that's something that I needed him to understand and has done...he didn't fall in love with the bags and drains he'd fallen in love with a person and other than these little bits extra that I've got, I'm no different." EE82. "The appearance... some people can be put off of it...I've seen them how they're supposed to look and it never bothered me but it might bother my partner." EE224

Most participants appear not to be intrinsically concerned about the appearance of the stoma, but in the context of intimate relationships the opinion of another person becomes important to be considered. This new dimension of self and bodily concept is observed with interest but not explored further here, as it was not considered a central part of the developing theory. It represents an area for future research.

Discussion so far of findings from the use of identity and bodily hierarchies as sensitizing concepts has led to a mixed picture emerging, and the theoretical question of why participants are still glad to have the colostomy despite complications is not yet fully answered. Whilst an elevation in identity is evident, it is not known whether this is achieved through participants re-writing losses so they can become gains, and the effect on bodily hierarchy is ambiguous and differs to the effect it has on those having a colostomy for another reason.

8.10.4 Means to an end

A code is now considered which emerged during early analysis of interview data alone, of colostomy being used as a *'means to an end'*. This code progresses understanding of how participants can still be glad to have the colostomy despite experiencing complications related to it, and the code was better understood through consideration of further theory from Charmaz (1995a) of *'identity trade-offs'*. In her interview Emily (49:49:2016) stated:

Emily (49:49:2016): "I was happy to have it because it was less intrusive and like I said, I had control over it." EE97. "That was a big thing, having a sense of control again and making sure that it didn't affect my partner and myself." EE204

She was happy to trade-off the change to the appearance and function of her body which having a colostomy entailed, in exchange for achieving the identity goal of regaining control. For other participants the colostomy was a means to ends of achieving independence, selfsufficiency, and freedom from reliance on healthcare professionals:

Jim (62:62:2016): *"I said what was happening and I was going [being incontinent] all over the place. When I get home that is going to be a very, very limiting factor and it might even mean I would have to have more care and it might actually preclude me from living on my own in a flat and my biggest target was to be self-sufficient."* JE106

Colostomy was perceived by participants as a relatively minor intervention to gain control and independence and solve body management issues, a perspective in direct opposition from that found in professional guidelines:

Sophie's (48:48:2013) husband: "I think in all fairness she wanted to come home so clearly that was a determining factor in all the things and I think you just saw that as another one that solved that particular issue wasn't it?" SE235. "I suppose my perception would be it was a relatively minor thing in the overall scheme of it." SE74

Emily (49:49:2016): "The operation, at the time of the operation, it is not a small op and yes it does interfere a little bit on a normal ... but there is a means to an end." EE347

Jim (62:62:2016): "I think I don't need to be doing that; I've got things to be doing with my grandchildren and my kids. So messing around with toileting, and it is a priority because it's got to be done, but I thought how can I minimise the time for treating myself for things?" JE71. "But you have to actually sit down and analyse it to get the big picture, and for me that was the paramount element in the decision making." JE84

Sampling the literature, examples were found in other areas of health care of interventions being used as a *'means to an end'*. In Nelissen et al's (2019) study, it is described how the ventilator becomes part of someone, and how:

"Overall they are glad to have invasive HMV [ventilation], since they can breathe again and get on with their lives." (Nelissen et al. 2019, p.1105)

Findings from literature support primary data analysis which suggests those with SCI are increasingly making the decision to have a colostomy as a *'means to an end'* of achieving more important goals. This reveals a mismatch of perceptions between professionals and those requiring bodily interventions. Individuals are not apprehending bowel management as healthcare professionals do in terms of maintaining body norms as far as possible and concern with what is 'least invasive' (concepts picked up on in the next chapter). Rather, they are considering bowel management in terms of how it can help them achieve their higher goal of independence, and how bowel management can fit in with their wider lifeworlds.

8.10.5 Towards answering why participants are 'still glad to have had it'

Musings in this section and sensitizing concepts from extant literature, have helped to explain why participants might still be glad to have the colostomy despite experiencing problems with it. Consideration of identity hierarchies and how participants use colostomy as a *'means to an end'* of achieving more important lifegoals led to reflection on Maslow's (1958) hierarchy of needs, a representation of which is given in Figure 26.



Figure 26: Diagram of Maslow's hierarchy of needs (Androidmarsexpress 2020)

Maslow's (1958) theory perceives human needs as arrayed hierarchically, with higher level needs only progressed to once lower level needs are satisfied at least in part. Physiological needs are found to be most important, as without these *"all other needs become simply non-existent or are pushed into the background."* (Maslow 1958, p.29). This makes sense, but analysis here has demonstrated that needs are not viewed by participants in isolation. Rather, the method used to meet lower-level need is decided in the context and with the aim of meeting needs at higher levels. Professional guidelines are flawed which concentrate

primarily on fulfilling physiological need for satisfactory bowel function, without doing so in relation to the impact a particular method will have on higher level needs and lifegoals.

This criticism of the focus on working solely towards achievement of physiological goals was made by Triecshmann (1978), who states SCI rehabilitation success to only be measured in terms of physical skills. It appears that decades after this was written, guidelines continue to remain perceived through a lens centred predominantly on physiological management of bodily needs. It is suggested that body management guidelines would be better which consider differing levels of need in relation to one another, rather than viewing them in isolation.

Theory here is developed by understanding the early colostomates to be making decisions through this alternative lens, in the context of their higher-level lifegoals and needs of belonging, esteem, and self-actualisation in Maslow's (1958) model. They appraise their lifeworlds and array their lifegoals in a hierarchy of relative importance. Higher-level lifegoals found in the higher levels of Maslow's (1958) pyramid are perceived as of greater relative importance, and they employ methods to satisfy lower-level needs and lower-level lifegoals which will best accommodate these higher lifegoals.

This discovery through interaction with extant theory is of key importance in understanding why individuals with SCI are rejecting traditional bowel management guidelines and the stepped progressive pyramid of interventions. These make passing reference to lifestyle and personal goals, psychological and emotional factors, home circumstances, and evaluating whether interventions maximise independence. In practice they are primarily concerned with achieving satisfactory physiological function of a body system, and this goal is apprehended in isolation from other lifegoals an individual may have (NICE 2007; MASCIP 2021a). To those with SCI, achieving satisfactory physiological function is one goal which can be arrayed along a continuum or hierarchy of possible lifegoals. Traditional bowel management guidelines are rejected if it is possible to achieve a lifegoal of greater importance through use of alternative bowel management methods. The preoccupation of professionals with management of physiological needs is a theme explored more fully in the Ideological Failure of Care considered in the next chapter.

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Further insight is given through Maslow's (1958) theory into the predicament of the later colostomates, who in their *'Progression into Suffering'* found themselves as he describes as: *"The organism is dominated and its behaviour organized only by unsatisfied needs."* (Maslow 1958, p.31). Starck's (1980) article taken from a larger study of 25 individuals with SCI, weakened by a lack of methodological detail in this report, affirms this:

"The struggle to meet basic physiological needs consumes such a large proportion of effort and energy that higher level need satisfaction cannot be sought. Indeed, health professionals may unwittingly limit goals to physical well-being." (Starck 1980, p.17)

This illustrates well the life-limiting findings of 'Loss' and 'Suffering' which the later colostomates were experiencing prior to the colostomy and were unable to progress beyond. They are unable to progress beyond the need to meet basic physiological need, and professionals have unwittingly limited them to achieving this lower level goal. This explains why having a colostomy leads to the resurrection experience of 'Being Alive Again' as higher-level needs become open to achieving.

Gathering of further information from extant theory and relating this to findings in constant comparison has increased understanding and progressed analysis towards answering the question of how participants can still be glad to have the colostomy in the face of experiencing complications related to it. Participant lifegoals are hierarchical, viewed relationally and not in isolation, and colostomy is employed as a *'means to an end'* to achieve higher priority goals. In doing this, any subsequent problems are of less relative consequence to them.

8.11 Confluence, divergence, and extension of theory in relation to extant literature

Findings of 'Being Alive Again' have been developed using secondary data from the literature. Considering extant literature related to theories of control, this research fits with theory which finds the experience of control as of universal benefit, even when actual control is compromised. Insider professional observation and suspicions by participants that the degree to which they truly had control in exerting choice led to an extension to control theory through a suggested construct of 'superficial control'. In this, control is apprehended as surface, outward and shallow, with yet unknown external factors limiting the amount of actual control participants had.

Confirmatory evidence is found of findings from literature discussed in the Wider Landscape chapter, that care becomes easier following colostomy. The later colostomates wished they had it performed earlier, and theory is extended in this study by questioning why this established finding has not been taken forward until those with SCI took matters into their own hands with the advent of early colostomy. This research is an extension of known theory as it starts to explore how bowel management methods and their complications are understood by those experiencing them, an area not adequately explored previously.

A difference is observed between literature that describes individuals feeling renewed and living more fully by adapting to changed health status, and this research which demonstrates achieving this through an actual improvement in health status. Theory from literature about this adaptive mechanism increased understanding of earlier codes of 'getting used to it' and 'determination through suffering' discussed in previous chapters.

Theory related to bodily and identity hierarchies, identity trade-offs and identity goals was useful in developing understanding of *'still being glad to have'* the colostomy despite complications. Contemplation of Maslow's (1958) hierarchy of needs theory found a fit for the experience of later colostomates of being tethered into meeting lower-level physiological needs, and extended understanding that the early colostomates are perceiving body management from a concern to meet higher level needs. Consideration of this revealed both Maslow's hierarchy and bowel management guidelines to be weakened in their usefulness when needs at one level are considered in isolation and not as an integrated whole.

8.12 Relating findings to research aims and question

Findings discussed in this chapter have demonstrated that the choices made by the early colostomates are made in relation to their wider lifeworlds and lifegoals, and are made to

achieve those of greater importance e.g., work and family priorities, and other higher-level needs. Priorities are decided and identity trade-offs may be made as colostomy is used as a *'means to an end'* of fulfilling desired lifegoals, including regaining control and dignity. Choices related to physiological function are made by individuals in the context of wider lives, and this leads to incompatibilities with the way in which guidelines have been structured by professionals, concerned almost exclusively with meeting isolated physiological needs.

The context of decision-making differs between early and later colostomates, with the later ones having little choice but to have a colostomy from a position of suffering and bodily decline. Despite arriving at the colostomy from two differing points, both early and later colostomates experience 'Being Alive Again'. The later colostomates are liberated from the consuming need to meet lower-level physiological needs, and together with the early colostomates in their active choice can progress to meeting higher level need.

It is an experience common to all that having a colostomy means bowel care fits in with participants' lifestyles, instead of dominating them. Colostomy enables new possibilities and raised identity goals, and despite any complications which may arise, participants are still glad to have had it.

8.13 Chapter conclusion

Findings in this chapter of 'Being Alive Again' have been discussed in relation to 'regaining control and dignity', 'relieving suffering', 'living with confidence', and 'having a day'. These have reversed the 'Experiences of Loss' and 'Progression into Suffering' experiences discussed in the previous chapters. Independence is gained from a reduced reliance on healthcare professionals and caring for the body becomes easier.

Consideration of findings in relation to control theory has helped to understand the dimensions of how regaining control is experienced and led to a provisional new construct of *'superficial control'* being proposed. Intentional searching for contrary data and negative cases led to fruitful development of theory concerning why participants are *'still glad to have'* the colostomy despite experiencing complications, and how colostomy is used as a *'means*

to an end' of achievement of higher-level lifegoals. Understanding has increased that individual needs and goals are not perceived in isolation but relationally.

In a continuation of the golden thread of findings in previous chapters, the relief of suffering and experiences of 'Being Alive Again' illustrate the restrictiveness of individuals' previous bowel management regimes and the diminishing effect they can have on people's lives. Guidelines are exposed further as failing to account for the lifeworlds and lifegoals which are at the heart of decision making for these participants. Stepping outside these means lifestyle activities and lifegoals can be pursued, and lives are no longer constrained and dominated by meeting physiological need. The choice for colostomy is made with reference to preferred identity goals of, amongst others, regaining control, and this is what professionals have failed to understand and that current guidelines are unable to accommodate.

These first three Findings and Theoretical Discussion chapters have considered findings from primary data analysis, developed through interaction with extant literature and theory. Analysis and discussion, data from interviews, data from the literature, and researcher insider knowledge have developed a sense that there is more to be known and understood about the wider and contextual factors which are influencing findings. The Wider Landscape introduced the starting point and justification for performing the research, and the Findings and Theoretical Discussion have constructed a theoretical framework grounded in primary data. The researcher gaze now widens to peruse the New Wider Landscape which the research journey has led to, to seek answers to theoretical questions which have emerged. Hints to what this new landscape contains have been suggested from analysis to include (but are not suggested as limited to) the Ideological, Professional, and Institutional context of findings. These emerged as of potential importance in contributing to the fourth major theme of '*Failure of Care'* and are now discussed in relation to this.

9.1 Chapter introduction

The starting point of this research was observation of the new phenomenon of early colostomy, understood in relation to management of a physiological body function as described in the Wider Landscape. Research aims and a question which seek to understand the experiences of those involved have led to the use of constructivist Grounded Theory. Interview data, extant literature and documentary data, and researcher insider knowledge have led to presentation so far of three Findings and Theoretical Discussion chapters. These have discussed '*Experiences of Loss*' and '*Progression into Suffering*' due to bowel function and its management, and how colostomy formation led to the transformative experience of '*Being Alive Again*'. A golden thread has emerged running through findings which can be summarised as the failure of present models of bowel management following SCI to achieve their aims of continence and regularity, and their failure to account for the wider lifeworlds of participants.

With the research journey nearing completion, the destination is found to be located within a New Wider Landscape, not anticipated at the journey's start. Emergent questions, incompletely understood data, and researcher insider knowledge have given clues that the new landscape contains features influenced by (and not limited to) the ideological, professional, and institutional context of the phenomenon of early colostomy. These are now sampled and explored in three further Findings and Theoretical Discussion chapters. These contexts emerged from reflection on previously incompletely understood codes and are perceived as comprising the fourth major theme, *'Failure of Care'*.

Codes within this theme have been found in Findings and Theoretical Discussion so far as including variability of information, the changing balance of power between patients and professionals, the variability of care provision, and the wider organisational factors which are impacting on the experiences of participants. Exploration of literature, constant comparison, and further analysis have led to discernment that ideology, professionals, and institutions are contributing to the finding that traditional models of bowel management are failing those they are designed to help. The presence of other contributing factors is likely and

acknowledged, but discussion will centre on these three key areas which have emerged. The complete theoretical framework model is presented in Figure 27.



Figure 27: The final theoretical framework

Labelling this major theme as 'Failure of Care' was reflected on throughout its development and at the conclusion of thesis writing. 'Failure of care' emerged from analysis of primary interview data. Examples of where this occurred included:

- Monty's care agency providing carers with inadequate knowledge and skills, and at times which suited organisational rather than Monty's needs
- Researcher insider knowledge of constraining factors which mean consultations and colostomy operations are not performed in the time frame individuals desire them to occur
- Instances participants described of bowel interventions leading to pain and the development of health complications

'Failure' was felt an appropriate code to describe these and other data segments, but due to the negative connotations of this word it was reflected on and consideration given as to whether an alternative label for the theme should be used. Descriptions including 'deficient', 'inadequate', and 'sub-optimal' were considered, and compared with primary interview data and codes. None of these alternatives were felt to convey as well or as fully the experiences of participants and the findings within the theoretical framework. The decision was therefore made to keep the label 'failure of care' as it is grounded in the data and provides the fullest description to account for it.

This chapter will consider the first aspect of *'Failure of Care'*, which is the underlying ideology within which health care is provided. How this has shaped the development of bowel management guidelines and affected the lives of these participants will be explored. Exposing the ideological paradigm within which experiences have occurred will inform understanding of experiences and the motives of both participants and involved professionals, and the institutional systems within which experiences occur. This increased understanding will develop and refine the theory by grounding it within the wider contextual setting in which it is found to be set.

These objectives will be achieved by discussing further findings from secondary data gathered from the literature, exploring theory in this area, and constant comparison of this new information with interview data and findings from the initial theoretical framework. Not intended as a deep discussion of ideology, this chapter will introduce how dominant ideological beliefs have contributed to findings of the *'preoccupation with norms'*, led to beliefs of *'pain as inevitable'*, misconceptions by professionals of what constitutes 'invasive' care, and how the ideology has led to stigma and prejudice which in turn has restricted the bowel management options available and how they are presented to those with SCI.

Comparison is made between findings of this research and extant literature. A final section will discuss how consideration of the underlying ideology within which health care is provided and bowel management guidelines have been developed, helps to answer the research question and aims.

9.2 Preoccupation with norms

The literature was approached to answer the theoretical enquiry about the nature of the ideological context of healthcare in the UK. Searches suggested it to be dominated by the biomedical model of health. This originates from Descartes' machine model of the body, compartmental concepts of body systems, and perceptions of health as the perfect working order of the human machine (Rossdale 1965; Kelman 1975; Larson 1999; Walker et al. 2004). Diseases are fully accounted for by deviations from normal measurable biological variables, and health is understood as the absence of disease (Engel 1977; Farre and Rapley 2017). The biomedical perspective of health is criticised as reductionist in this narrow perspective of health. In its focus on the individual, the biomedical paradigm fails to account for the influence of the wider dimensions of health including psychological, social, cultural, and environmental (Dixon-Woods 2001; Shapiro et al. 2001; Mirowsky and Ross 2002; Willis and Elmer 2007). Attempts have been made over recent decades attempts to broaden this definition, and with the participant timeline stretching back to the 1960s, it is relevant to consider ideological context across this period.

Other criticisms arising from the biomedical model of health are found in the work of Foucault (1973), who described the *'medical gaze'* with which doctors select only the biomedical aspects of patients problems to address as that is what suits them. The medical gaze is described as having led to concepts of norms and average, and the perception of illness and disability as deviations from a norm determined by authorised and authoritative professionals and controlled by regulatory structures (Rose 1998; Hughes 2000). The disabled are labelled *'deviant'* and in need of management by professionals to normalise function of their deficient parts (Siegler and Osmond 1973). Participants of this research have been described in Findings so far as having their bowel function managed by authoritative professionals using guidelines produced by professional and regulatory bodies.

Comparing these theories with participant experiences, a fit is seen as participants describe inpatient education sessions centred on physiological presentations about separate body systems:

Dan (52:52:2015): "They do go through all parts of the body." DE118

Jim (62:62:2016): "The bowel treatment, well not treatment, but the daily bowel regime is discussed in-depth and there is a module that we had that was all about bowel." JE207

Confirmation of the biomedical ideology of health is found in the bowel management guidelines detailed in the Wider Landscape chapter. These focus on one bodily system which injury has made deviant and which requires manipulation to re-establish the desired norm for stool evacuation. The criticism of the biomedical model as reductionist are seen in this isolated management of bowel function, with limited reference and practical application to the needs of wider personhood. These wider dimensions were in fact crucial in the decision-making of participants as seen in Jim's (62:62:2016) words: *"But you have to actually sit down and analyse it to get the big picture."* JE84. A mismatch is observed as participants approach bowel management from a wider lifeworld perspective, Jim's (62:62:2016) *'big picture'*, whereas professionals approach it from a physiological biomedical one.

These ideological notions were taken back to interview data as sensitizing concepts and were useful in understanding why professionals endeavoured to maintain the continuity of the body and make it conform to functioning in as 'normal' a manner as possible. Graham (21:71:2012) in the 1960s experienced this in an extreme way, as force was used to try and make his bladder empty without the use of a catheter (a tube inserted into the bladder to allow urine to drain out):

Graham (21:71:2012): "The orderly would bounce, literally a sandbag which weighed probably ten kilos onto my bladder and they would bang it up and down, bang it up and down before giving me a catheter, to see if they could get my urethra to open up. And they used to do that three times a day. And when it wouldn't work eventually they would give me a catheter so they would try that for ten minutes or so." GL171

Having to insert a catheter was perceived as violating the norm of how urine should exit the body. The almost barbaric sounding practice Graham (21:71:2012) describes was considered more desirable in maintaining a norm than what would today be considered the simple and relatively painless process of catheter insertion.

Terry's (28:51:2015) insightful words describing his experiences in the 1990s provide further evidence of the concern of professionals to maintain bodily norms rather than resort to alternatives which 'interfered' with normal function:

Terry (28:51:2015): "You're kind of reconditioned initially, when you're in the spinal unit, to try and keep your body as whole as possible, by that I mean not to have tubes, pipes, a lack of interference." TL147

These participants' words demonstrate the practical outworking of the biomedical health ideology which seeks to maintain bodily norms. Understanding this ideology makes sense of and increases understanding of why these experiences occur. The *'tubes, pipes and interference'* are likely medical technologies which can be used to make necessary bodily function easier, but from Terry (28:51:2015) and Graham's (21:71:2012) words were considered by professionals at the time to interfere with norms.

Understanding the historical concern with norms and correction of isolated deviant body systems offers insight into how existing bowel management guidelines have been created. The guidelines, and the professionals propagating them, reflect the dominant historical ideology from which they have been birthed. This helps explain earlier finding of experiences of care provision not accounting for the wider lifeworlds of those receiving it. The biomedical paradigm of health in which professionals operate and care is provided differs from the lifeworld perspective of participants. In the emerging phenomenon of early colostomy, the early colostomates can be understood to be rejecting these reductionist guidelines because they are approaching bowel management from a different perspective. Realisation of this enables professionals to understand the choices those with SCI are making and illuminates the phenomenon as related to clashing paradigmatic perspectives of body management.

9.3 Pain and suffering as inevitable

The 'reconditioning' described by Terry (28:51:2015) during inpatient rehabilitation, together with subsequent ongoing struggles to manage their bodies led to development of the belief in some of '*pain and suffering as inevitable'*. This code was found in the interviews of those injured longest ago, notably Graham (21:71:2012) who sustained a spinal injury in 1962, and

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Terry (28:51:2015) who sustained his injury in 1992. The code and reasons for it were not fully understood from primary data analysis. Exploring the ideological context at a later stage provided illumination. In Graham's (21:71:2012) case in the 1960s the harsh hospital culture reflected the dominant ideology, as professionals tried to force the body to function without interventions such as painkillers or catheters which are used as standard today:

Graham (21:71:2012): "It was a very rough and ready type of nursing care, there was no sympathy given. It was 'Right you're a paraplegic, you get on with it. If you're in pain, you shut up.' We weren't allowed any painkillers, not an aspirin or paracetamol. So the pains that you'd get, I mean I'd broke my back in three places, and having to be turned over every two hours is just like breaking your back again. Three people would lift you up while they remade the bed, turn you over and put you back on to what was a very hard roll where my break was. It would be underneath my back so I would be leaning backwards and my shoulders and my hips would hardly be on the bed, until I relaxed and relaxed. The pain was such that it would have to be morphine or something of that type and it goes on for many weeks." GL101

Reflecting on his experiences, Graham (21:71:2012) is observed to have assimilated this perspective of pain as something to be endured, or possibly used it as a mechanism to accept his experiences at this time: "*I mean it sounds brutal but in actual fact it was probably the right thing to do.*" GL136. Terry (28:51:2015) had also assimilated this belief from his inpatient period and states in relation to bowel management procedures:

Terry (28:51:2015): "I actually thought that pain and discomfort was par for the course, I thought that's what it was and you just deal with it." TL172. "I must admit that then, pre-colostomy, I didn't think there was any way out, I thought this is the way it's going to be." TTL178

Exploring ideology theory within the literature increased understanding of this data, and relatable experiences were found in other areas of healthcare. The perspective and era in which painkillers, catheters, and other medical technologies were avoided has been described by DeJong (1979) as a 'rehabilitation ideology'. This stresses independence and minimal resort to mechanical support, and perceives recovery and re-entry into the community as contingent on willpower and effort. This theory makes sense of Graham

(21:71:2012) and Terry's (28:51:2015) experiences in which medical technologies were avoided and lengthy, painful, and tiring regimes preferred and enforced by professionals.

It was also a dominant feature of the institutional context of Locker & Kaufhert's (1988) study of individuals undergoing rehabilitation following polio. They performed in-depth interviews studying the impact of different forms of respiratory support on ten individuals who had polio in the 1950s and developed post-polio respiratory disability. They observed a similar prevailing ideology which stressed independence and not using aids such as wheelchairs and rocking beds which would have made mobility and breathing easier. One of their participants describes:

"We were encouraged to keep pushing ourselves to the limits. You just kept going; whatever you were doing, you just kept on doing it until you were so tired you couldn't go any further. And we sort of had this drilled into our heads." (Locker and Kaufert 1988, p.28)

Further supporting evidence of this ideology is found in Gullick & Stainton's (2008) rigorous study of 15 individuals undergoing palliative surgery for Chronic Obstructive Pulmonary Disease (COPD) and 14 family members, which is rich with interview data. They describe how:

"These people with COPD not only forced themselves to attempt a task, but would consciously push themselves to their absolute physical limit to complete it. This could bring on extremes of breathlessness that people with 'normal' breathing would never entertain merely for the completion of a household chore." (Gullick and Stainton 2008, p.610)

It was not considered how the changed body could best be aided or manipulated with an electric wheelchair, catheter, colostomy, or any other medical technology. Such devices could have enabled the individual to live a maximally independent and freer life, but instead physically difficult regimes were imposed to make the body work in the way that professionals considered the desired norm. Surrounded by an ideology which required maximum effort and pushing the body to the limits, it can be understood how individuals would then become indoctrinated with the belief that life is going to be difficult and the body

must be forced to conform to norms. This was a revelation from extant theory in explaining how the observed belief of *'pain and suffering as inevitable'* developed in participants injured longer ago. Graham's (21:71:2012) tone as he stated the option of colostomy to be: *"It's the easy option. It's very easy,"* GL397, reflected the belief that to choose an easier body management alternative was questionable or even morally inferior.

To further understand participant experiences and beliefs, the influential works of Ivan Illich were examined, who believed and lived out in personal experiences towards the end of his own life, that pain is a personal challenge rather than something to be avoided (Illich 2003; O'Mahoney 2016). From this perspective Graham (21:71:2012) and Terry (28:51:2015), Locker and Kaufert's, and Gullick and Stainton's participants' experiences are expected and acceptable. The belief of *'pain and suffering as inevitable'* is an appropriate response to the situations participants found themselves in.

Illich further criticises over-medicalisation, medical technologies, organisations, and professional behaviours as leading to individuals having their competence and autonomy undermined (Illich 2003). Constant comparison of this criticism with interview data gives a mixed picture of its truth here, as the avoidance of the available technology of a colostomy in fact *created* dependency on professionals in some of these participants. Bowel dysfunction following SCI means intervention of some kind is required for the necessary function of bowel emptying to occur. Rather than accepting Illich's view of medical interventions as necessarily creating dependency and removing the autonomy of the individual, it is perhaps more appropriate to differentiate between the degree of harm or loss of autonomy each one may result in.

The historical reliance on manual bowel management within a biomedical perspective preoccupied with maintaining bodily norms has led to many with SCI becoming necessarily and permanently dependent on healthcare professionals to do this for them. This has resulted in not only the loss, pain and suffering of earlier findings chapters, but also in the belief described here that this is inevitable and their lot in life. This belief is found only in this research in those injured longer ago, but it is of concern that it may be pervasive in the wider population of those alive today who sustained a SCI in this period.

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Alternative medical technologies e.g., wheelchairs, catheters and colostomies can avoid the harm of overmedicalisation perceived by Illich, and it is suggested the prevailing ideological perspective is what creates harm rather than technologies in and of themselves. These one-off operations or mechanical aids are a deviation from the norm of bodily function, but in fact mean individuals are less reliant on health services and are freed from an ongoing dependency on health professionals. This reinforces the finding from the previous chapter that rather than focusing on a compartmentalised bodily function which needs to be normalised, a perspective needs to be utilised in which the wider lifeworlds of individuals are considered. Choosing medical technologies which will best meet individual needs and aspirations within such an alternative ideology will minimise reliance on professionals and organisations, facilitate independence, and avoid the harms of over-medicalisation.

For Terry (28:51:2015), an awakening came as the easier body management option of colostomy reversed his indoctrinated beliefs of pain and suffering as inevitable:

Terry (28:51:2015): "When my PA or carers talk about where we were compared to where we are, it's one of the head nodding tutting moments, and 'Goodness me!', and that's the difference I think. Pre-colostomy, I didn't think there was any way out, I thought this is the way it's going to be." TTL175

Similar awakenings are found in Locker and Kauhert's (1988) research as their participants found medical technologies which improved their well-being. Examples could doubtless be found in research in other areas of healthcare in this period too. Consideration of the ideological context influencing participant experiences provides insight into the previously not understood code of *'pain and suffering as inevitable'*. It also raises apprehension of a potential tragedy of unknown numbers of people today with a variety of conditions existing within an ideological prison, living restricted lives, and perceiving pain and suffering as unavoidable.

9.4 Misconceptions of 'invasiveness'

Consideration of the dominant ideological perspective developed understanding of a further code from interview data related to differing notions of *'invasiveness'* of bowel management interventions between professionals and recipients. It was discussed as elusive in the Wider

Landscape chapter how and by whom notions of conservative and invasive body management options were decided. Professionals can now be understood to view manual rectal interventions as 'conservative' because they meet their paradigmatic concern with maintaining the 'norm' of stool exiting the body. Colostomy is perceived perhaps as a deviant distortion of the body, and is placed at the opposite end of the bowel management spectrum of interventions where it is described as 'invasive', risky and less easily reversible (MASCIP 2021a) (MASCIP 2012, p.31). Discussion so far in this chapter suggests these professional perceptions arise from immersion in the biomedical perspective.

When recipients of procedures are consulted, interview data reveals a divergence from this professional perception of what is invasive. For recipients, manual bowel care is invasive by its very nature. A private part of the body is invaded by a succession of different others, repeatedly throughout life and often for prolonged periods. The colostomy operation by contrast is to them a one-off event which as they were anaesthetised, they have no recollection of, and was therefore quick and painless. After the actual operation, bowel care becomes completely 'non-invasive', as stool now passively exits the new opening on the abdomen with no further intervention necessary. The only management now required is to change the collecting receptacle adhered to the outside of the body once or twice a day. Terry (28:51:2015) reflects on the erroneous professional misconception about invasiveness:

Terry (28:51:2015): "Now ironically you actually had the maximum amount of interference [with manual bowel care] but in fact having a colostomy reduces all that down tremendously." TL150

Others shared this view of manual bowel management as invasive and unpleasant:

Dan (52:52:2015): "It's invasive isn't it. It's not very pleasant for either party." DE34

Emily (49:49:2016): "I think the longer that you spend in hospital the more appreciative you become of your body and the less interfering from outside sources." EE192

Dan's (52:52:2015) Personal Assistant (PA) turned the dominant biomedical ideology aimed at normalising bowel function on its head with her view that with the colostomy:

Dan's (52:52:2015) PA: "For me it seems to be absolutely like nature by without any stimulation, everything goes nature way." DE386

Insider perspective reveals that following the colostomy, bowel emptying becomes completely non-invasive. This view is disruptive and nonsensical to those immersed in the dominant biomedical paradigm, and perhaps explains why practice has not progressed from research findings which have indicated those with SCI to be happy with a colostomy and wish it had been performed earlier. Differences in perspectives of bowel management between professionals and individuals are summarised in Figure 28.

Professional perspective	Insider perspective
Concern with norms	Concern with ease of bowel management
Focus on physiological need	Focus on needs of wider personhood and
	lifeworld
Notions of surgery as invasive, manual	Notions of surgery as non-invasive, manual
interventions as non-invasive	interventions as invasive
Arise from biomedical perspective	Arise from insider lifeworld perspective

Figure 28: Differences in ideological bowel management perspectives

Displaying these differences in perspectives in table form helps to explain the increasing choice for early colostomy and demonstrates the weakness of existing guidelines in their failure to incorporate insider experiences. Already found to be built on a weak evidence base and developed with a lack of user involvement, early colostomy may herald a final rejection of professional guidelines and the ideological basis from which they originate, and may even herald a paradigm shift (Kuhn 1996). Presently the phenomenon of early colostomy is a perplexing 'anomaly', and as Kuhn would state 'subversive' to the accepted bowel management paradigm. This notion will be returned to in the Further Discussion chapter.

9.5 Stigma and prejudice

A final area of interest arising from consideration of the dominant biomedical ideology, is how the concern with measurement, norms, and deviations can lead to stigma. Originally a bodily sign such as a cut or burn, stigma signifies an individual as having something unusual or bad about them (Goffman 1963). Goffman (1963, p.5) suggests that someone with *'an abomination of the body'* which violates norms will be discriminated against, is viewed as *'not quite human'*, and will experience reduced life chances.

In the biomedical ideology, a colostomy is perceived as violating the bodily norm for defecation, and this makes sense of why those who have a stoma may report feelings of stigma and concerns about disclosing its presence to others (Danielsen et al. 2013; Rademacher 2018; Jin et al. 2020). Following SCI individuals may already experience stigma related to their changed body and deviant function in not being able to walk unaided. To voluntarily undergo stigmatizing surgery by creating a colostomy, risks further discreditation and marginalisation.

Even amongst health professionals there are observed to exist beliefs of stomas as undesirable and stigmatizing. To probe unconscious professional perceptions of stomas, extant literature was sampled. In their rigorously conducted systematic review of QOL after SCI, Waddell et al (2020) found:

"Due to stigma, colostomy formation is performed only once conservative management has 'failed' ... Owing to the stigma associated with ostomy formation, many clinicians are reluctant to suggest the procedure early after a patient's injury." (Waddell et al. 2020, p.1058)

It is not clear from the wording of the text whether it is patients or professionals who associate stigma with stomas. Casati et al's (2000) literature review exploring the concerns of those with Inflammatory Bowel Disease (IBD) is revelatory of the beliefs and attitudes of the authors as medical professional when they describe those with a stoma in terms of: *"…individuals who have undergone such disfiguring surgery."* (Casati et al. 2000, p.28).

Exposing these authors' perceptions of stomas illustrates how critiquing extant literature can yield a rich source of unintended data.

Understanding the dominant biomedical ideology within which doctors and other healthcare professionals have been educated and practise within, with its focus on norms and deviations, it can be understood why professionals might perceive a stoma as an undesirable and disfiguring deviancy. In the population of those with SCI, the Being Alive Again chapter demonstrated substantial benefits to individuals having a colostomy through the *'relief of suffering'*, *'regaining of control and dignity'*, being able to *'live with confidence'* and *'have a day'*. The beliefs of professionals of colostomy as stigmatising jeopardises them making this transformational option available to those who may benefit from it. This represents a further failure of the underlying ideology in which bowel management options are being decided. The entrenched and unconscious beliefs of professionals could mean some who may benefit from colostomy remain in ignorance of its potential benefit, and have their choices reduced.

Taking this data and knowledge from the literature back to participant data revealed limited evidence of prejudicial attitudes in this study. Monty's (69:70:2011) wife describes one healthcare professional causing them to question momentarily their decision to proceed with the colostomy:

Monty's (69:70:2011) wife: "...that sort of attitude you would have thought oh perhaps this isn't the way we should be going." ML265

Overall, however, there was more evidence of healthcare professionals speaking positively about the option of colostomy. The staff in this researcher's spinal unit and colorectal department may be unusual in their positive approach to stoma formation because increased demand has made it an accepted modality of bowel management in the population of those with SCI. Or, conversely, their positive attitude may have contributed to the increased demand. Whatever the reason, these positive attitudes contrast with the conscious and unconscious negative and stigmatising attitudes to stoma which sampling the literature revealed. Further research into professional perceptions of colostomy in other spinal injury units and colorectal departments would be of interest. It would be beneficial for professionals to reflect on their own attitudes to colostomy, as this may influence their practice and the choices they make available, and therefore their patients' lives.

From a patient perspective, having a colostomy did not lead to these participants feeling stigmatised, and in fact led to individuals perceiving their bodies more positively, as discussed in the previous chapter. The ideology which prevents some with SCI from hearing of the option of colostomy due to negative and stigmatised perceptions in healthcare professionals must be challenged. This is especially important in the light of the positive transformation it brings discussed in the Being Alive Again chapter.

9.6 Confluence, divergence, and extension of theory in relation to extant literature

Consideration of theory related to the ideological context of healthcare in the UK found it to be dominated by a biomedical paradigm. The concern with maintaining norms makes sense of and is compatible with the theoretical framework, particularly when considering the experiences of those injured longest ago. Data concerning present day educational content during inpatient rehabilitation suggests it continues to be provided within a primarily physiological lens.

The suggestion in the literature that health has been perceived narrowly and not to have incorporated wider dimensions of personhood is confirmed in findings of bowel management provision which does not adequately account for dimensions of wider lifeworlds. Literature which informs of a rehabilitation ideology made sense of a previously not fully understood code of *'pain and suffering as inevitable'*, and this code confirms and extends this theory.

Interacting with theory which criticises medical technologies has developed understanding that these are not inherently detrimental to health. Instead, it is suggested each be assessed to ascertain the degree of harm or loss of autonomy they may lead to. Critical interaction with literature when considering stigma and prejudice has exposed hidden attitudes and prejudices of healthcare professionals towards colostomies, and is demonstrated to potentially impact the choices they make available to those requiring bowel function intervention.

9.7 Relating findings to research aims and question

Findings considered in this chapter have yielded insight that bowel management options are created and apprehended in relation to the dominant ideology within which they occur. Historically, choices have been made by professionals, not participants, and limited by the dominant biomedical paradigm with the aim of normalising a deviant body part. For participants injured longer ago, they acquiesced with decisions made for them in relation to managing an isolated body function. They persisted with this option even if it caused pain and suffering, due to their submersion in a reductionist perspective of health which historically considered professionals the legitimate people to make decisions about their body management.

This dominance of this ideology has been challenged and reduced over time. The power structure traced within participant experiences in previous chapters demonstrates a degree of redistribution of power, with those injured more recently having greater involvement in decision-making. Discussion in this chapter has confirmed that individuals make decisions from an insider lifeworld perspective rather than as professionals do from an outsider biomedical compartmentalised body system perspective. The degree of choice and choices made by those with SCI in relation to bowel management are seen to be contingent on the dominant ideological context within which they occur.

9.8 Chapter conclusion

The purpose of this chapter was to develop the theoretical framework by considering the ideology within which participant experiences occurred. The aim was to increase understanding of the motivations of those involved and ground the theory within its revealed ideological setting. This was achieved by gathering secondary data from extant literature and existing theory and comparing these with interview data.

Doing this has continued the golden thread of findings in demonstrating 'Failure of Care' as related to the historically dominant biomedical ideological perspective which fails to understand the wider lifeworlds of those who are the subject of care. From a reductionist compartmentalised notion of the body, efforts are made to normalise function in a body which has become deviant. This not only leads to pain and suffering, but imbibes in participants the belief that this was inevitable and their lot in life.

The dominant ideology has been exposed as the cause of professional misconceptions of what constitutes invasive care. These misconceptions have been influential in the development of body management guidelines which fail to incorporate insider perspectives and needs of wider lifeworlds. Consideration of medical technologies has demonstrated the importance of considering which can make life easier and reduce dependency, rather than favouring those which most closely maintain notions of bodily norms.

The ideology has been seen to produce further '*Failures of Care*' in how notions of norms and deviancy create views of colostomy as stigmatising. This has led to unconscious professional prejudice against this option, potentially restricting information and choices which are made available. These findings need challenging in the face of insider experiences of colostomy leading to resurrection experiences of '*Being Alive Again*'.

The emerging phenomenon of early colostomy has been seen as potentially disruptive, subversive, and nonsensical within the dominant ideological perspective. The possibility of it heralding a paradigm shift has been raised for later consideration. Understanding the ideology within which professionals are educated and practice, together with previous findings of *'Experiences of Loss'* and *'Progression into Suffering'* in which professionals are implicated, makes it now pertinent to further explore in the next chapter ways in which professionals contribute to the theme of *'Failure of Care'*.

Chapter Ten: Professional Failure of Care

10.1 Chapter introduction

The theoretical framework with central themes of *'Experiences of Loss'*, *'Progression into Suffering'*, and *'Being Alive Again'* relating to bowel management following SCI has been discussed. Golden threads have emerged which demonstrate present guidelines to be failing in their aims of maintaining satisfactory bowel function and continence, and failing to understand or incorporate the wider lifeworlds of those they seek to help.

From this framework, questions have emerged which ask how the theme of 'Failure of Care' has been produced by the wider context in which participant experiences have occurred. The previous chapter considered the ideological context. This provided understanding that a biomedical perspective has led to compartmentalised notions of bodily functions and produced a professional preoccupation with maintaining norms. This has contributed to 'Experiences of Loss' and 'Progression into Suffering'. The historical rehabilitation ideology which demanded individuals use maximum effort to try to re-establish norms in bodies which have become deviant through illness and injury, has led to the belief developing in some participants of 'pain as inevitable'.

The disparity between what professionals and the subjects of their care perceive to constitute invasive body management has been demonstrated. The pervasive finding that present bowel management guidelines fail to incorporate the wider lifeworlds of participants is seen to be related to the ideological paradigm within which professionals operate. This presents an explanation for the failure of present guidelines and the emergence of the phenomenon of early colostomy.

With this new understanding, it will now be explored further how healthcare professionals and their actions contribute to participant experiences of *'Failure of Care'*. This will increase understanding and develop and refine the theory. Findings will be discussed in sections discussing *'professional practices restricting lives'*, *'assumptions of superior knowledge'*, *'failure to understand lifeworlds'*, and *'variation in care provision'*. How these findings relate

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to the existing literature and answer the research question and aims will be considered at the end of the chapter.

10.2 Professional practices restricting lives

Reflection on data and codes which led to the notion of the professional *'Failure of Care'* led to sampling the literature to discover more. The code of *'professional practices restricting lives'*, was developed from reflection on Charmaz' (1983) discussion of *'living a restricted life'* from her analysis of in-depth interviews with 57 people housebound with chronic illness. She describes professional practices to 'set in motion' restricted lives, through failure to provide adequate information about all possible treatment options (Charmaz 1983, p.173). This theme was discussed in earlier findings in relation to the lack of consistent information about alternative bowel management interventions.

Charmaz (1983) does not develop further here the contribution of professional practices to restricting lives, but taking this sensitising code back to interview data, the concept is confirmed and extended. Not only do professional practices set in motion restricted lives. Persistence with lengthy regimes and bowel management guidelines in the pursuit of maintaining norms, have been found to lead to loss of time, shrinking lifeworlds and experiences of pain and suffering.

Constant comparison found evidence of 'professional practices restricting lives', with bowel management described by Monty's (69:70:2011) wife as: "It just took over your life, didn't it?" ML54. Those injured more recently envisioned this happening if they continued with manual bowel management after leaving hospital. With their greater access to information and increased relative power they were able to challenge this:

Jim (62:62:2016): "Every time you need to deal with your bowels, there is a strict regime that takes time." JE56. "The regime, I was going to have to rethink it because it wasn't effective and I could see it was going to restrict me a lot." JE28

This expanded theoretical notion of professional practices continuing to restrict lives rather than just setting them in motion was sampled further in the literature. Its presence was revealed in other areas of healthcare with evidence of it being linked to the biomedical ideology within which professional practices and regimes occur. In Locker & Kaufert's (1988) study on individuals with post-polio respiratory disability, there is a similar restriction on lives as professionals forced individuals to perform everyday tasks without the use of technologies which would help them, as discussed in the previous chapter. This led to their time being consumed by these tasks. Professionals did not consider whether individuals may like to use the time and energy they had in alternative pursuits, and this links to their ideological perspective which is reductionist in its focus on physiological management of isolated body parts.

In the earlier decades in which these experiences occurred and Graham (21:71:2012) sustained his injury, it appears no consideration was given to patient perspectives of injury, illness, or treatments. Professionals dominated the provision of healthcare and dictated body management regimes. Despite changes in health care ideology and provision over time, and the emergence of more patient centred research and treatments, sampling the literature finds a strong physiological focus of treatment to persist. Garcia-Sanjuan et al (2016) in their scoping review of the life experiences and perceived social support for those with Crohns disease, found a lack of professional knowledge about patients' experiences. They found that the design of standard programs mostly addresses clinical symptoms and omits social and emotional dimensions of how patients understand and cope with illness.

Bowel management guidelines following SCI have similarly been found to fail to incorporate patient's perspectives and wider lifeworlds, and the continued focus by professionals on physiological management has been demonstrated to produce the unintended result in some participants of years of living restricted lives.

10.3 Assumption of superior knowledge

Considering the nature of knowledge and professional expertise, the literature provides further context. Professionals are described by Parsons (1939) as having authority over others due to their specific function and superior technical competence and knowledge,

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which makes health professionals more competent than lay people in matters concerning health. Professional regulation and authority can be traced to the fifteenth century when petitions to King Henry V asked that only those with appropriate qualifications be allowed to practise medicine (Policy-Navigator 2020). Discussed in earlier findings chapters has been the way in which information is withheld by professionals. It is only in recent decades with the digital revolution and policy change discussed later that information about the option of colostomy has become more readily available to some of those with SCI.

Despite these recent shifts in information and availability, and the increased selfdetermination perceived by participants in choosing bowel management options, professionals retain power in controlling who receives what information and when. Superior physiological knowledge may quite rightly be ascribed to professionals, but professionals need to awaken to the understanding that this knowledge is of importance only due to it being deemed so within the biomedical ideological perspective. Emerging in this research as important is the need to understand that those requesting colostomy are approaching it with alternative knowledge from a differing lifeworld perspective. In their lifeworld perspective, physiology, maintaining norms, and notions of risk and invasiveness of procedures are of secondary importance to their wider lives, aspirations, and concerns.

This disparity in perspective is demonstrated in a recent article by Cooper et al (2019), which encouragingly gives the first evidence this researcher has seen of another spinal unit actively informing and counselling those with SCI earlier about the option of a colostomy for bowel management. Studying the article more closely reveals however that early colostomy is offered only to those the professionals consider will benefit from it. This is revelatory of the unconscious assumption of superior knowledge of professionals in knowing who will benefit from a colostomy without asking them, as well as the power they have to offer or withhold options:

"With greater understanding it is hoped we can improve our ability to select appropriate individuals who would benefit from a stoma." (Cooper et al. 2019, p.1415)

It is the professionals deciding who will benefit and therefore be given information, with the basis for selecting patients described as relating to bowel dysfunction. The wider lifeworlds of their patients are not mentioned and presumably not considered when they decide who will be given information:

"When a stoma is indicated a clinical nurse consultant discusses the various aspects of bowel care and how a stoma may improve their ability to manage their bowel regimen." (Cooper et al. 2019, p.1418) (emphasis mine)

The approach in this researcher's spinal centre has been different. On reflection, it has redistributed power to patients by imparting information about the alternative option of colostomy to all who wish to hear it. This has been done by the introduction of regular spinal unit inpatient information sessions since 2019, at the point when lack of readily available information about colostomies was identified as a repeated finding in participant interviews. Differing to the approach of Cooper et al (2019), in this spinal unit all inpatients are made aware of when information sessions are scheduled, and attendance is then self-selective and voluntary. Power resides with patients choosing to attend and receive the information, rather than professionals selecting who hears about the option. This is important as interview analysis revealed reasons for choosing colostomy are not just related to bowel dysfunction as Cooper et al (2019) appear to assume. It is more often chosen by the early colostomates for the freedom and independence it brings, and the desire to avoid reliance on healthcare professionals once they have left hospital.

Giving this information to all who wish to hear it does risk, however, opening a Pandora's box and leading to further problems related to organisational failures, discussed in the next chapter. In the open ward environment of a spinal inpatient unit information travels quickly. It has been observed by the researcher to be the norm for bowel management to be widely and freely discussed between inpatients. Cooper et al (2019) although only giving information to those they consider would benefit from a colostomy, may find themselves in a similar situation to the one which occurred in this spinal unit. Once inpatients are given information about the option of a colostomy and one patient proceeds, word of its benefits spreads quickly, and they may receive a similar influx of requests for colostomy as has occurred here.

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10.4 Failure to understand lifeworlds

In creating guidelines based on physiological knowledge with a concern to make deviant body parts conform to preconceived norms, professionals have failed to understand that the choice to have a colostomy is frequently made due to wanting a simpler bowel management system. 'Wanting easier management' was a theme which emerged from primary data analysis. Traditional bowel care is based on the professional supposition that manipulating diet, use of laxatives and manual removal methods are the least invasive and therefore the best and most desirable ways of managing the bowel. Options higher up the bowel management pyramid are considered more invasive and have historically been utilised only as a last resort. This has been demonstrated in the previous chapter to be a professional misconception and a failure to understand insider perspectives of what is invasive.

For the individuals on the receiving end, a lifetime of being subjected to what can be a lengthy and painful procedure involving loss of dignity as stool is manually removed from the bowel, is weighed against the option of a one-off operation which then leads to bowel management involving simply changing a pouch attached to the abdomen once or twice a day. Terry (28:51:2015) explained the relative ease of changing a colostomy pouch, particularly when teaching someone else how to do it:

Terry (28:51:2015): "I think it is infinitely easier to show someone say from an agency how to change a simple bag than it is to how to avoid haemorrhoids and be careful and what happens if you get a big bleed." TL265

As well as ease of management, Terry (28:51:2015) described reasons related to dignity and control of why people might choose a colostomy over traditional bowel care:

Terry (28:51:2015): "Some people I believe just the idea having to do their own bowels anyway would wish for another option, something easier. Something where you can at least see what you are doing perhaps, something that doesn't have physical consequences underneath, where you don't have to worry about waiting so long." TL396. "These are all really important factors so for some people their decisions could be made based upon those points." TL412
With failure to understand the lifeworlds of recipients of healthcare interventions a finding here and in the wider literature, further data analysis reveals a changing picture emerging over the timeline in the setting being studied. As the choice for colostomy is increasingly made, professional attitudes and practices are observed as changing and developing and suggest an evolving perspective which is now discussed.

10.5 Tracing changes in professional attitudes in this setting

Changes in professional and caregiver attitudes towards bowel management options in this healthcare setting can be traced through the timeline of patient experiences given in Chapter Five. The experiences of those injured earliest have been previously discussed, and between 2011 and 2015 professionals are discerned to perceive colostomy within a primarily biomedical perspective. They suggested a colostomy to improve physiological management for later colostomates including Graham (21:71:2012). They permitted, but appeared not to comprehend, the request for those such as Monty (69:70:2011) who desired it primarily related to inadequate care provision and competency. Sophie (48:48:2013), an early colostomate in 2013, learned about colostomy from another patient and asked her consultant if she could have one: *"I mean [they] knew I knew sort of about it because we had someone in our room with one."* SE62. Although agreeing to Sophie (48:48:2013) having a colostomy, professionals were not particularly forthcoming about it and were surprised by her choice:

Sophie (48:48:2013): "[They] just said it was an option." SE60. "[The consultant] was quite surprised how quickly we came to it." SE101

The surprise and difficulty in comprehending the choice for colostomy so soon after injury demonstrates this to be a puzzling anomaly at the time, not understood by professionals operating within the biomedical paradigm that bowel function is predominately managed within. The wider and insider lifeworld context for Sophie (48:48:2013) was that her bowels were proving difficult to manage under the standard regime, she found bowel care itself to be embarrassing, and importantly to her she was *'planning ahead'* for independence at home. Within an interpretive lifeworld framework her choice for a colostomy makes sense. To health professionals operating within a biomedical paradigm, it was perplexing for an

individual to choose so soon an option considered more invasive without first progressing through less invasive options as was accepted and entrenched practice.

Progressing along the timeline, a couple of years later the same consultants seem to have shifted in their perspective of bowel management and had started to advocate colostomy, actively suggesting it to early colostomate Emily (49:49:2016): *"[The consultant] spoke to me about having a colostomy and how did I feel about it?"* EE47. Colostomy is no longer apprehended as a last resort due to physical problems, and professionals are now actively seeking insider perspectives and giving choice. As the numbers of those with SCI within their spinal unit requesting colostomy at an earlier point increased, these professionals' attitudes are observed to have changed. It is possible but not known that this may have occurred as they perceived the wider lifeworld benefits of colostomy, and this led to them giving more information and choice. It would be of interest to study this further by interviewing the involved professionals to learn more about their changing perspective and attitudes towards colostomy and the phenomenon of early colostomy which has unfolded.

10.6 Variations in care provision

A final area in which professionals were found to contribute to 'Failure of Care' is due to 'variations in care provision'. This was seen in earlier chapters and particularly in Monty's (69:70:2011) experiences of receiving healthcare in the community setting. Manual bowel management can only be performed independently by those with lower-level injuries, sufficient dexterity, and favourable body habitus. For the rest a dependency on others to perform this is created, putting them at risk as Illich (2003) suggests and has been discussed, of loss of autonomy and declining health. Evidence of this is seen in the first Findings chapters. Interview data also demonstrates variation in the skill of individual healthcare professionals in manual bowel methods, and this is identified as part of a more systemic failure of care provision. Terry (28:51:2015) described the variation in care provision:

Terry (28:51:2015): "It would depend on who you had assisting you. It was never going to be the same person doing it every single time. During that time you would have all different people doing bowel care. I think all those things play a significant part in how things are going to react underneath to this possible intervention." TL64. "I would also bleed quite a lot sometimes. If you have someone different, who didn't quite know how to deal with in and around the haemorrhoids that could be quite a lot." TL125

Terry (28:51:2015) knew he wasn't alone in experiencing variable quality of care:

Terry (28:51:2015): "I have a friend who has his bowels done on the bed and he has a district nurse who he doesn't wish to do his bowels because of the way in which she does them which he finds aggressive and he ends up bleeding. I can totally relate to that, there were specific people shown how to do bowel care and some of them were definitely more aggressive than others, there was no doubt about that. There were some that you would think that you didn't want them to do that, but you kind of bizarrely put up with it, because you didn't want to rock the boat or annoy anybody, you didn't want to seem to be ungrateful or anything like that." TTL94

The last part of Terry's (28:51:2015) statement is telling of the vulnerability of individuals dependent on others to provide ongoing care to them, and the power imbalance which can exist between recipients and providers of healthcare interventions. This may be especially the case for NHS provision of care where the individual is the recipient of state funded benevolence, compared to those directly employing carers or PAs, an area returned to in later discussion.

The variation in skill of individual professionals is suggested as related to the training they have in manual bowel management practices. Digital stimulation and manual evacuation have not been skills included in general nurse training and require attending specific courses to include theoretical knowledge and simulated practice on mannequins. In this spinal injury unit, a full day of training is provided free to hospital staff but may be chargeable to external attendees. Whilst in hospital, participants had bowel care performed by nurses and carers working in a highly specialized environment, all of whom are trained and assessed in these methods before being permitted to perform them. After leaving hospital, if unable to do it themselves, bowel care is performed by district nurses, carers, PAs, or in some instances by family members. MASCIP guidelines state that carers and PAs employed by statutory or care agencies must receive appropriate training, be assessed as competent to perform bowel care, and the competency be evaluated at regular agreed intervals (MASCIP 2021a). It is not known how this is checked or enforced. For those directly employing PAs, it becomes the

responsibility of the employer (i.e., the person receiving the care) to provide this training. Potential difficulties relating to this are returned to in the next chapter.

The experience of participants demonstrates that bowel management in the community setting is variable in quality. In *'Progression into Suffering'*, it was seen that Monty (69:70:2011) and his wife were existing in a *'shrinking lifeworld'* with their day revolving around waiting for nurses to come and perform bowel care before he could get up, and then dealing with incontinence resulting from the ineptitude of care. His wife further identified the lack of knowledge and training in the community nurses doing his bowel care, and how it was often a different nurse every time:

Monty's (69:70:2011) wife: "Actually I complained to the manager and she said 'we haven't got that many [nurses]', I said 'look at the signatures...', 'oh yes!' I would think out of the eighteen [nurses] only two or three had ever been trained on how to do bowel care...most of them would come and just thought it was a manual evacuation, didn't realise they had to stimulate to get it going and you see the odd two or three used to do it ok and the rest didn't and they didn't empty the bowel properly." ML40. "I can remember chucking my carpet out and all the different ones coming and just assuming that bowel care on a spinal injured person was a manual evacuation. They would come in and do further digital examination and say 'Well there is nothing in the bowel so we'll just go."" ML310

Monty's (69:70:2011) wife suggested to the manager that further training was needed but this was seemingly ignored, and they were not included in decision-making when for unknown reasons the care agency decided to reduce the frequency at which he received bowel care each week:

Monty's (69:70:2011) wife: "They decided that they would come every other day. Ok so what happens the days in between? 'Well don't put the suppositories in, and then it won't happen, will it?' And then they decided they would come twice a week." ML88

It is not known but possible that this decision to reduce the frequency of visits was based on organisational needs rather than Monty's (69:70:2011) needs, as the care which the agency was providing was already not meeting aims of adequate bowel emptying and continence.

Eventually Monty's (69:70:2011) wife took matters into her own hands and paid to go on a training course herself so she could perform bowel management which was timely, correctly performed, and fitted in with their desired lifestyle. This is fortunate when someone has a relative willing and able to do this, but it must be assumed that there are others continuing to live with similar unsatisfactory care provision.

The newly injured inpatients of the spinal unit had an awareness of the variability in quality and availability of care in the community and this contributed to their decision to undergo colostomy formation. Jim (62:62:2016) had learnt from other patients:

Jim (62:62:2016): "Well I heard from a lot of people that the district nurses in the field are so pushed in certain areas, particularly places like where I live that they might not be on time." JE119

Emily (49:49:2016) as an ex-carer herself had additional insight into this:

Emily (49:49:2016): "You can never guarantee what they've got on their case load. So, they may say they are going to be there at half past eight, but they may not be there until half past nine and then I get fraught." EE136

Sophie (48:48:2013) heard from another patient how bowel care in the community wasn't performed as well as it was in hospital:

Sophie (48:48:2013): *"I know when my friend in the bed next to me went home it was one thing she was dreading, and when she visited and came back in a few times she said it was the worst."* SE261

Sadly, the gathering of secondary data from the literature similarly found instances of failures in the provision of care. Nelissen et al's (2019) participants receiving invasive ventilation found that not all care staff have the same competence and some are poorly trained. Dewar and Morse (1995) concluded that interactions with health care professionals can lead to unbearable aspects of illness and injury through procedures not being explained, injury from care, and insensitive or rude care providers. Morris (1989) found that disabled peoples' autobiographical accounts are plagued with examples of care being given without choice and at worst in a physically damaging way. Coggrave (2012) reflected that problems experienced by many in accessing appropriate bowel care, lead to some having a stoma to solve problems relating to care issues. The context of receiving or anticipating receiving unsatisfactory and untimely care is seen to be a factor in the decision to have a colostomy. This indicates that professional *'Failures of Care'* contribute towards the way that individuals choose to manage their bodies.

Reasons for inadequate care provision, seen particularly in the community setting in this research, were sought to be understood further by exploring the wider institutional context, and this is explored in the next chapter.

10.7 Confluence, divergence, and extension of theory in relation to extant literature

Professional practices not only set in motion restricted lives as extant theory suggests, but professional persistence with them is observed to lead to *'Experiences of Loss'* and *'Progression into Suffering'*. Literature explored has supported the finding of this research that professionals often fail to consider insider experiences of ill health and the interventions they prescribe.

Literature which promisingly shows evidence of early colostomy being utilised in other spinal units has demonstrated this to be still apprehended from a biomedical physiological perspective, with professionals retaining control over who can access it. This demonstrates practice in this spinal unit as continuing to be divergent from that of others, as here colostomy is available in relation to wider lifeworld and lifegoal needs of individuals, not just physiological ones.

The wider literature studied confirms the finding here of *'variation in care provision'*. It has been seen how healthcare professionals can unwittingly inflict pain and suffering onto those they are seeking to help.

10.8 Relating findings to research aims and question

Consideration of findings of professional 'Failure of Care' in this chapter has deepened insight into the research aims and the question themselves. The degree of choice, if any, which individuals have about bowel management is seen as contingent on professionals in their position of relative power.

When the choice for colostomy is permitted, participants make decisions based on knowledge of their insider lifeworlds, and this knowledge differs in nature from the physiological knowledge which is prized by professionals and healthcare providers and used in their decision making. Changes in the degree of involvement and choice in decision making professionals allow participants to have is observed to have changed over time. In this hospital setting this appears related to the shifting and broadening perspectives of the professionals involved.

Failures of care management systems and the desire for autonomy and prevention of further harm to themselves are seen to contribute to the body management decisions made by some participants.

10.9 Chapter conclusion

This chapter has developed themes from previous chapters concerning the impact of professionals and their actions on participant experiences of *Failure of Care'*. The ways in which *'professional practices restrict lives'*, *'assume superior knowledge'*, fail to understand participant lifeworlds, and *'variations in care'* have been considered as contributing to this observed theme. Theoretical understanding has developed with further evidence of conflicting ideologies and viewpoints between professionals and those requiring healthcare services. In the setting being studied, change has been observed over time as professional perspectives of the bowel management method of colostomy have shifted, and power has been redistributed to allow participants greater choice and knowledge from their insider lifeworlds to be considered.

In other spinal units, where there appears to be encouraging expansion of practice to offering early colostomy, analysis reveals this is only offered to those whom professionals consider will benefit from it from a physiological perspective. This demonstrates further the failure of professionals in not understanding the wider lifeworlds that lead to individuals choosing to have a colostomy.

The observed 'variation in care' and the harm this can lead to is concerning. Earlier chapters demonstrated bodily suffering caused by bowel management practices, and this chapter has added observations of variability of skill and inadequate organisation of care provision in the community setting. A care agency which had a duty to ensure nurses were adequately trained, appears to have failed in this.

In continuation of the golden thread of findings from previous chapters, the assumed superior knowledge of professionals, constrained within a biomedical perspective, risks restricting the lives of those it seeks to help. Other forms of knowledge which stem from alternate paradigms can fail to be sought or incorporated when assessing health and deciding on body management strategies and clinical guidelines.

Findings in this chapter, particularly the variations in care provision, point to a greater institutional level of *'Failure of Care'* and leads into investigation of this in the next chapter. Other questions previously raised concerning institutional and organisational failures such as difficulties related to increased demand and organisational capacity will also be investigated in a final area of exploration of the wider context of findings related to the phenomenon of early colostomy.

Chapter Eleven: Institutional Failure of Care

11.1 Chapter introduction

Findings from primary data analysis of '*Experiences of Loss*', '*Progression into Suffering*', and '*Being Alive Again*', have raised awareness that findings are influenced by the wider context in which the phenomenon of early colostomy is occurring. Arriving at the end of the research journey, further and final data collection related to the New Wider Landscape are explored in relation to ways in which the Ideological, Professional, and Institutional contexts have contributed to the final major theme of '*Failure of Care*'.

The ideological context has been found to fail due to being constrained within a biomedical perspective concerned with bodily functions, maintaining norms, correcting deviant body parts, and which fails to account for wider lifeworlds and lifegoals. The professional context contributes to failure through professional practices restricting lives, variations in care provisions, and an assumption of the superiority of the biomedical knowledge which professionals possess over other forms of knowledge.

The final context explored (although it is suggested that other unknown factors also exist), is termed the institutional *'Failure of Care'*. This will explore social arrangements felt to be contributing to participant experiences and the phenomenon of early colostomy. Ideas and findings which arose in earlier analysis, but which were not fully understood, are further developed and explored to better understand the landscape in which the theoretical framework has emerged.

These findings will now be discussed in new and evolved codes of the changing social context, *'society disabling people'*, empowerment and shifting care relationships, *'unmet need'*, failure to train and regulate care, having a voice in care provision, and professional and organisational control. These will be related to extant literature and research aims and the question, and their contribution to findings discussed in the final sections of the chapter.

11.2 The changing social context of healthcare

In consideration of the Ideological 'Failure of Care', it was discussed that healthcare in the UK is framed within a biomedical perspective with a physiological focus on measurement, compartmentalisation of the body, norms, and correction of deviant parts. It is criticised for failing to account for wider aspects of health and the wider lifeworlds of recipients of care, and creating guidelines with similar failings.

This was especially relatable to the experiences of those injured earliest, and the literature was sampled to better understand institutional and societal changes over the participant timeline. Over the decades in which participants' experiences occurred, these changes were reflected in the health care provision they received. Understanding of this, although not an initial aim, became relevant in developing theory and gave insight into the differing experiences observed over the length of the participant timeline provided in Chapter 5.

At the start of the timeline of injuries is Graham (21:71:2012), who has been discussed as receiving care in an environment he likened to a prisoner of war camp. This was dominated by professional power, with no choice in body management decisions, and with effort and hard work prized in forcing the body to conform to norms. At this point in time, the literature describes a dominant biomedical paradigm and a society in which disabled people had lower status, and their bodies were considered deviant from the norm. Goffman describes the standard social response to those with a disability as being to confine and 'infanticize' them (Goffman 1963; Watson et al. 2004). In this social and ideological context emerged the Independent Living Movement (ILM), born in the 1960s in the USA, and which spread to the UK in the 1970s.

The ILM criticised services which viewed disability as a deficiency requiring repair, disempowered disabled people by perceiving them as sick and dependent, was medically orientated, paternalistic and institutional, services which were out of touch with real need, and which led to social stigma, dependency, and loss of agency (Hughes 2000; Watson et al. 2004; Beckett 2017). Greater choice and control in how those with disabilities were helped was demanded, with this movement being described as a paradigm shift (DeJong 1979;

Sanderson and Hawdon 2019). Taking these notions back to interview data, elements of these criticisms have been observed and discussed in earlier Findings chapters.

The previously described changes over time of increased availability of information and involvement in decision making, and a shift in the balance of power between participants and the hospital consultants can be located within the context of this social movement. It is interesting to note, however, that these changes have occurred only relatively recently with a transition in experiences observed between 2011 and 2015. This represents a time lag of several decades from the first work of the ILM until it was translated into meaningful change in this setting in this area of body management.

This new information about participant experiences spanning a period of social change increases understanding of findings, explaining and giving social context to differing experiences across the timeline. This knowledge is, however, provisional. Within the purposes and constraints of this research the literature was only sampled. Further investigation may reveal additional or alternative information. There is insufficient data and sampling of participants and gaps in the timeline which limit inferences which can be drawn from this. Further research would be required to investigate more fully how changes in society and culture have contributed to participant experiences.

11.3 Society disabling people

From exploration of theory relating to the demand for the disabled to have equal recognition and the right to participate fully in society, of interest was the perspective that people are disabled by society rather than their bodies (Morris 1993; Watson et al. 2004). Social change is sought rather than medical intervention, and the blame of disabled people 'not fitting in' is attributed to the creators of restrictive environments, roles, and occupations, and not on disabled people (Gill 1997). This links with criticisms of the biomedical perspective as reductionist in narrowly perceiving health as the perfect working order of the body, and not accounting for the wider context of people's lives such as their working or social lives. It supports the long-held ambition for a wider definition of health than merely the absence of disease (WHO 1948). Within a reductionist perspective, healthcare does not identify or seek to address disabling barriers to greater health such as those which prevent access to employment.

The disablement of people by society rather than their bodies was considered potentially of relevance in how participants might choose to manage their bodies. This sensitizing concept was taken back to interview data in constant comparison to search for evidence of it, and participant experiences confirmed the presence of barriers to desired lifestyle activities:

Terry (28:51:2015): "...travelling, going away, not everywhere can you get the shower chair over the loo." TL333

Graham (21:71:2012): "It was an issue in terms of where could we go and where could we stay. There were many times I booked hotels and asked, was it wheelchair accessible and they replied 'yes, it is', but it wasn't." GL72

Jim (62:62:2016): *"If I need to attend to that in the day then that's another huge issue because if you go into somewhere that doesn't have a place for you to deal with it. You are sort of stumped, it would restrict my lifestyle."* JE37

This data confirms that even in Jim's (62:62:2016) more recent experience in 2016, people using a wheelchair to aid mobility and requiring additional space for body management encounter barriers in society which restrict their lives and prevent them from accessing public spaces. These places are described by participants in relation to leisure and travel but extend to workplaces and all areas of social lives. Use of this sensitizing concept added to the theoretical framework by identifying how failures in society contribute towards experiences of *'Failure of Care'* through disabling environments. Importantly, there is evidence of individuals making body management choices to try and overcome these barriers. It could be speculated whether if these disabling environments were changed, would these individuals have made alternative choices and not had the colostomy? If buildings, workplaces, transport, and all other public and social spaces were designed with the needs not only of those using wheelchairs in mind, but also the needs of those requiring space and equipment to manage their bodies, what would the impact be on the decision-making of those individuals?

11.4 Empowerment and shifting care relationships

Over the participant timeline a further societal change of suggested importance in sampling the literature is the rise in consumerism (DeJong 1979). This has been influential in challenging the professional dominance in health provision policy, stimulating change towards the view that disabled people are the best judges of their own interests, and their voice should be larger in determining service provision. This translated into policy changes in the UK aimed at redistributing power to long-term service users, such as those with care needs resulting from SCI. This and other areas of interest were investigated through sampling relevant NHS policy documents released over the participant timeline.

The first policy change is found in the Community Care Direct Payment Act 1996 (DOH 1996) which allowed users to directly employ PAs rather than be provided with local authority commissioned care. This is consistent with the aim of disability rights movements of changing the relationship from patient and carer to one of employer and employee. The relationship becomes a business arrangement and power redistribution is facilitated (Watson et al. 2004). A time lag is observed before the social movements started in the 60s and 70s were translated into these policy changes.

More recently, a further policy aimed at strategically empowering individuals and improving the quality of services has been through the introduction of Personal Health Budgets (PHB) (Larsen et al. 2015). In England this was a concept extended from social care users to NHS users first in a pilot in 2009, and then rolled out to all with long term conditions from 2015 (DOH 2009; Norrie et al. 2014; Norrie et al. 2020). Individuals are given a PHB from which they directly employ their own PA to meet care and support needs agreed with the local Clinical Commissioning Group (CCG). It can also be used to purchase broader and alternative services and support such as transport, complementary and talking therapies, even football season tickets, education, or training (Jones et al. 2013; Larsen et al. 2015; Welch et al. 2017). The degree to which PHBs truly empower individuals to choose how their care needs are met is complex to evaluate and studies and opinions differ. This was not an area investigated further in this study and is still in relative infancy.

Taking this changing structure back to interview data in constant comparison, different care arrangements are observed in those with higher level injuries who required assistance with daily needs. As interview data was not gathered with the aim of exploring the dynamics of care provision, limited insight and inference can be drawn about this.

Monty (69:70:2011), injured in 2011 (receiving intermittent carer visits and with his wife helping at other times), described care received from a care agency and district nurses. Dan (52:52:2015), injured in 2015 (receiving 24-hour care), had a live-in PA who was present and contributed to discussion during the interview. Terry (28:51:2015), injured in 1992 (receiving 24-hour care), is the only participant to refer to receiving assistance from both care agencies and PAs at different times, perhaps reflecting the changed care arrangements. Clear differences are seen between Terry's (28:51:2015) interview where he is directive in how his care is performed, and Monty's (69:70:2011) in which a high degree of disempowerment and loss of autonomy is evident.

There is insufficient data and too small a sample of participants to fully explore and determine the cause of these differences. It could be due to political changes to care arrangements over time, or the known difference of Monty (69:70:2011) receiving intermittent visits and Terry (28:51:2015) having more constant assistance, or there may be other unknown reasons why experiences differed so greatly. Further study would be required to examine more fully the influence of the nature of the relationship between care provider and recipient, but it may be that personal employment of a PA leads to a greater level of power and autonomy for the care recipient.

11.5 Unmet need

It is not known whether these participants held PHBs but sampling the literature in relation to these raised areas of interest due to potential issues they can create related to the theoretical framework. One area of interest is the concept of *'unmet need'*, which is described by Slasberg et al (2014) as leading to the collapse of the PHB system in the Netherlands, as the broader and more personalised concepts of health revealed unmet need which could not then be funded. Unmet need in this research has been mentioned earlier in the context of researcher insider knowledge of the growing waiting list for those with SCI

wanting to have a colostomy. To understand more about unmet need and waiting lists, the literature was sampled to explore these further.

In a publicly funded NHS free at the point of need, limited resources mean that at multiple levels within health care systems decisions will need to be made about what is and is not available and to whom, and gatekeeping roles are created. Klein & Maybin (2012) in their Kings Fund report on health care rationing state:

"Decisions that determine who will eventually get what are taken at all levels within the system: central government determines the overall budget for the NHS, commissioners and providers decide between competing priorities when allocating funding, and clinicians decide how to allocate their limited time and resources." (Klein and Maybin 2012, p.vi)

In other literature data related to rationing and unmet need, Tarrant et al (2015) describe how GPs in their role as gatekeepers make judgements about the legitimacy of patients' claims to using services. They found that although GPs may have valid reasons for denying access to services at times, this can lead to patients expressing significant unmet need and distress. Their finding is evidenced with interview data where a participant suffering with a chronic condition and depression expressed insider feelings of being alone and unable to cope, and the GP's response was: "There's nothing wrong, we can't do anything" (Tarrant et al. 2015, p.84). Tarrant et al (2015) discuss this in terms of the concept of legitimacy. Considering this in relation to findings here, legitimacy can be understood as being upheld when need fits with the biomedical paradigm in which the healthcare system is operating. The expressed need of Tarrant et al's (2015) participant in not coping and feeling alone is related to their wider lifeworld. This is outside of the sphere of concern of the GP's biomedical perspective, and went unrecognised, unacknowledged, and unmet. There may have been no service to meet the need, but the need itself was denied in the GPs words, and in their role as gatekeeper they denied access to any potential state funded source of help. The frequently stated finding of health provision occurring primarily within a biomedical perspective, is demonstrated again as failing to meet need by not comprehending or acknowledging wider components of health, insider perspectives, and the life-worlds within which individuals exist.

Using this literature data in constant comparison, there is evidence of incomprehension in some healthcare professionals of participant need. This occurred when participants wanted a colostomy for reasons which were not purely physiological, but instead related to care arrangements or their wider lifeworlds. Monty's (69:70:2011) wife spoke of an unhelpful interaction with one gatekeeping professional who said to them:

Monty's (69:70:2011) wife: "So is that what you want done? Are you telling me you want a colostomy?' ... I just thought, [they're] not interested basically..." ML250

Monty's (69:70:2011) decision was not understood by this professional as it was due to failing care arrangements and not primarily about a physiological need. It was in this instance, however, allowed to proceed to the next stage by this gatekeeper, and he was able eventually to have the colostomy. In other geographical areas it is known by the insider researcher that gatekeepers sometimes deny the legitimacy of this choice of colostomy for non-physiological reasons. This is seen in 'out of area' patients who are referred to this hospital when professionals within their local one have denied them a colostomy, with instances even of individuals contacting this researcher via social media to find out how they can access the novel service it seems is being offered here.

Unmet need is seen in this hospital setting in the lengthening waiting list of patients with SCI wishing to undergo colostomy formation. This has emerged due to limited resources of operating theatres and surgeon availability to meet a new and increasing demand, competing demand from patients deemed to require more urgent surgery, and more recently due to a growing backlog of people requiring operations due to the Covid-19 pandemic. It is a frustration that the organisation at the start of this research in 2016 was able to offer this surgery often within a period of weeks or a few months, and now the waiting time suggested by surgeons is that it is likely to be considerably longer than this. Further knowledge about this was sought from sampling literature.

Wider insight into the problem of unmet need seen in lengthening waiting lists, came from reflection on a statement by Slasberg et al (2014) concerning healthcare rationing:

"Clinical need is therefore a judgement made by a clinician about whether one of a range of available health services should be provided to the individual...health services adopt a service centred approach to assessment of need in that it only recognizes needs for which there is an established service." (Slasberg et al. 2014, p.186)

This data segment from sampling the wider literature offers a potential explanation for what is being observed in this setting. The growing waiting list for colostomy has arisen in this organisation due to a novel and increasing patient-led demand, for which there has not been a professionally or organisationally planned and established service. When the phenomenon started and demand was small, the organisation and professionals within it were able to flex and provide additional inpatient consultations and operations on an ad-hoc basis. Now that demand has increased considerably, this is becoming more problematic. Like an elastic band which can only stretch to a certain point, professionals and the organisation appear to be recoiling back as the unplanned and ad hoc service encounters issues of capacity.

Slasberg et al's (2014) statement that organisations refuse to acknowledge a need for which they do not have an established service, adds to the previous finding from Foucault's (1973) work that clinicians only select biomedical problems to address as that is what suits them. With deeply entrenched guidelines and practices for bowel management following SCI, the need is not recognised within commissioning or provider organisations, or the professionals and managers within them, for spinal colostomy to be a standard and readily available bowel management option at an early point following injury.

11.6 Failure to train and regulate care

A further area of institutional failure was considered, related to the finding of *'variability of care provision'* discussed in Section 10.6. This failure of individual caregivers to have the skills required must be related to the failure of the institutions within which they work to provide adequate training. Reasons for this failure are not known. Exploring this is beyond the scope of this study, but is of crucial importance in this and other areas of healthcare where inadequate skill and training is found.

A further layer of complexity to provision and regulation of training stems from the PHB system described earlier. This transfers responsibility for ensuring care providers have adequate training onto the individual receiving it in their new status as an employer. These individuals, often with complex health needs, must now navigate employment law, data protection, recruitment, and payment into pension schemes (Skills-for-Care 2021). Not enough is known about how this works in practice to make meaningful inference, but exploring the literature reveals a lack of clarity about who is responsible for the training of PAs by those who choose to have their care managed in this way.

PAs are not currently regulated, and approaches to delegating clinical skills from trained professionals and processes for examining and maintaining competency vary (NHS-England 2017; Skills-for-Care 2020). Contentious areas discussed in the literature include how some employers (i.e., the person receiving the care) prefer to train PAs themselves in how they want their health care needs to be met, and feel that professional training interferes with their decisions. Community nurses who are being asked to train and sign off PAs can feel it is not part of their role. Many PAs would prefer more training and there is a risk of them being asked to perform tasks beyond their knowledge and competence (Larsen et al. 2015; Norrie et al. 2020). These factors create uncertainty in how it can be ensured that PAs performing the specialised task of manual bowel management have sufficient knowledge to do so.

By directly employing PAs there may be a benefit of the recipient having more power in determining how their care needs are met. If Care Quality Commission (CQC) regulated care agencies such as Monty's (69:70:2011) cannot ensure adequate training of employees, it can be conjectured there may be even greater difficulties for individuals and their PAs to fund and access quality training, and to assess and verify levels of knowledge and competence.

Taking these findings from literature back to interview data, there is evidence of variation in the skill of PAs in performing bowel care and unsafe practices being requested by recipients of this: Dan's (52:52:2015) PA: "The first client was very happy that I did it better than another PA. I think also the client suffers very much when the PA is not good in this manual evacuation." DE397. "Another client we used many suppositories or wanted us to do evacuation longer than it is allowed so I warned him that it is dangerous for him." DE383

Empowerment is laudable, but the potential detriment of not having regulated organisations supplying care providers and ensuring they are adequately trained is of concern. There is also evidence in the interview data above that recipients of care with inadequate physiological knowledge may demand care which may be physically damaging to them. Professional power and their assumed superior knowledge has been criticised in this study. Professionals are however likely to possess superior physiological knowledge relating to how bowel management practices, when they are indicated, should be performed, and potential harm which can arise if incorrectly performed. Knowledge of this nature must be incorporated into the training and practices of PAs and other healthcare providers.

11.7 Having a voice in care provision

Social movements have been discussed as influencing changes towards greater choice and control for those requiring care provision. This correlates with changes discussed over the participant timeline towards service users having increased awareness of available body management choices and the ability to select them over time. Limitations to this have been considered in how much *actual* power individuals had to do this (Section 8.8). To understand and provide further context to this, the political institutional context of these themes was explored through examining policies aimed at increasing the voice of service users and the public in healthcare provision, including through Patient and Public Involvement (PPI) initiatives.

NHS policy documents reveal themes of strategies which appear to enable choice and reduce the power and dominance of professionals. This was done through the introduction of general management and market models of health care provision, and seeking views of the public and service users through PPI (DOHSS 1972; Thatcher 1975; DOH 2005; Healthwatch 2020; Policy-Navigator 2020). Inspecting policy documents reveals however these ambitions are predominantly conceived in terms of information about waiting times, performance

indicators, and choice of care provider. Earlier findings demonstrated these participants wanted more meaningful information about all possible body management options available to them rather than these somewhat superficial choices. Policies do not address this desire of those living with chronic illness. Which services are made available continues to be controlled by professionals and health provider organisations, and it appears PPI has not yet found a method to meaningfully and consistently involve the public in shaping health service provision, or if it has clear and consistent evidence has not been gathered.

11.8 Professional and organisational control

In consideration of policies aimed to give those receiving care a greater voice, documentary analysis suggests that professionals and organisations put structures in place to maintain control over healthcare knowledge and which services will be made available. The Darzi Report (2008, p.27) highlights concerns that the lay population should not access *"myth and hearsay"* on the internet, and stresses the importance of evidence-based medical knowledge. The evidence-based knowledge used to decide best treatment options can be accessed on the NHS Evidence portal, and allows organisations to regulate what is deemed to be evidence-based and scientifically proven to be of benefit, and therefore permitted and provided (NICE 2020b). The assumption prevails that only biomedical knowledge proven by medical practitioners and regulated by NICE constitutes valid knowledge for determining what healthcare provision is made available.

In areas such as pharmaceutical use, it is desirable that only treatments with proven efficacy and safety are provided, but some areas of health management are not amenable to or meaningfully tested using only scientific study and reasoning. This includes the neurogenic bowel management guidelines, where examination has revealed that guidelines do not have the scientific rigour that is boasted or assumed. This guideline has already been discussed in the Wider Landscape chapter as admittedly based on weak evidence, and yet is included on the NICE website and will therefore be assumed to be based on sound scientific evidence.

Considering Darzi's (2008) report further, it purports to encourage innovation and quality improvement, but is limited to perceiving innovations which arise from within the biomedical paradigm. With the stated goal that every care provider will *"systematically measure,*

analyse and improve quality" is hidden the assumption that quality can only be improved by considering aspects of care which lend themselves to measurement and analysis, which insider experiences of care often do not (Darzi and DOH 2008, p.51). The focus of this and other documents persists to be on quantifiable measures of improving quality such as cleanliness and infection rates. Although important, such measures cannot yield knowledge which can be used to find ways to meaningfully improve quality of care, such as that discovered from seeking insider perspectives.

Comparable to the way in which Foucault (1973) suggests doctors select only the biomedical aspects of patients' problems to address as that is what suits them, and the finding that organisations only acknowledge need for which they have a service to meet, a further 'Failure of Care' emerges here. This is that political concern is to select only services to improve which are amenable to measuring and benchmarking. Aspects of care which are meaningful to those requiring care provision including dignity and independence as identified in this research, cannot be measured in this way. Where aspects important to service users are included, such as empowerment, this is limited to allowing choice between existing providers and services rather than a true empowerment to shape and request services, which is the nature of choice these participants have been demonstrated to desire.

More recently, the Five Year Forward View (NHS England 2014) aspired for a more engaged relationship with patients and carers in the health service. Stated aims are for patients to have improved access to information to help make informed choices, empowerment to take more control over their care and treatment, and for services to recognise the importance of patients' own life goals. A key outcome of care is the promotion of wellbeing and independence. These aims echo the desires and motivations of those who underwent early colostomy formation.

Unfortunately and once again, the detail within the document reveals a continued narrow perspective. Improving access to information is defined as access to personal health records, use of personal data, and choice of hospital or care-provider. This is not a vision to inform patients about all potentially beneficial options or truly empower them in decision-making.

The NHS, NICE and professionals remain gatekeepers of what is available and what information is disclosed.

The Five Year Forward View also contributes to failures of care in its ambition to rapidly integrate innovations in health care, as it limits its concept of these to new medicines and improved technology (NHS England 2014, pp.31-34). The assumption persists that innovations will be scientific ones, developed within the biomedical paradigm of health care. It is suspected that qualitatively discerned innovations such as the way in which early colostomy can transform and expand lives will not be amenable to rapid integration, as it is not as easy to quantify and test by the biomedical perspective's gold standard of randomised controlled trials. The stated aim of shifting power to patients is to be done within the parameters put in place by regulatory bodies and professionals. Choice is between existing professionally and organisationally endorsed options, not a choice to step outside these.

Findings in this area now draw to a close and are considered in relation to extant literature and meeting research aims and the question.

11.9 Confluence, divergence, and extension of theory in relation to extant literature

Confluence is observed with theory that suggests society is what disables people by failure to make places fully accessible, with several participants identifying barriers to them accessing public spaces. This research extends theory by demonstrating some participants to be making body management choices to overcome barriers of disabling environments, and this is of potential concern and an area for further investigation.

Examining the literature has informed about institutional movements which have sought to redress power imbalances by changing care arrangements. This research appears to demonstrate a positive translation into practice with those who employ a PA enjoying greater power and autonomy than those receiving intermittent care agency visits. This is however a preliminary finding with insufficient sampling to fully support this finding.

Comparing literature data concerning healthcare rationing with participant experiences and researcher insider knowledge, added understanding to the perceived limits to control in decision-making. Confirmation was found in this research of the gatekeeping roles of healthcare professionals.

In critiquing documentary policy data, the limited vision for innovation, quality improvement, information availability and choice could be discerned. This research provides evidence of an area of healthcare where recipients of care desire more meaningful information and choice. Theory is extended through observation of a phenomenon where a specific patient population are pushing beyond the limitations of what policy makers provide and aspire to.

11.10 Relating findings to research aims and question

Findings in this chapter expand theory by demonstrating previously uncovered limitations to the degree and nature of choice which participants were able to enjoy. These are observed through policies and PPI which only allow this within a pre-determined range of services. This choice is constrained by organisations, professionals, and politicians who only perceive healthcare need which suits them. The legitimacy of the choice to have colostomy is presently controlled by gatekeepers of services operating within a biomedical paradigm, permitted in this healthcare setting but known not to be universally available in others.

The choice to have a colostomy is observed in some early colostomates as related to an effort to overcome disabling environments, from a desire to return to society and pick up their former lives as fully as possible. In the later colostomates, the choice is made by some to overcome limits imposed by disempowering experiences of care provision.

11.11 Chapter conclusion

This chapter has added to Findings by exploring the contribution of institutions to participant experiences of *'Failure of Care'*. This has been done through examination of literature and health policy, and constant comparison with interview data and researcher insider knowledge. Participant experiences have been found to be related to societal change. This

explains the transition from them as passive recipient of care at the start of the timeline, to actively making decisions about body management at the end. Exploring the way in which society disables people has led to the discovery of body management choices being made in response to disabling environments, and the question is raised of whether addressing this would lead to different choices.

Examination of the direction of the political agenda over the course of the participant timeline has revealed failures of policies to meaningfully meet their stated aims of empowerment and choice and to lead to unmet need. Added to earlier findings that healthcare professionals select only physiological needs to address which suit them, is knowledge that organisations only acknowledge need for which they have established services to meet, and policy makers only seek to improve what can be measured. This has illuminated previously hidden potential barriers to accessing and the more widespread adoption of colostomy as a method of bowel management.

Presentation of findings over these six chapters have discussed the detail of the theoretical framework. From universal '*Experiences of Loss*' related to bowel management practices, differing experiences between the early and later colostomates have been demonstrated. Whilst the early colostomates reject widely used bowel management guidelines, the later colostomates are failed by them and '*Progress into Suffering*'. Having a colostomy from a position of active choice or as a continued lack of choice then leads to universal experiences of '*Being Alive Again*'. These themes and experiences of '*Failure of Care*' have been better understood through locating them in the Ideological, Professional, and Institutional contexts in which they have occurred.

A Further Discussion chapter will now reflect upon the research, bring all the findings together, discuss these in final relation to research aims and question, and consider areas for future development of this research.

12.1 Chapter introduction

The research journey started with observation of a deviation from accepted clinical practice occurring within a physiological perspective of bowel function following SCI. This deviation was described in the Wider Landscape as the new phenomenon of the choice for early colostomy following SCI in one UK spinal injury unit. With reasons for this choice not known, constructivist Grounded Theory methodology has been used to investigate this. This has enabled an explanation to emerge which is grounded in data from insider knowledge of those involved, and which allows for shaping of emergent theory by the researcher as a professionally involved expert.

Data has been obtained primarily from semi structured interviews with those with SCI who have chosen to have a colostomy (and two who have not). Secondary data from relevant demographic and statistical information, researcher insider knowledge, the extant literature, and health policy documents have been used. These have provided additional data, identified sensitizing concepts, been used in constant comparison to aid analysis, and been integrated into theory construction. The Methodology and Methods chapters have justified the non-inclusion of a formal literature review and the presentation of findings as six Findings and Theoretical Discussion chapters. The first three presented themes of *'Experiences of Loss'*, *'Progression into Suffering'*, and *'Being Alive Again'*. The final theme, *'Failure of Care'*, was sensed during data analysis as related to the research journey's destination in a New Wider Landscape. This has been explored in the final three Findings and Theoretical Discussion chapters which detail the Ideological, Professional, and Institutional contexts which have contributed to experiences of *'Failure of Care'*.

The Further Discussion chapter will start by restating the research question and aims, and discuss key findings in relation to each of these. The final theory is presented diagrammatically, explanation given, and a theory statement is made. The location of findings within the existing literature is discussed. Clinical guidelines, demonstrated throughout exploration of Findings to be failing, are revisited in the context of what has been learned.

The unique contribution to knowledge which this research makes is examined and implications considered. These include the need for a paradigm shift in professional understanding of bowel management, and for a new model to assess and guide this. In the context of what has been found, it is suggested there is a moral imperative to make information and choice about methods of bowel management more consistently and widely available. Actively working as a clinician over the time span of this research, several early developments have been instigated into clinical practice by the researcher. These will be discussed.

Several limitations of the study have been identified throughout the thesis, and these are reflected on. Areas for further research and methodologies which could be used are discussed. In a final reflection on the quality and rigour of this research, Charmaz's tests of Grounded Theory research are considered.

12.2 Relating findings to the research question and aims:

In each of the six Findings and Theoretical Discussion chapters, research findings have been related to the research aims and the question. These are now brought together in a final discussion of how each has been met. The research aims have been stated to:

- Explore choices made related to bowel care management
- Explore reasons for the decision to have an early colostomy
- Discover differences in experiences between those who have early or later colostomy

The research question is:

'What are the experiences of those living with SCI in relation to choices about bowel management?'

Answers to the aims and the question are interconnected but are considered separately to clarify how each has been met.

12.2.1 Exploration of choices made related to bowel care management

The research journey started with an appraisal of the Wider Landscape of bowel management following SCI. This demonstrated it to be perceived by the healthcare professionals governing it (and this researcher) within a clinical physiological context. Choices, when available, were made in relation to professionally determined and widely used guidelines. These describe progressive stepped interventions from least invasive or conservative methods up to a final intervention of colostomy, deemed the most invasive method. Interview data has demonstrated that historically, limited choice was available to those with SCI and bowel dysfunction, and this was related to a lack of information.

The Wider Landscape described how within the guidelines and in practice, colostomy has been a choice made as a last resort due to the failure of the lower-level and less invasive methods of bowel management, or when complications were severe. This research has confirmed this as the predominate reason why the later colostomates chose to have a colostomy. This choice was made from a position of *'reaching the end of the road'* and is found to be a *'continued lack of choice'* about methods of bowel management. This differs from the *'active choice'* made by the early colostomates discussed in the following section.

Further understanding of why the later colostomates underwent colostomy as a 'continued lack of choice', was gained through exploration of the ideological context of bowel management. This found choices related to bowel management options to exist in relation to the dominant biomedical perspective within which professional knowledge has understood them to occur. With aims of normalising a body function which has become deviant, available options are appraised in terms of how close to 'normal' each is. This ideology favours those which deviate least from normal functioning over ones which most alter it.

Underpinning this is the ideological assumption that it is the healthcare professional who is the appropriate expert to decide how those with SCI should manage their bodies. For those injured longest ago at a time when professionals had greater relative power, individuals have had little choice in bowel management. Reflecting societal changes which have challenged

this ideology, those injured more recently have had greater relative power and involvement in decision-making.

12.2.2 Exploration of reasons for the decision to have an early colostomy

As greater information and choice about possible bowel management options has become available over time, the decisions of the early colostomates have been found to be made from a differing perspective from that of the healthcare professionals who make choices based on the concern to maintain bodily norms. Instead, exploration of insider experiences has revealed an alternative perspective of bowel management, and this has been described as a lifeworld perspective. Choices made from a lifeworld perspective have been found as made in relation to alternative concerns of achieving lifegoals, and maximising freedom and independence. In an inversion of the professional physiological perspective in which lifestyle must be arranged to accommodate bowel management, the insider lifeworld perspective demands that bowel management should be arranged to accommodate lifestyle.

Colostomy for these early colostomates is a choice made as a *'means to an end'* of achieving valued lifegoals. This differs to and cannot be comprehended within an ideology and bowel management guidelines concerned primarily with meeting physiological needs. It has been found that decisions are made about different levels of need in relation to one another and not in isolation.

Exploration of the institutional context of findings led to the additional understanding that for some the choice to have an early colostomy is made to overcome disabling environments in society. It facilitates reintegration into society and enables individuals to re-establish their former lives as fully as possible. It is also a choice made to avoid care provision in the community setting which is known to be inadequate.

12.2.3 Differing experiences of those who have early or later colostomy

With both early and later colostomates '*Experiencing Loss*' related to bowel function, differences then emerge between the two groups. The later colostomates adapted to losses by 'getting used to it', 'Progressed into Suffering', and had a colostomy from a 'continued lack'

of choice'. In contrast, the early colostomates 'rejected guidelines' which failed to accommodate their lifeworlds and lifegoals and made an 'active choice' to have a colostomy. In doing so, they avoided the years lost by the later colostomates through 'Progression into Suffering'.

Explanations for these differences have been found to relate to the participant timeline of injuries and include changes to institutional contexts, information availability, and the power differential between themselves and involved professionals. Participants injured longest ago experienced care provision in a biomedically dominated health setting, where professionals had great power. Decisions in relation to the physiological management of their body function were made by professionals and not questioned. Indoctrination in the pervasive ideology of working hard to make the deviant body conform to idealised norms led them to persist with prescribed management despite the difficulties it created. This led to the belief in some of *'pain and suffering as inevitable'*. Later colostomates eventually *'reached the end of the road'* and were deemed by professionals as requiring the last resort of colostomy. The early colostomates, living in times when the championing of rights for those with disabilities in earlier decades has become fruitful, have benefited from having greater power, more information available to them, and being able to exert greater choice in how their bodies will be managed.

Further differences are observed in how participants utilised colostomy as part of 'planning ahead'. The later colostomates did so to mitigate against further bodily deterioration, and the early colostomates to reduce carer reliance and in relation to achieving higher-level lifegoals. For some later colostomates the decision to have a colostomy was made due to suffering caused by disempowering and failing care provision, with the early colostomates making the decision to avoid this known situation and maximise their independence.

12.2.4 The experiences of those living with SCI in relation to choices about bowel management

Discussion of the research aims has illustrated similar and differing experiences of those living with SCI in relation to choices about bowel management. All *'Experience Loss'*. Loss of

control and loss of dignity related to changes to bowel function and management appear to be an unavoidable aspect of sustaining a SCI.

For the later colostomates whose early experiences occurred within a perspective concerned primarily with physiological management, rigid adherence to progression through stepped guidelines, and without choice in how bowel function will be managed, over time this leads to a '*Progression into Suffering*'. Experiences of this include 'bodily suffering', living in an ongoing state of 'battle with their bodies', the development of beliefs of 'pain and suffering as inevitable', and lives which are dominated by meeting physiological need. This prevents individuals from reaching or aspiring to higher-level lifegoals. In contrast, the early colostomates whose experiences following SCI are occurring in an evolved setting where lifeworld needs are considered, through their 'rejection of guidelines' avoid this 'Progression into Suffering'.

Despite arriving at the decision to have a colostomy from two differing points, both early and later colostomates found this led to resurrection experiences of '*Being Alive Again*'. Managing bowel function by means of having a colostomy enabled the physiological need for bowel function and continence to be met. This then freed individuals to progress to achievement of higher-level lifegoals related to work, family, and lifestyle, and to enjoy new possibilities and raised identity goals. Despite any complications which may arise with the colostomy, participants were unanimously '*still glad to have had it*'.

The phenomenon of early colostomy has arisen in a changed ideological context in which those with SCI have greater relative power in determining how their bodies will be managed and have greater information available to them about potential options for doing this. Exploring reasons for the choice for early colostomy has revealed that this is related to a difference in perspective from the traditional one of healthcare professionals. This difference in perspectives is important and leads into consideration of whether this is indicative of a paradigm shift in the management of bowel function following SCI. This is discussed shortly.

12.3 Relating research findings to extant literature

Stemming from the methodology used, the use and presentation of extant literature in this research has been somewhat unusual. Exploration of the Wider Landscape contextualised the research area within its clinical context and knowledge base. At the point when analysis of primary interview data was complete, extant literature was used as a secondary data source to develop theory. At a late stage in theory development the literature was consulted again to explore the New Wider Landscape and increase understanding of the wider context of participant experiences.

Using literature in this way it has been demonstrated how findings from this research converge, diverge, and extend existing theory. These have been discussed at the end of each Findings and Theoretical Discussion chapter and are now brought together.

12.3.1 Experiences of Loss

Literature consulted in relation to '*Experiences of Loss*' increased understanding of the fundamental need to control the body. This explained the importance to participants of employing methods of body management which would enable them to regain control and independence. Consideration of extant theories increased understanding of participant data and extended theory. One extension was the finding that those with less severe bowel symptoms were able to adapt to '*Experiences of Loss*' by '*living with luck and chance*' in relation to their unpredictable bodies. Those who endured more extreme and relentless suffering in experiences of '*playing Russian Roulette*' were unable to use this adaptive strategy and went on to have a colostomy.

Interaction with literature increased understanding of power differentials within healthcare institutions, and experiences of disempowerment were related to these and to the lack of information and choice given to those injured longest ago. Experiences of bowel management as a loss of dignity and even an assault were echoed in other areas of healthcare. Understanding of dignity itself was increased by perusal of extant theories relating to this, with manual bowel management apprehended as an activity which may inherently lead to a loss of dignity.

An important divergence from extant literature was observed in the nature of information being sought by the early colostomates. Other studies examined described individuals wanting more information about professionally pre-determined management plans. In contrast, participants here went further in questioning such plans and seeking information about alternatives not being readily suggested or made available. From this, new theory was developed that the emergence of the phenomenon of early colostomy may represent a revolutionary patient movement. In this movement, the widely used professionally dictated regimes are rejected and alternatives demanded which fit better with the wider lifeworlds of those they help. This novel phenomenon was not described elsewhere and there is no previously existing theory available to explain it.

12.3.2 Progression into Suffering

The 'Progression into Suffering' observed in the later colostomates was confirmed in literature describing the experiences of others with chronic health needs. 'Struggling with and against the body' was a resonant theme which aided data analysis. The concept of 'conscious body management' enabled distinctions to be made between those who could successfully manage their bodies using traditional methods, and those for whom this led to more severe symptoms which could not be managed in this way. Consideration of 'shrinking lifeworlds' and 'living restricted lives' developed theory relating to the struggles of the later colostomates, and extension of theory was observed in how they responded to this by 'fighting shrinking lifeworlds' and displaying 'determination through suffering'.

12.3.3 Being Alive Again

Sampling of control theory confirmed the benefit of experiencing control even in limited circumstances. Consideration of extant theories of control found that none quite fitted the experiences being observed here and this led to the development of the provisional construct of *'superficial control'*. This describes the surface, outward, and shallow nature of control which participants here were found to have from researcher insider knowledge and consideration of the institutional context of experiences.

Notions of *'identity and bodily hierarchies'* found in the literature together with reflection on Maslow's hierarchy of need aided understanding of the decision-making of participants in relation to bowel management. This led to the creation of theory that decisions about body management are made through a lifeworld perspective in relation to seeking solutions to facilitate attainment of higher-level lifegoal. Needs and goals are perceived relationally and not in isolation.

12.3.4 The wider context of the Failure of Care

During data analysis, an elusive and not fully understood category of 'Failure of Care' emerged. Breakthrough for development of this category came at a late stage of theory development. This was when the theoretical framework became apprehended as situated within a New Wider Landscape, which differed from the starting location of the clinical physiological perspective discussed in Chapter Two. Exploring this new Wider Landscape through exploring and sampling extant literature developed understanding of how the context of participant experiences has contributed to experiences of 'Failure of Care'.

Comparison of participant experiences with dominant ideological concepts of norms and deviancy developed understanding of the interventions professionals instigate to manage bowel function following SCI. The limitations of this perspective resulted in a failure of professionals to understand the importance of wider lifeworld needs in relation to bowel management. *'Pain and suffering as inevitable'* became understood as related to the rehabilitation ideology in which this belief developed, and represents an extension of theory in this area.

Theory which criticises medical technologies as inherently leading to harm and dependency was appraised and developed through constant comparison with participant data. This theory was extended by the suggestion that technologies need to be considered individually in relation to the risk of harm and dependency. Traditional bowel management was seen in fact to raise the risk of these, and colostomy to be a technology likely to reduce them. Critiquing the literature exposed the presence of stigma and prejudice to exist in

professionals relating to colostomies, and a new area of theory suggests this may prevent the option of colostomy being made available to some who may benefit from it.

Consideration of extant literature developed theory by demonstrating how not only can 'professional practices restrict lives', but persistence with them leads to individuals progressing from 'Loss' into 'Suffering'. Compounding this is the finding of 'variations in care provision'. Recent literature has demonstrated the perpetuation of earlier colostomy being perceived only in relation to solving physiological problems, with a continued lack of understanding that it can meet wider and higher lifegoal needs. In many areas there appears to be limited access to information and choice about colostomy formation, with this spinal unit appearing divergent in offering colostomy at an early point after SCI in relation to meeting wider lifeworld needs.

Exploring the institutional context of experiences has informed of theory that 'society disables people' rather than their bodies. An important extension to this is evidence of body management choices being made to overcome barriers of disabling environments. Limits to choice have been identified through consideration of the gatekeeping role of professionals, organisational limitations, and lack of political drive to truly empower health service users. The phenomenon of early colostomy is observed to be a situation in which these barriers have been pushed and which is now being restrained by the recoiling of these barriers.

12.4 The failure of guidelines

A golden thread throughout this research appeared in the introduction of the Wider Landscape and has continued throughout discussion of Findings. This has been the failure of existing bowel management guidelines. As discussion of Findings reaches its conclusion and the research journey destination is arrived at, these guidelines are now revisited in the light of what has been discovered.

The guidelines for bowel management following SCI were introduced in Section 2.4. Their objectives are to facilitate regular bowel emptying and maintain continence, and it is stated

they should be tailored to meet individual need (NICE 2007; Hughes 2014; MASCIP 2021a). Investigation in the Wider Landscape chapter revealed a self-confessed weak evidence-base, and problems of representation on panels which create the guidelines. Together with the acknowledgement that there may be a low uptake of them, multiple problems with these guidelines were indicated at the start of this research and the question raised of their usefulness.

As the research unfolded, evidence was found of the failure of the 'least invasive' methods which the guidelines advocate to provide satisfactory bowel function. Universal and mortifying experiences of incontinence have been discovered in these participants. Persistence with least invasive methods in accordance with guidelines led for some to 'Suffering' and loss of years consumed by difficulties related to bowel function. The expectation within MASCIP guidelines is that effective bowel management can require:

"...considerable resources in terms of time, effort and self-discipline and possibly the input of a carer." (MASCIP 2021, p15)

The wording reinforces professional beliefs within the rehabilitation ideology discussed in Chapter Nine, of how the maintenance of norms is prized no matter the effort involved, and the loss of independence this may produce. The practical outworking of this has been found to not only create *'Suffering'*, but to also develop in some the belief of *'pain and suffering as inevitable'*.

The observed inconsistency within guidelines which state they should be individually tailored and yet follow a successive stepped approach, have been found in practice to translate in the experience of these participants into homogenised regimes. Although lifestyle factors are mentioned in guidelines, these appear not to be adequately incorporated into decisions about bowel management methods. The alternative lifeworld perspective emerging from this research conversely demands bowel management practices should be decided on to accommodate the lifeworld and lifegoals of those requiring them. In a contradiction of the previous quote which advises the help of a carer may be needed, guidelines purport to advocate independence:

"Plan bowel management in collaboration with the individual in the context of their goals and intended lifestyle, aiming to promote autonomy and independence." (MASCIP 2021, p11)

Evidence of the failure of this aim is found in the dependency guidance has created in some on provision of interventions by healthcare professionals. Suspicion is raised of the degree to which bowel management planning truly works in this intended way. Evidence of joint planning of interventions within the context of individual goals and lifestyles is absent for the later colostomates, and only starting to emerge in the experiences of those injured most recently. The mainstay of interventions can in fact reduce autonomy and create dependency, as many are unable to perform them independently.

Consideration of the Ideological, Professional, and Institutional contexts within which guidelines have arisen provides additional information about their potential to fail. From exploration of these contexts, it has been suggested that professionals only select biomedical problems to address which suit them, organisations do not recognised need for which there is not an existing service, and politicians only select services to improve which can be measured and benchmarked. Applying this knowledge to the guidelines lends understanding of the wider factors which have led to the creation and perpetuation of guidelines which are unable to account for the lifeworlds of those requiring them. Professionals working in healthcare settings are concerned primarily with normalising deviant body function, organisations are unable to flex and easily provide a service to meet the increased demand for colostomy, and there is no political drive to incorporate into services an intervention which at this stage can demonstrate only qualitative benefit.

In summary, this research indicates the failure of widely used guidelines to meet the needs of some with SCI requiring bowel management intervention. Their contribution to *'Experiences of Loss'* and *'Progression into Suffering'*, together with ways in which they have led to *'Failures of Care'*, provides evidence of the need for guidelines to be reconsidered and
re-imagined. The new knowledge from this research suggests new guidelines should be created with involvement of those for whom they are made, in a way which incorporates their wider lifeworlds and facilitates achievement of personal lifegoals, as well as containing the physiological knowledge of involved professionals.

12.5 Theoretical framework and theory statement:

Discovery and development of the key themes discussed led to the development, redevelopment, and refining of a theoretical framework to account for the experiences of those living with SCI in relation to bowel management. This is summarised in the final theoretical model (see Figure 29).



Figure 29: The final theoretical framework

All participants '*Experience Loss*' related to bowel management following spinal injury. A divergence then occurs between the early colostomates who '*reject traditional guidelines*', and the later colostomates who '*get used to*' these losses, and then experience a '*Progression Into Suffering*'. From these differing positions the early colostomates make an '*active choice*' for colostomy, and the later colostomates have it from a '*continued lack of choice*'. Both groups of participants following the colostomy enjoy the transformation into '*Being Alive Again*'. The Ideological, Professional, and Institutional context of the framework are found to account for observed experiences of '*Failure of Care*'.

The theoretical framework can be summarised in a theory statement:

Colostomy formation, whether by early active choice soon after SCI or as a last resort with no other choice years later, leads to the transformative experience of Being Alive Again. This occurs as individuals are released from the consuming need to meet physiological goals and become able to achieve higher-level lifeworld goals. This represents an inversion of the reductionist biomedical perspective and guidelines which considers lifestyle must accommodate physiological needs, to a lifeworld perspective which considers bowel management must accommodate lifestyle and lifegoals.

12.6 Original contribution to knowledge

This research has produced new knowledge in an area not previously researched and led to the creation of a novel Grounded Theory. Existing literature has long confirmed the desire to have a colostomy earlier in this population, but this desire has not been explored or understood, with a lack of impetus from professionals and organisations to progress knowledge.

The novel phenomenon of those with SCI seizing the initiative and requesting earlier colostomy represented a new area for research, not known to be previously investigated. The phenomenon has been discussed as representing a puzzling anomaly for involved professionals, as the documented desire for earlier colostomy is translated into the actual performing of the colostomy at a much earlier point.

By exploring insider experiences, this research has contributed new knowledge about the experiences and motivations of those with SCI in relation to choices about bowel management. More has been uncovered about the '*Experiences of Loss'* and '*Progression into Suffering'* which reliance on 'least invasive' methods of bowel management can produce. New knowledge about the nature of information desired by individuals has revealed that more meaningful information is demanded than has been made readily available by professionals, or which politicians and organisations wish to publish.

This research has provided a unique insight into the experiences of people having colostomy at differing times post injury. The important discovery has been made of the differing perspectives between professionals conceiving bowel management in terms of managing deviant physiological function, and participants who conceive it from a differing perspective in which higher-level lifegoals determine how bowel function can best be managed. Notions of 'invasive' and 'conservative' methods of bowel management have been disrupted by exploration which has demonstrated these terms of elusive origin to be understood differently by professionals and those who experience them. It has demonstrated that colostomy is chosen because it meets the need to fulfil higher-level lifegoals such as for independence or to re-establish social, family and working lives and aspirations.

From this, the research has exposed the need for the development of new guidelines for bowel management following SCI. It has been demonstrated that widely used guidelines are failing to meet their own aims, and the discrepancy observed that purportedly evidencebased guidelines acknowledge themselves to have a weak evidence-base. It has further been found that in practice guidelines are not being used to develop individualised management plans which reduce dependency and incorporate individual lifegoals.

The new knowledge presented in this research of failing guidelines, differing perspectives, the transformative benefits of an option perceived previously as a last resort, and exploration of a novel phenomenon has revealed important areas for further research and development of services. The implications of findings are now discussed.

12.7 Implications of findings

The findings of this research have important implications for practice. These will be discussed as representing an impending paradigm shift in how bowel management is conceived, the need for a new question to be asked of bowel management, the requirement for a new model for bowel management to be created, and the imperative for information and choice to be made more freely and consistently available. This is in response to the fear that some with SCI are imprisoned in suffering related to bowel management, and living lives limited by the need to meet lower-level physiological goals. These implications are now discussed.

12.7.1 The need for a paradigm shift

Paradigms are described by Kuhn as defining reality for the scientist and providing a framework to identify and solve problems (Kuhn 1957, 1996). He considered that rather than being cumulative or evolutionary, scientific facts emerge from new ways of thinking or new paradigms. 'Paradigm shifts' are described by Kuhn as being precipitated by increasing numbers of anomalies appearing, a crisis occurring, and disaffected individuals seeking alternative explanations (Kuhn 1957; DeJong 1979; Kuhn 1996; Younas and Parsons 2019). A paradigm shift occurs when one paradigm is simultaneously discarded in favour of another.

Kuhn's (1957) theory has explanatory power for the phenomenon of early colostomy. Statistical evidence from this setting has demonstrated the increasing occurrence of the anomaly of early colostomy (see Figure 16 on page 113). This anomaly cannot be explained within the present biomedical paradigm within which bowel function is understood. The early choice for a more 'invasive' method of body management is nonsensical in this paradigm. This has been a stumbling block and the point at which previous research has halted.

A looming crisis in this area can be discerned from Findings of the research. It has been described how colostomy is denied in some regions, and not understood by some healthcare professionals and gatekeepers. Despite being allowed within the hospital setting being studied, organisational issues of capacity are emerging, and inadequacies have been revealed in pathways and availability of information. This research represents an attempt to find an explanation for the observed phenomenon of the anomalous choice for early colostomy (although the researcher would not describe themself as necessarily 'disaffected'!).

The stage is set with new knowledge created from this research, understanding increased, and a new lifeworld perspective of bowel management suggested. It must now wait to be seen how this research is received by involved communities and professionals, and whether a new paradigm informed by the lifeworld experiences of those involved will emerge to replace the old physiologically conceived one.

12.7.2 The need for a new question

The new knowledge that decisions about bowel management are being made in relation to the wider lifeworlds of those requiring them and not purely in terms of physiological function, leads to the need to reframe the question which is asked in relation to bowel management. It is when a new question is asked that Kuhn (1996) states scientific revolutions and paradigm shifts to occur. Bowel management following SCI can be understood as presently operating within a biomedical paradigm which asks the question: 'How can adequate bowel function be achieved following SCI in the closest to normal and least invasive way possible?' Findings from this research lead to a new question emerging of 'How can bowel function best be managed to accommodate wider lifeworlds and facilitate achievement of higher-level lifegoals for those with SCI?'

Bowel management guidelines need to be developed which answer this new question, and consideration of how they might do this has led to the development of a provisional new model, now discussed as a further research implication.

12.7.3 A new model is needed and is tentatively proposed

From this alternative question asked within an alternative framework of understanding, a new bowel management model and guidelines are needed. With no existing alternative model available, a provisional new model is suggested in Figure 30 for future testing and development by professionals, those with SCI, and researchers in the field.

The model is conceived as a basis for discussion between healthcare professionals and the individual, for joint decision-making and planning of bowel management interventions. This model starts by establishing understanding of the lifeworld of the individual with SCI. From understanding what is important to them, goals can be developed and prioritised. It is important to identify limiting factors, which will include bodily limitations and resource availability. The decision to have a colostomy has been found in this research to be made at times in relation to disabling environments and the availability of ongoing care provision. Whether these *should* be factors which need to be considered is open to discussion, but of necessity they will need to be taken into account. From consideration of the first three areas,

it can then be jointly decided how bowel management can best be performed, and how and when it will be evaluated.



Figure 30: Lifeworld Body Management Model

This provisional Lifeworld Body Management Model is proposed in terms of management of bowel function. It is not known what models are used presently for management of other body systems as this is outside the scope of this research, but this model could potentially be used in other areas or for planning of whole body management.

12.7.4 The need for equal access to information and choice

As themes of '*Experiences of Loss*' and '*Progression into Suffering*' have emerged, and the limited existences of some individuals prior to having their colostomy has been revealed, the question is posed of how many individuals are still living in similar situations and remain in ignorance of the potential life expanding option of having a colostomy? This question gives a moral imperative to increase the availability of information and choice concerning bowel care management following SCI.

It is hoped that publication of this research and increased awareness of the findings will lead to information about alternative bowel management options being made more widely and consistently available. It is of further importance that information about the option of colostomy is made available to all and not only to those whom professionals consider will benefit physiologically from a colostomy. The wider lifeworlds and contexts in which people may arrive at the decision to have a colostomy are not known by professionals and have been demonstrated here as not limited to physiological concerns.

It is hoped that wider dissemination of information and increased choice availability will prevent individuals from living lives dominated by meeting lower-level physiological goals and developing the life view of Terry (28:51:2015) and Graham (21:71:2012) of *'pain and suffering as inevitable'* aspects of life following SCI.

12.7.5 Wider research finding implications

Interaction with the literature during this research has demonstrated that bowel management following SCI is not the only area of healthcare in which limited information is available, choice is not allowed, and professional practices have led to individuals living restricted lives. In demonstrating the need to gain insider knowledge of the experience of professionally developed and instigated body management guidelines, it is hoped this will be replicated in other areas of healthcare. This may expose misconceptions, and reveal further areas where paradigm shifts and new questions are needed. This may increase the possibility of experiencing '*Being Alive Again*' through having the choice to adopt body management methods which can lift individuals from the all-consuming task of meeting physiological need, and enable them to re-enter lost worlds and meet higher-level goals and aspirations.

12.8 Early developments from this research

Continuing in active clinical work throughout this research has enabled the researcher to innovate change as it became indicated. An early, consistent, and compelling thirst for information was identified during data collection and analysis. This led to the researcher liaising with spinal unit senior nurses and introducing a novel colostomy information session open to all inpatients. This now forms part of the rolling programme of education provided

by the unit for inpatients. It comprises information about anatomy and function involved in a colostomy, practical management information which includes use of visual aids and a mannequin, discussion of lifestyle implications, the advantages, disadvantages, and potential problems of having a colostomy. An insider perspective is provided by an individual with a spinal injury who chose to have a colostomy, and the opportunity to ask questions of both them and the stoma care nurse is given. Practice packs are given so that inpatients can if they wish experiment with what it might feel like to wear a colostomy pouch. (See Figure 31).



Figure 31: Colostomy information session

In tandem with this, it was found that no existing written information was available to meet the needs and answer the questions of specific relevance to this group in considering a colostomy. The researcher has therefore written a short, tailored information booklet which gives relevant information, and discusses advantages and disadvantages of having a colostomy following SCI. This includes a section where two individuals with SCI and a stoma give their perspectives of the difference having a colostomy has made to them. A printed version of this booklet is freely available from the stoma department and spinal unit of this hospital, is given to inpatients and outpatients of the spinal unit, is available for download on the website to members of the Association for Stoma Care Nurses, on the hospital intranet, and by contacting this researcher. It can be found in Appendix 9. The inconsistent way in which those interested in having a colostomy were managed, led to multidisciplinary team discussion of the best pathway for this. A new referral process was instigated, and a novel 'joint clinic' was introduced in which individuals met with both the colorectal surgeon and the stoma care nurse for joint assessment and provision of information. Frustratingly the Covid-19 pandemic halted this clinic and has disrupted the pathway, but efforts are presently underway to re-establish this more cohesive service.

A final development from this research arose during the later stages of this research, and because of the publication of quantitative findings related to this research being published in an international journal (Boucher et al. 2019). This publication was used in a recent update to the clinical practice guideline for bowel management guidelines following SCI, written by an international team of experts from a wide range of professionals (Johns et al. 2021). These guidelines were written with the aim:

"...not as a revision of the previous guidelines, but as a fresh review and critical analysis of the available literature and practice in this area." (Johns et al. 2021, p.77)

In detailing and advising on all potential methods of bowel management, guidance in this document relating to colostomy has changed for the first time and as a direct result of the early findings of this research. The researcher's publication is quoted by them, and advises that colostomy be not only performed as a last resort, but in a new additional clause it is stated that it may be performed earlier if the individual prefers this:

"10.3 Colostomy is recommended for individuals with severe NBD [Neurogenic Bowel Disorder] for whom other treatment modalities have failed or who have had significant complications.

10.4 Colostomy can be a choice for individuals with NBD who prefer the option after thorough education regarding risks, benefits, and complications and after shared decision making with their providers." (Johns et al. 2021, p.121)

The addition of this new clause in relation to the option of colostomy marks an important step towards guidelines changing to incorporate knowledge from insider experience of bowel

management, to allow the individual to choose options which fit with their wider lifeworld perspective, and is an encouraging development.

12.9 Limitations of the study

Potential limitations of this research are now considered. This study was undertaken to explore the experiences of those who chose to have a colostomy at differing times following SCI. An amendment was made to interview participants who had not had a colostomy when this became theoretically relevant. As other areas of potential interest emerged later such as in Section 7.4, there was insufficient data from the small sample of those without a colostomy to fully develop theory. This limitation was accepted in the decision that whilst useful to start developing answers to theoretical questions of differences between those with and without a colostomy, it was not possible to fully explore all potential lines of investigation. The study was reigned back into focussing on the pursuit of understanding the experiences of those who had a colostomy at differing times.

Related to this is potentially 'missing data' from those who received information about a colostomy but did not choose to have it. In this study it would not have been possible to identify such individuals, but with the introduction of the regular information sessions for spinal unit inpatients, it could be possible in future study to identify and explore the experiences of this group of people.

Data collection was stopped when theoretical saturation was felt to have been reached, but late-stage analysis revealed gaps in the participant timeline, with no one interviewed who sustained their SCI during the 1970s or 80s. With theory well developed at this point, it was considered whether further purposive sampling was required to interview participants injured during the gaps in the timeline. Despite the largest gap in time occurring between Graham (21:71:2012) and Terry (28:51:2015) sustaining their injuries in 1962 and 1992, data from their interviews in key areas concerning information availability and lack of choice was similar. Contrarily, participants injured within only five years of each other demonstrated marked differences relating to this. Deliberating this, it was unknown whether change occurred most rapidly in the period 2010 - 2016 from which participants had already been

interviewed, or whether sampling more participants in timeline gaps would reveal other periods of rapid change.

A conclusion had not been reached about this when the Covid-19 pandemic started, and in March 2019 most in-person outpatient appointments in the research setting ceased. The routine follow-up appointments which had been the basis of convenience sampling halted, those with SCI were amongst those required under government rules to 'shield', and in person interviews would not have been permissible. Any future interviews would therefore have to take place virtually or by phone, meaning they were not performed consistently. Consistency of sampling strategy as it is described in Section 4.2.2 would also not have been possible, as there were no future appointments to search for on the hospital booking system. Together with uncertainty about whether it was necessary to sample participants from gaps in the timeline, the decision was made not to attempt any further interviews. The gaps in the timeline are acknowledged as a limitation of the research and are an area for future study.

A further potential limitation of the study is the eclectic use of literature as a secondary data source. Secondary data was sampled by searching the library database using codes or theoretical questions as key terms. Using exact words of codes as search terms, for example *'Being Alive Again'*, at times yielded no relevant results. This led to searching using related terms such as in this example *'regaining self'*. Using alternative search terms was problematic as it imported researcher interpretation of meaning into searches, at times yielded unmanageably high numbers of search results, and literature of potential importance may have been missed. This limitation was difficult to overcome on a practical level and may raise concern relating to the rigour of literature searching.

In defence of this, the methodology and methods of this research must be considered. A comprehensive literature review has not been a stated aim of this research. Literature has instead been used as stated in Section 4.5.2 to explore emergent themes, provide secondary data, identify and contextualise emerging theory, add quality and rigour by comparison with existing theory, and develop and explore themes and ideas. Decisions were made in sampling data about which codes were most central to the theory. Incidental findings of pertinent

codes such as *'living with luck and chance'* were drawn into theory development, and search terms were used which seemed most related to codes and themes.

Literature was treated as data and sampled rather than all possible relevant literature rigorously searched. This means it may not be representative of all possible literature which could have been found from sampling all possible codes, with other incidental findings, and using alternative search terms. This mirrors the fact that data from participant interviews may not be representational of everything a participant could possibly have stated or what the entire population of those with SCI and a colostomy could have stated. Gathering all possible data is not perceived as possible within the methodology and methods being used. This has not been performed as positivist or post-positivist research seeking an objective and external reality, rather it is a unique constructivist Grounded Theory which gives a single representation of the particular data sampled and interacted with by one researcher. Data here is only representative of this research journey, and not the whole available landscape. The eclectic use of literature is therefore acknowledged as a limitation which is inherent in the methodology used, but is consistent within it.

Other potential limitations of this research arise from the presence of a relative or carer which may have influenced what a participant stated or withheld. The individual's preference in whether a companion was present during interview was respected, as it was considered that their choice in this would best facilitate them feeling comfortable and relaxed in the interview setting.

Further efforts could have been made to check the emergent theory for resonance with those interviewed. Only one person was interviewed a second time to clarify meaning and gain further information. It was not felt practicable to interview others a second time as they were not due to return to the hospital, but they could have been contacted by other methods. Simultaneous data analysis and collection did allow for emerging concepts to be checked in future interviews, and participants did in this way confirm resonance and were therefore co-constructors of theory.

12.10 Areas for further research

As this study commenced, there was no published research on the experiences and outcomes of early colostomy following SCI. At its conclusion only one publication, other than by this researcher, was found to discuss it, by Cooper et al (2019). With more now understood about the choices and timing of colostomy, areas have been revealed in which further research now needs to be undertaken.

This constructivist Grounded Theory has provided a starting point for research in an area in which little was known. Further interpretivist constructivist research can be used to build upon understanding gained here and further increase knowledge about the themes identified, some of which it was not possible to fully explore within the constraints of this study. This includes dignity within bowel management, experiences of shrinking lifeworlds, the proposed construct of *'superficial control'*, and exploration of professional attitudes relating to stoma formation and the impact this has on practice and availability of information and choice.

The experiences of those undergoing early colostomy suggest it may ease transition back into life following inpatient rehabilitation after SCI by enabling freedom, reducing reliance on caregivers, and increasing experiences of control. Further research is needed to test and support these findings. It may also be that the provision of information about body management alternatives may be of benefit in coming to terms with changed life circumstances following SCI, and this is of interest to research.

The early clinically driven questions can be returned to and explored now that a framework has been constructed to understand choices. These questions include the risk and benefits of early colostomy, and a post-positivist framework may be a useful paradigm to help quantify these. This research found a high number of participants to be experiencing complications related to their stoma, and more needs to be known about the clinical and physiological dimensions of this. It will also be useful to learn more about why this population are *'still glad to have'* their stoma despite experiencing complications relating to it.

Research including that performed within a conflict theory perspective will help to identify why bowel management guidelines have not changed despite repeated findings that colostomy is an acceptable method which is desired earlier following SCI. Conflict theory will also be helpful in further exposing the barriers which have been identified in the exploration of the ideological, professional, and institutional context of the research. Other as yet unknown areas impacting experiences may be identified, and more can be discovered about changes related to the participant timeline. By developing knowledge and understanding and exposing barriers, it is hoped change will follow.

Further research is needed to develop new guidelines for bowel management following SCI. The evidence used for existing guidelines needs a fresh and transparent appraisal, and consideration needs to be given of their usefulness in their present form. Whether an 'evidence-based portal' such as NICE is the correct place for guidance based on weak evidence to be displayed may need to be reconsidered. MASCIP guidelines which have not meaningfully reappraised evidence in their latest version may need to be examined again. The new model which is tentatively and provisionally proposed in this thesis will require further research and development. It is hoped that publication of these findings will lead to professional debate and the inclusion of those requiring bowel management interventions in future research which will redefine bowel management guidelines.

12.11 Reflecting on quality and rigour of the research

Criteria for assessing quality and rigour in Grounded Theory research were discussed in section 4.7. Charmaz has described tests for these as to consider the credibility, originality, resonance, and usefulness of research. How this research has met these criteria is demonstrated in the table below.

Charmaz's criteria		Evidence of meeting criteria			
Credibility:					
•	Has research achieved intimate familiarity	•	Rich interview data has provided depth and		
	with the setting of topic:		management following SCI.		

•	Are the data sufficient to merit your claims?	•	Data provided demonstrates themes of
			Loss, Suffering, Being Alive Again, and
			Failure of Care.
•	Have you made systematic comparisons	•	Experiences of early and later
·	have you made systematic comparisons		colostomates, and those with higher and
	estogeries?		lower-level injuries have been explored and
	categories!		analysed in relation to codes and themes
			Systematic and consistent constant
			comparison has been performed.
	Do the categories cover a wide range of	•	Primary and secondary data were gathered
•	empirical observations?		until theoretical saturation was reached
	Are there strong logical links between the	•	Constant comparison ensured the
•	Are there strong logical links between the		theoretical framework is grounded in the
	gathered data and your argument and		data
			Extensive data segments are quoted and
•	Has your research provided enough		mothods have been clearly explicated
	evidence for your claims to allow the reader		methous have been clearly explicated.
	to form and independent assessment – and		
	agree with your claims?		
Origina	ality:		
•	Are your categories fresh? Do they offer	•	Comparison with existing literature has
	new insights?		demonstrated new codes and extension of
			existing knowledge.
•	Does your analysis provide a new	•	A new understanding of insider experiences
	conceptual rendering of the data?		has been demonstrated
•	What is the social and theoretical	•	This work gives new understanding of
	significance of this work?		bowel management insider experiences
			and must lead to reassessment of current
			guidelines and practices to improve the
			lives of those they affect.
•	How does your grounded theory challenge,	•	Current ideological understanding and
	extend, or refine current ideas, concepts,		practices are challenged and fresh insights
	and practices?		given.
Resona	ance:		
•	Do the categories portray the fullness of the	•	The categories describe well the depth and
	studied experience?		breadth of experiences
•	Have you revealed both liminal and	•	Evidence is provided of divergent insider
	unstable taken-for granted meanings?		and outsider understanding of practices.
			and a potential paradigm shift is described.
•	Have you drawn links between larger	•	Findings are linked to their wider
	collectivities or institutions and individual		ideological, professional, and institutional
	lives, when the data so indicate?		contexts.
		1	

•	Does your grounded theory make sense to	•	Sensitizing concepts of early interviews
	your participants or people who share their		resonated with those interviewed later.
	circumstances? Does your analysis offer		Ongoing professional encounters give
	them deeper insights about their lives and		evidence of the resonance of findings in the
	worlds?		wider population with SCI.
Usefulness:			
•	Does your analysis offer interpretations	•	Findings help individuals understand the
	that people can use in their everyday		benefits of colostomy in the context of their
	worlds?		wider lifeworlds.
•	Do your analytic categories suggest any	•	The importance of control, independence,
	generic processes?		and higher lifegoals are demonstrated.
•	If so, have you examined these generic	•	The need to incorporate these into body
	processes for tacit implications?		management guidelines is demonstrated.
٠	Can the analysis spark further research in	•	Several areas for further research have
	other substantive areas?		been demonstrated and discussed.
•	How does your work contribute to	•	The unique contribution to knowledge has
	knowledge? How does it contribute to		been stated. This knowledge can be used to
	making a better world?		create guidelines which accommodate
			understanding of the lifeworlds of those
			using them, and facilitate the meeting of
			higher lifegoals.

Figure 32: Charmaz's criteria for Grounded Theory Studies (Charmaz 2014, p337)

12.12 Chapter conclusion

The Further Discussion chapter has restated the research question and aims and discussed findings in relation to each of these. The use of literature in this research has been summarised, and it has been discussed how this developed key themes and extended knowledge. Bowel management guidelines have been revisited in the light of research findings. The failure of these has been found to not only be the failure to meet their stated aims, but also to lead in some to years of suffering, the belief that this was inevitable, and homogenised routines which dictate and restrict lifestyle and create dependency.

The final theoretical framework has been stated and the final framework given. The original contribution which this research makes has been discussed. This includes new theory about a previously undescribed emerging phenomenon for which no extant literature was

available. A novel Grounded Theory has been developed. Experiences and motivations in relation to choices about colostomy in those with SCI has been discovered, differences found in how bowel management is perceived by professionals and those with SCI, and the need for new guidelines has been identified.

Research implications have been discussed as including the need for a paradigm shift in how bowel management is understood, the need for more meaningful information and choice to be made available, and the need to include those who will be using bowel management guidelines in their future development. Early developments from the research have been disclosed, made possible by the researcher continuing to engage in clinical practice as findings unfolded. These developments have included innovations to practice and the encouraging additional clause in international guidance which suggests early colostomy may be deployed. This clause is related to an early publication of this research.

Limitations have been discussed, and areas for further research have been identified. Having reached the end of the research journey, the final chapter will now reflect on this and provide concluding remarks.

Chapter Thirteen: Concluding Remarks

This research has explored an important and revolutionary phenomenon. Individuals with SCI are stimulating change by requesting earlier a bowel management option considered by healthcare professionals to be invasive, and which historically has been used as a last resort intervention. Evidence from previous research that those with SCI benefit from colostomy and would like to have it performed earlier has not been understood or progressed. Healthcare professionals, limited by understanding bowel management from within a biomedical perspective, have remained tethered to physiological guidelines which are ostensibly evidence-based. Investigation has revealed these as based on weak evidence and created without the involvement of those for whom they are designed. There has been a failure to understand or, until this research, little attempt made to understand why individuals may make the choice to have a colostomy following SCI at an increasingly early point following injury.

Insider knowledge uncovered in this research has revealed that those with SCI are making body management choices in the context of their wider lifeworlds. Solutions to the functional problems they experience are sought in relation to achievement of their higherlevel lifegoals and ambitions. This is important and has not been appreciated or adequately incorporated into professionally instigated bowel management guidelines. These instead focus on hard work to force the body into maintaining norms, with lifestyle having to fit around body management rather than vice versa as these individuals desire.

This research suggests that the phenomenon of early colostomy may herald a scientific revolution and paradigm shift in how bowel management is understood. A new question is emerging of how bowel management can best accommodate the wider lifeworlds and facilitate independence and freedom to pursue lifegoals for those with SCI. Professionals need to acknowledge the revolution which these individuals have started and reflect on their own understanding of bowel management.

This novel Grounded Theory has created a knowledge basis from which understanding can be progressed. Further research is now required using a variety of methodological perspectives to progress knowledge, answer the new question, and develop new guidelines which better account for the lifeworld and lifegoals of those who require them. This should be done with the involvement of those they concern. Clinical and physiological questions which were the original motivation for embarking on this research, can now be better framed, and pursued. Consideration of the ideological, professional, and institutional context of the phenomenon has demonstrated the presence of barriers to innovation in this area. These require further exploration and understanding to identify how they might be overcome. Future research using different perspectives to answer a variety of questions will develop and enlarge the relatively small body of knowledge in this area.

In exploring this phenomenon, the researcher has undergone a transformation in understanding. Starting as an involved healthcare professional with a biomedical understanding of bowel management, this research was conceived initially in relation to clinical concerns and physiological outcomes. At the finish, and now as a researcher, there is greater understanding of the lifeworlds, experiences, and motivations of those with SCI when they make choices about body management.

The personal driving force to continue developing knowledge in this area for this researcher arises from repeated and ongoing professional encounters with those living with SCI, whose lives are limited to the point of them being imprisoned by their bowel function and management. New understanding of the transformation into '*Being Alive Again*' which having a colostomy can produce, will motivate this researcher to keep investigating, and to ensure that information and choice become more widely and freely available so that others can have this resurrection experience.

This Grounded Theory is a starting point which it is hoped will stimulate professional debate and lead to development of knowledge and practice in this area. The proposed new model is offered for refinement and others invited which will transform bowel management guidelines into ones which are centred on the lifeworld perspective of those they affect. It is hoped professionals will join the revolution those with SCI have started, and changes to

professional practice in this area will enable others enduring 'Loss' and 'Suffering' to be transformed into 'Being Alive Again'.

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Appendices

Appendix One: Interview guide

Early or later elective colostomy following Spinal Cord Injury (SCI)

Interview Guide

Date:	
Interviewer:	
Participant ID no:	
	My notes
Introduction:	
 Thanks for participating 	
Overview of research	
Use of audio recorder	
May take notes	
Tell me about your decision to have a	
colostomy	
How do you feel about the colostomy	
How did you first hear about colostomies as	
an option	
what factors did you consider when thinking	
about naving a colostomy	
who did you discuss it	
notionts?	
How are things different for you before and	
rinco the colostomy	
What has been the impact on your	
Work	
Belationshins	
Salf actoom	
Have there been any problems related to the	
colostomy	
Tell me about the timing of the operation	
following your injury	
When do you think the best time to have a	
colostomy following SCI iswhy?	
Is there anything else you would like to talk	
about concerning colostomy following SCI	

Interview Guide

17/11/16

Version 1.0

Appendix Two: Example of coding spreadsheet

		Loss	
		Later colostomates	Early colostomates
Loss	Loss of	Loss of time	Loss of time
	personal		
	journey		
		Being restricted by body	Being restricted by body
		Loss of confidence in body	Loss of confidence in body
		Loss of independence	
	Loss of agency	Loss of dignity	Loss of dignity
		Loss of control	Loss of control
		Homogenization of care	Homogenization of care
		Not being given choice	
		Passivity	
		Not having care needs met	
		Being powerless	
	Failure of care	Wanting easier management	Wanting easier management
		Failure of the regime	
		Variations in care	
	4	Pain and suffering	
		Later colostomates	Early colostomates
Pain and suffering	Bodily suffering	Reaching the end of the line	
		Experiencing distressing	Experiencing distressing symptoms
		symptoms	
		Being damaged by bowel care	
		Bowel care impacting on life	
		Bodily decline	
	Pain as inevitable	Being told to get on with it	
		Pain as inevitable	
		Regaining self	
		Later colostomates	Early colostomates
Regaining self	Regaining self	Care becoming easier	Care becoming easier
		Living with confidence	Living with confidence
		Regaining dignity	Regaining dignity
		Body healing	Body healing
		Experiencing freedom	Experiencing freedom
		Reducing need for care	Reducing need for care
		Life being made easier	
		Regaining roles/being alive	
		again	
		Release from suffering	
			Regaining control over body
			Choice helping adaptation
		Regaining agency	Regaining agency

Appendix Three: Excerpt from literature search codes and questions list

Search terms	Number of articles
	reviewed
"Regaining self" OR "regaining identity" AND "injury" OR	18
"injuries" OR "accident" OR "trauma" OR "chronic illness"	
OR spinal injury OR "spinal cord injury"	
'Identity' AND 'self'	23
'Identity' AND 'self' AND 'spinal cord injury'	10
'Dehumanization' AND 'chronic illness' OR 'chronic disease'	2
OR 'chronic sickness' OR 'chronic disorder' OR 'chronic	
condition'	
'Loss of dignity' AND 'chronic illness' OR 'chronic disease'	2
OR 'chronic sickness' OR 'chronic disorder' OR 'chronic	
condition'	
'Loss of control' AND 'spinal cord injury' OR 'SCI' OR 'spinal	5
injury' AND 'experiences'	
'Loss of control' AND 'chronic illness' OR 'chronic disease'	6
OR 'chronic sickness' OR 'chronic disorder' OR 'chronic	
condition' AND 'experiences'	
'Failures of care' AND 'community care provision'	3
'Variations in care' AND 'community care' OR 'community	1
setting' OR 'community nurse' OR 'community nursing'	
'Shrinking life world'	2
'Loss of time' AND 'spinal cord injury' OR 'SCI' OR 'spinal	1
injury' AND 'bowel management'	
'Suffering' AND spinal cord injury' OR 'SCI' OR 'spinal injury'	1
AND 'bowel management'	
'Reaching the end of the road'	1
'Expanding self' AND 'grounded theory'	2
'Changes over time' AND 'NHS' or 'National Health Service'	11
AND 'policy'	
'Patient and public involvement' AND 'shaping services'	8
'Personal health budgets' AND 'evaluation' AND 'control'	9
'Spinal cord injury' OR 'SCI' OR 'spinal injury' AND	29
'colostomy' OR 'stoma'	
"Regaining self" OR "regaining identity" AND "injury" OR	18
"injuries" OR "accident" OR "trauma" OR "chronic illness"	
OR spinal injury OR "spinal cord injury"	
'Patient and public involvement' AND 'shaping services'	8
'Personal health budgets' AND 'evaluation' AND 'control'	9
Superficial control	0

Appendix Four: REC Ethical approval letter



East of Scotland Research Ethics Service (EoSRES)

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

Mrs Michelle Boucher Stoma Care Clinical Nurse Specialist Salisbury NHS Foundation Trust Salisbury District Hospital Stoma Care Dept, Level 3 SP2 8BJ TAyside medical Science Centre Residency Block Level 3 George Pirie Way Ninewells Hospital and Medical School Dundee DD1 9SY

1

 Date:
 01 December 2016

 Your Ref:
 Drift

 Our Ref:
 LR/16/ES/0144

 Enquiries to:
 Mrs Lorraine Reilly

 Direct Line:
 01382 383878

 Email:
 eosres Layside@nhs.net

Dear Mrs Boucher

Study title:	An exploration of the experiences of patients who choose to have a colostomy for bowel management after sustaining a Spinal Cord Injury (SCI) either early in their rehabilitation or later on.
REC reference:	16/ES/0144
Protocol number:	n/a
IRAS project ID:	214879

Thank you for your letter of 30 November 2016, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Mrs Lorraine Reilly, eosres.tayside@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.



Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise). Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, <u>www.hra.nhs.uk</u> or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant. There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact <u>hra.studyregistration@nhs.net</u>. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:



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Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [insurance and indemnity]		18 July 2016
Interview schedules or topic guides for participants [interview guide]	1.0	17 November 2016
IRAS Application Form [IRAS_Form_17112016]		16 November 2016
IRAS Checklist XML [Checklist_30112016]		30 November 2016
Letter from funder [funding certificate]		
Letters of invitation to participant [invitation letter]	1.1	17 November 2016
Other [sponsorship letter]		06 September 2016
Other [Response to research ethics service provisional opinion]		30 November 2016
Participant consent form [Consent form]	1.2	30 November 2016
Participant information sheet (PIS) [Participant information sheet]	1.2	30 November 2016
Research protocol or project proposal [Research protocol (highlighted changes)]	1.1	17 November 2016
Summary CV for Chief Investigator (CI) [Desiree Tait CV]		02 November 2016
Summary CV for student [Michelle Boucher CV]		11 November 2016
Summary CV for supervisor (student research) [Peter Thomas CV]		01 November 2016
Summary CV for supervisor (student research) [Desiree Tait CV]		02 November 2016

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback



You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/guality-assurance

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

Please quote this number on all correspondence

16/ES/0144

Yours sincerely

I Reilly

pp Mr John MacLeod Alternate Vice-chair

Email: eosres.tayside@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to:

Dr Fiona Knight, Bournemouth University Mrs Louise Bell, Salisbury NHS Foundation Trust Dr Desiree Tait, Bournemouth University HRA Approvals



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Appendix Five: REC Amendment approval letter



East of Scotland Research Ethics Service (EoSRES)

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

Dr Desiree Tait Senior Lecturer in Adult Nursing Bournemouth University Bournemouth House B215, , 19 Christchurch Road Bournemouth BH1 3LH
 Date:
 25 July 2019

 Your Ref:
 DL/16/ES/0144

 Enquiries to:
 Mrs Diane Leonard

George Pirie Way

Dundee DD1 9SY

TAyside medical Science Centre

Ninewells Hospital and Medical School

Residency Block Level 3

Enquiries to: Mrs Diane Leonard Direct Line: 01382 383871 Email: eosres.tayside@nhs.net

Dear Dr Tait

Study title:

REC reference: Protocol number: Amendment number: Amendment date: IRAS project ID: An exploration of the experiences of patients who choose to have a colostomy for bowel management after sustaining a Spinal Cord Injury (SCI) either early in their rehabilitation or later on. 16/ES/0144 n/a AM01 (For REC Reference Only) 11 July 2019 214879

The above amendment was reviewed on 24 July 2019 by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

No ethical issues were raised.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP)	AM01	11 July 2019
Other [Covering Email]	22	17 July 2019
Participant information sheet (PIS) [(Highlighted Changes)]	1.3	11 July 2019
Research protocol or project proposal [(Tracked Changes)]	1.1	11 July 2019



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Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities- see details at: <u>https://www.hra.nhs.uk/planning-and-improving-research/learning/</u>

16/ES/0144: Please quote this number on all correspondence

Yours sincerely

Leonard. (1)

for Mrs Natalie McInally Vice-Chair

Email: eosres.tayside@nhs.net

Enclosures:

List of names and professions of members who took part in the review

Copy to:

Mrs Julie Northam , Bournemouth University



East of Scotland Research Ethics Service REC 1

Attendance at Sub-Committee of the REC meeting on 24 July 2019

Committee Members:

Name	Profession	Present	Notes
Mrs Alison Ballantyne	Retired Nurse	No	
Mrs Natalie McInally	Clinical Scientist	Yes	Vice-CHair
Miss Emma Wilson	Trainee Health Psychologist	Yes	

Also in attendance:

Name	Position (or reason for attending)
Mrs Diane Leonard	Assistant Co-ordinator



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Appendix Six: Participant information sheet



Participant Information Sheet

Study Title: Early and later elective colostomy following Spinal Cord Injury (SCI)

Invitation and brief summary

The aim of this project is to understand more about the experiences of people with a Spinal Cord Injury (SCI) who choose to have a colostomy. This leaflet gives you some basic information so you can decide whether or not you would like to take part.

Who is doing the research?

The research is being carried out by one of the Stoma Care Nurses working in Salisbury NHS Foundation Trust. It is being done as a research degree sponsored and supervised by Bournemouth University.

What is the purpose of the project?

We have noticed more patients with SCI are choosing to have a colostomy, and some have it soon after their injury. We want to find out the reasons for this and learn more about the effects of having a colostomy. This will help when we talk to future patients who are considering a colostomy.

Why have I been chosen?

You are being invited to take part because you have chosen to have a colostomy following SCI.

Do I have to take part?

We would be very pleased if you can help with our research, but it is for you to decide. If you say no, this will not affect your future healthcare with the stoma care team or the hospital in any way.

What will taking part involve?

We would like to interview you about your experiences before and after your colostomy. The interview will take place at Salisbury District Hospital, last for up to an hour, and will be with one of the Stoma Care Nurses who works in the hospital. You can bring a friend or family member. We will try and coincide the interview with other appointments you may have at the hospital, and we will refund any travel costs. Please contact us if you would like to be interviewed but are unable to travel to the hospital. The interview will be recorded and the interviewer may take notes. We would also like to access your hospital medical record to gain further relevant information.

You don't have to answer every question if you don't want to, and you don't have to give permission for us to access your hospital patient record. If you do give permission, we will only be using the part of your patient record that is relevant to the research topic.

You will be asked to sign a consent form agreeing to take part in the research. If you decide at any time that you no longer want to take part, you can withdraw from the study without

giving a reason. There will be a point in the research after data has been anonymised, where it may not be possible to separate your individual answers and exclude them.

We will notify you once the research has been completed if any findings are going to be published.

Will my taking part in this project be kept confidential?

All information collected about you will be kept strictly confidential. The recording will be destroyed once the interviews are completed. The transcript and notes taken will be kept securely on password protected files accessible only by the person doing the research, and destroyed five years after the research has been completed. We will make sure that if we publish your comments in research reports or health professional journals, that you cannot be identified.

How might the research affect you and other people with a SCI

Taking part or deciding not to take part will not affect any future care you might receive, but we hope you will enjoy the opportunity to tell us of your experiences, and your answers will help us to improve the information and service we give to other patients with SCI considering a colostomy.

Who has reviewed this project?

The East of Scotland Research Ethics Service REC 1, which has responsibility for scrutinising all proposals for research on humans, has examined the proposal and has raised no objections from the point of view of research ethics. It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from Bournemouth University and Salisbury NHS Foundation Trust, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

Who has funded this project?

The Association of Stoma Care Nurses (ASCN) provided funding to help with this project.

What should I do if I have a concern or complaint about this research?

The deputy dean for research and professional practice at Bournemouth University will independently guide you through the complaints process if you have any concerns or complaints about the research. Their contact details are below.

For further information please contact:

Michelle Boucher Stoma Care Clinical Nurse Specialist Stoma Care Department Level 3 Salisbury District Hospital Odstock Road Salisbury SP2 8BJ Tel: 01722 429256 Email: michelle.boucher@nhs.net

If you have any concerns or complaints please contact:

Professor Vanora Hundley Deputy Dean for Research and Professional Practice Faculty of Healthy and Social Sciences Bournemouth University Royal London House Christchurch Road Bournemouth BH1 3LT Tel: 01202 965206 Email: <u>vhundley@bournemouth.ac.uk</u>

Thank you for reading this leaflet and considering taking part in the research

Appendix Seven: Invitation letter





NHS Foundation Trust

Michelle Boucher Stoma Care CNS Stoma Care Department Salisbury District Hospital Salisbury SP2 8BJ

Invitation Letter

Dear

I would like to invite you to take part in research being done through Bournemouth University by one of the Stoma Care Nurses at Salisbury District Hospital.

The enclosed Participant Information Sheet explains more about the research, and who to contact if you have any questions. Please read the information sheet carefully, and return the tear off slip in the enclosed stamped addressed envelope to indicate whether or not you would like to take part in the research.

Kind regards

Michelle Boucher Stoma Care Clinical Nurse Specialist Salisbury NHS Foundation Trust

Name.....

I would/would not* like to take part in the research "Elective Colostomy following spinal cord injury"

*Delete as appropriate

Appendix Eight: Consent form:



Consent Form

Full title of project:

Early and later elective colostomy following Spinal Cord Injury (SCI)

Name, position and contact details of researcher:

Michelle Boucher, Stoma Care Clinical Nurse Specialist, Salisbury NHS Foundation Trust, Stoma Care Department, Level 3, Salisbury District Hospital, Odstock Road, Salisbury, SP2 8BJ

Tel: 01722 429256 Email: michelle.boucher@nhs.net

Name, position and contact details of supervisor:

Dr Desiree Tait, Senior Lecturer in Adult Nursing, Bournemouth House 215, 19 Christchurch Road, Bournemouth, BH1 3LH

Tel: 01202 967315 Email: dtait@bournemouth.ac.uk

I confirm that I have read and understood the Participant Information Sheet (version 1.2, dated	
30/11/2016) for the above research project and have had the opportunity to ask questions.	
I understand that my participation is voluntary and I am free to withdraw up to the point of	
anonymization of data without giving any reason, and without my medical care or legal rights being	
affected. In addition, should I not wish to answer any particular question(s), I am free to decline.	
I give permission for members of the research team to have access to my anonymised responses. I	
understand that my name will not be linked with the research materials, and I will not be identified or	
identifiable in the report or reports that result from the research.	
I agree for my voice to be audio-recorded, and understand that the recording will be deleted once it has	
been transcribed and all interviews have been completed.	
I agree to the researcher accessing my patient information record to gain additional data relating to my	
decision to have a colostomy.	
I agree to take part in the above research project.	

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

If you have any concerns or complaints please contact:

Professor Vanora Hundley

Deputy Dean for Research and Professional Practice

Faculty of Healthy and Social Sciences, Bournemouth University, Royal London House, Christchurch Road Bournemouth, BH1 3LT Tel: 01202 965206 Email: <u>vhundley@bournemouth.ac.uk</u> Appendix Nine: Colostomy information booklet



Information for those with Spinal Cord Injury considering colostomy



Horatio's Garden, Duke of Cornwall Spinal Treatment Centre Salisbury District Hospital

Introduction

This booklet is an introductory guide for those with a spinal cord injury wanting to know more about colostomy as a method of managing their bowels.

Please contact the Stoma Care Nursing Team at Salisbury District Hospital or your local stoma care nursing team if you wish to know more.

Hoping you find this information helpful.

Michelle Boucher Stoma Care Clinical Nurse Specialist Salisbury NHS Foundation Trust Tel: 01722 429256 Email: sft.salisburystomacare@nhs.net

Understanding your digestive system

After you eat, food is broken down in the stomach, nutrients and fluid are absorbed in the small and large intestine (bowels), and what is left becomes stool (poo). This is stored in the rectum and then exits through the anus (bottom).

Following Spinal Cord Injury (SCI), the nerves which give you control over emptying your bowels can be affected. If you are unable to empty your bowels by straining it may be necessary to use digital stimulation or manual evacuation to remove stool from the bottom.



What is a colostomy?

A colostomy is an alternative way of managing your bowels, and involves a short operation in which the last part of your colon is brought through a small opening made in your abdomen (tummy).

The opening is called a colostomy, which is a type of stoma ('stoma' literally means 'opening'). This is usually done on the lower left side of your abdomen.

Instead of stool being stored in the rectum and then removed manually or through stimulation or straining, it will passively come out of your body when



it reaches the colostomy. A pouch (bag) is attached to the skin around the colostomy to collect stool as it passes out.

Understanding your colostomy operation

The operation to form a colostomy will be done under a general anaesthetic. The surgeon makes several small incisions (cuts) in your abdomen (keyhole surgery) and divides the colon.

Occasionally the surgeon may need to make a larger incision if it is not possible to do keyhole surgery. The end of large bowel through which stool will travel is brought out through a small opening on your abdomen and stitched in place. This is the colostomy. The other end of your bowel which carries on to your anus (bottom) is stitched closed and left inside your abdomen.



Photograph of a colostomy

What to expect after the operation

It is normal to feel a little tired for a few days following a colostomy operation, but you should quickly get back to your normal level of activity. You will be able to eat and drink straight after your operation, and can mobilise as you normally would the day after your operation. The colostomy doesn't have any sensation and won't be painful, but you might need to take mild painkillers for a week or two while your body recovers from the operation.

When you wake up after the operation you will have a pouch on your abdomen over the colostomy. This will be transparent so that your nurses will be able to check on your new stoma easily. At first, your stoma may be swollen, but this will subside over the first 6 weeks. Most colostomies are slightly raised from or flush with the skin once the swelling subsides, although some may stick out or in a little.

It can take a few days after the operation for the stoma to pass any stool, and when it first starts working it may pass a looser stool. As the body settles down from the operation this usually changes and becomes a more formed stool.

Colostomy pouches (bags)

After your operation, poo will pass out through your colostomy instead of being stored in the rectum and then coming out via your anus. There are no sphincter muscles around the colostomy, so faeces and flatus (wind) will pass out without any intervention when they reach the colostomy. You will need to wear a colostomy pouch, which sticks securely to the skin, to collect stool as it leaves the body.

There are several different types of pouch and your stoma nurse will show you ones that are suitable for you. Colostomy pouches have a special filter so there is no odour (smell) apart from when you are changing the pouch in the privacy of your bathroom.



Colostomy pouches

Changing your colostomy pouch

The stoma nurses and ward nurses will help you change the pouch until you or your carers are ready to do it by yourselves. The stoma nurses will show you (or your carers) how to do this and help you (or them) to become competent at doing this. This usually takes only a few days.

There will be an instruction sheet in your stoma kit bag that tells you what equipment you need and the steps involved in changing the pouch, and your stoma nurses will explain everything to you.

Why have a colostomy?

Some people find bowel care following spinal injury to be difficult or lengthy. Others develop problems related to bowel care such as haemorrhoids, fissures or autonomic dysreflexia. Some people want to simplify their bowel care routine to make it easier to get on with activities such as work, socialising and holidays.

What are the benefits of colostomy?

There are several benefits to having a colostomy:

- Bowel care becomes quicker and simpler
- You may be able to be independent with your colostomy
- Bowel care related problems such as haemorrhoids, fissures and bowel related dysreflexia may reduce or resolve
- It is easier to tell carers how to change a stoma pouch than perform bowel care, and you can see what they are doing
- It is easier to change a stoma pouch when you are away from home

What are the potential problems with a colostomy?

 Any operation and anaesthetic involves the risk of potentially serious health problems, and you must think carefully about this before deciding to go ahead

- Your stoma may become prolapsed (stick out more) or retracted (stick inward) over time. The opening can become stenosed (narrowed). You may develop a hernia around your stoma. These problems occasionally mean you need a further operation
- A common problem is mucous produced by the last portion of your bowel being discharged from your anus (bottom). In a small number of people (1-2%) this leads to them having a further operation to have the last portion of the bowel removed
- Some people experience sore skin around the stoma or it can take a while to find the most suitable pouch. Your stoma nurse will help you if this happens

What else do I need to consider

It is important to understand that having a colostomy will not solve problems of constipation or bloating. You are likely to still have these issues if you had them before the operation.

The last portion of the bowel which is left inside will continue to produce mucous to a varying degree. It is important approximately every 6 weeks to have a rectal examination performed to check whether mucous has formed a hard plug inside. If it has, this will need to be removed and you may need suppositories to help with this.

Minor dietary changes are suggested in the first 6-8 weeks following colostomy, and your stoma nurse will discuss these with you. After this most people revert to a normal diet, although you may find some foods affect your stoma output.

Having a colostomy and wearing a pouch changes the appearance of your abdomen and you need to think carefully how you may feel about this. A colostomy doesn't usually alter your sexual function.

After having a colostomy it is possible to wear a "plug" rather than a pouch, or some people choose to irrigate their colostomy so they only need to wear a small dressing over it rather than a pouch. These are things that your stoma nurse will be able to tell you more about.

Although technically a colostomy can be reversed, this can be a difficult operation, and you should proceed with having a colostomy only if you are certain this is the right option for you.

It is a good idea to talk through having a colostomy with your doctors, the stoma care nurse and your family or friends before deciding whether it is the right option for you. You may also wish to speak to other people with a spinal injury who have decided to have a colostomy; your stoma nurse will be able to put you in touch with someone.

After your colostomy

You will have the support of a stoma nurse during your hospital stay and after you have gone home, and they will remain your point of contact and support. They will help you with any problems you may encounter with your colostomy, and will guide you through the process of how to obtain supplies, which will come on prescription.

Many areas have voluntary groups to support people who have a stoma, or you may find online forums or the Colostomy UK helpful sources of information.

What people with a spinal injury have said after

having a colostomy:

Fran Brown



"I sustained a C4 incomplete spinal injury in 2006. I can walk with splints and crutches, run with braces and ride a bike. I work as a physic and compete internationally as a para-triathlete. My active lifestyle has however been compromised since my accident by bladder



and bowel dysfunction, and like many I find these aspects of my injury probably the hardest to deal with both physically and psychologically. They have prevented me from both training and working.

In August 2020 I had a stoma formed to allow me to manage my bowel whilst being active, removing the risk of accidents and dysreflexia, and also removing some of the issues caused by having Crohn's disease. This has been a complete game changer. Now I am able to train without worry of accidents, I can ride outside without needing to plan routes around toilets and I am returning to my practice as a physio.

The decision to have a stoma wasn't easy but has been transformational. My stoma is really easy to manage, even with my reduced hand function and I am now independent in managing my bowel. I am training to qualify for the Tokyo Paralympic Games and hope to show the world that a stoma can really free you be more active and importantly, more happy."

Dave Thraves



"Since sustaining a spinal injury at C4 in 1992, my bowel routine caused increasing discomfort, a pressure mark that led to weeks of bed rest, pain from suppositories and bowel care, and difficulties commiting to things such as work, gatherings or holidays. I came to expect to live with pain for the rest of my life, and learned to 'put a brave face on'. Bowel care was undignified, and I would often be devastated by having an 'accident'.

After over 20 years of this I had exhausted other methods of bowel care, and decided that a colostomy was the only possible solution left to me. So, in 2015 I went ahead and had the operation. Within weeks of my colostomy, the pressure mark cleared up almost completely, as I no longer spent so much time over the toilet on my shower chair. The pain has reduced, and I can sit in my electric

wheelchair on a daily basis without the fear of bed rest looming. That freedom is priceless!

It is also easier to teach somebody how to change a colostomy bag, then it is to train someone to carry out suppository bowel care. The colostomy has significantly improved my life. My dignity has returned, and my ability to socialise and commit to activities and events, has been improved hugely.

In hindsight, had I known at the beginning of my spinal injury what it is like to live with a colostomy compared to without, I would have opted for it from the outset. It is, without doubt, a game changer!"

For more information contact the Salisbury Stoma Care Department on 01722 429256 / <u>sft.salisburystomacare@nhs.net</u> or your local stoma care nurses.

Abbreviations

Abbreviation	Explanation
MASCIP	Multidisciplinary Association for Spinal Cord Injury Professionals
NBD	Neurogenic Bowel Dysfunction
NICE	National Institute for Health and Care Excellence
NMC	Nursing and Midwifery Council
QOL	Quality of Life
PA	Personal Assistant
РНВ	Personal Health Budget
PPI	Patient and Public Involvement
REC	Research Ethics Committee
SCI	Spinal Cord Injury
SCN	Stoma Care Clinical Nurse Specialist
WHO	World Health Organisation

Glossary

Term	Definition
Colostomate	A person who has a colostomy
Colostomy	A type of stoma. An opening on the
	abdomen through which the colon is
	diverted
Stoma	General term for an artificially created
	opening from the body
Tabula rasa	Blank slate, without prior knowledge