The Choice for Colostomy following Spinal Cord Injury: A Grounded Theory study

Abstract

Aim: Explore experiences and choices related to bowel management following spinal cord injury.

Background: In one UK spinal centre more are choosing a colostomy soon after injury in contravention of professional guidelines. Reasons for this were unknown.

Keywords: spinal cord injury, colostomy, stoma, neurogenic bowel management, long-term care, grounded theory

Methods: Grounded theory study using semi-structured interviews with twelve individuals living with spinal cord injury.

Results: All 'Experienced Loss' related to bowel function. Those who chose colostomy later 'Progressed into Suffering'. Colostomy transformed lives and was likened to 'Being Alive Again'. 'Failures of Care' contributed to experiences and decision-making.

Conclusion: Possessing information and choice emerge as key in transforming lives following spinal cord injury. They allow individuals to make choices from a lifeworld perspective, which may differ from those professionals assume. Present neurogenic bowel management guidelines fail to account for the wider lifeworlds of those they are designed for.

Implications for the profession and patient care: An imperative emerges to make information and choice available and involve patients in the reconstruction of guidelines.

Impact: Unique knowledge emerges about patient experiences and motivations, and points to a patient-led revolution in how bowel management following spinal cord injury is understood and managed. The imperative for adequate access to information and choice is demonstrated.

Reporting method: EQUATOR Standards for Reporting Qualitative Research (SRQR) were adhered to.

Patient or Public Contribution: The methodology facilitated discussion of areas important to patients and made them co-constructors of theory.

What does this paper contribute to the wider global clinical community?:

- The increase in the choice for colostomy is demonstrated
- Reasons why those with spinal injury might choose a colostomy are discovered
- Knowledge about increasing demand and understanding why will inform and aid planning of service provision for those living with spinal injury

INTRODUCTION

In one UK spinal cord injury centre more patients with Spinal Cord Injury (SCI) are choosing to have a colostomy and choosing it much earlier. This was observed by the first author, a Stoma Care Clinical Nurse Specialist employed in the NHS Trust involved. This change contravenes published guidelines and accepted professional wisdom, which suggest colostomy as a last resort when conservative methods have failed. Exploratory research was undertaken to understand experiences and develop theory to explain this puzzling phenomenon.

Background and context

SCI is rare, with approximately 1,200 new cases per year and 40,000 people living with SCI in the UK (McDaid et al 2019). SCI occurs from trauma (e.g., falls, road traffic accidents, sporting injuries) or non-trauma (e.g. tumours, degenerative disorders, vascular events) (Rodger 2019). The higher the level of injury, the more function is lost. Demographically, 79.8% of those with SCI are male, and the mean age it occurs is rising due to an ageing population more prone to injury by falling (Ahuja et al 2017). Effects include bladder, bowel and sexual dysfunction, paralysis, cardiovascular and respiratory complications, and risk of pressure injuries (Rodger 2019). Work, relationships, leisure, and social well-being are affected (Bolling-Hansen et al 2016). The wide-ranging and long-term effect on the individual is apparent.

Of relevance here, defecation and continence problems can occur, termed Neurogenic Bowel Dysfunction (NBD) (MASCIP 2021). This affects 80% of those with SCI and complications include constipation, haemorrhoids, pain, and autonomic dysreflexia (a potentially life-threatening rise in blood pressure) (Johns et al 2021). Complications tend to worsen over time, and bowel management can become increasingly lengthy (Bolling-Hansen et al 2016). With a relatively small population, few large-scale studies are available, and are often weakened by low response rates. A lack of consistency and detail reduces quality and rigour of some studies, but it is evident that the lives of many are impacted or dominated by difficulties related to bowel function.

Professionals have developed bowel management guidelines including those by the Multidisciplinary Association of Spinal Cord Injury Professionals (MASCIP) (MASCIP 2021). A pyramid model of interventions (Figure 1) is in widespread use (Christensen et al 2006). Conservative interventions are advocated, with more invasive methods used only if these fail.

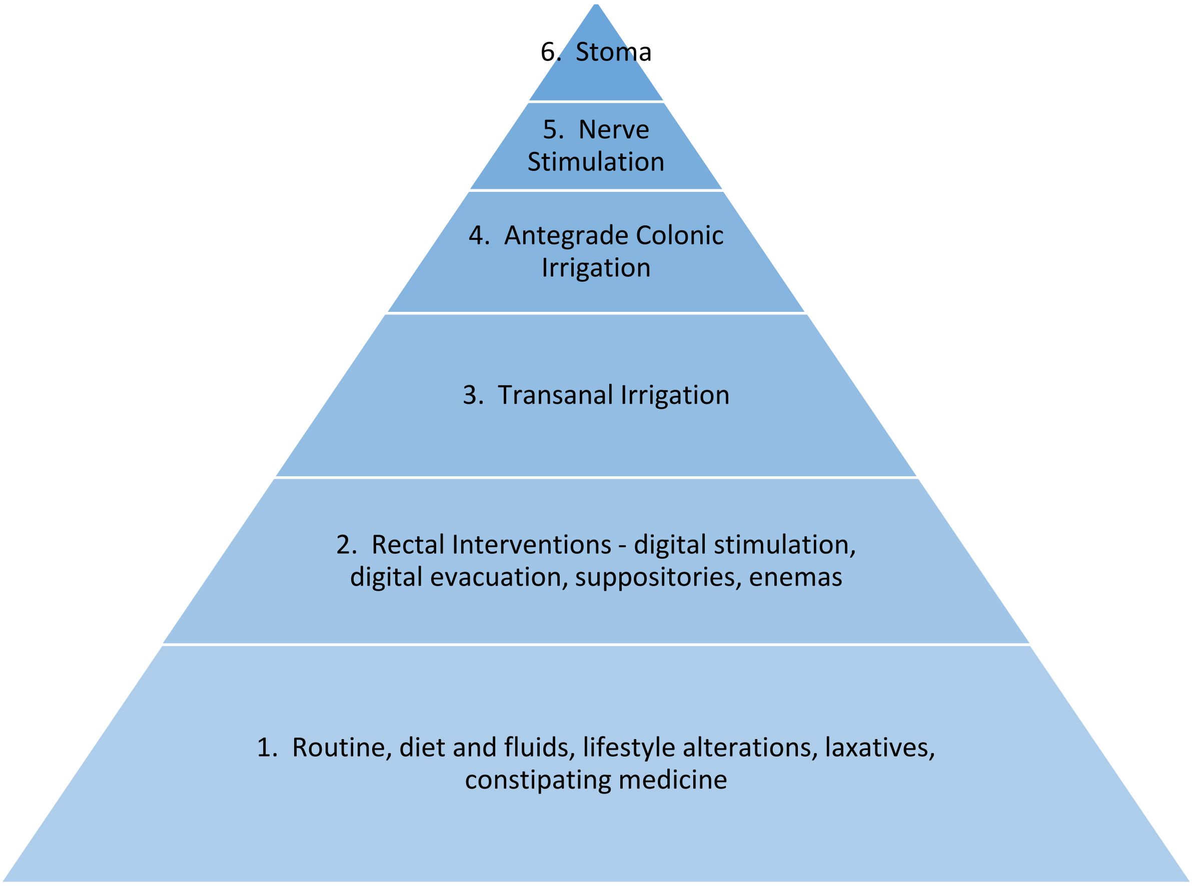

Figure 1: Pyramid of bowel care interventions by Christensen et al 2006 in MASCIP 2021

- Rectal interventions involve insertion of a gloved finger
- Transanal irrigation instils fluid rectally through a tubing system to initiate defecation
- Antegrade Colonic Irrigation flushes fluid through a surgically-created opening into the appendix or caecum to cause defecation
- Nerve stimulation controls defecation through implanted electrodes
- Colostomy is the colon surgically brought through a small opening in the abdomen. A pouch worn over the colostomy collects stool as it exits.

(MASCIP 2021)

In this spinal centre, nerve stimulation and ACI are rarely used, and transanal irrigation was discontinued due to factors preventing its continuation following discharge from hospital. Colostomy is popularly conceived as the most invasive option, used as a last resort. Cooper et al (2019) describe it being used to prevent stool from contaminating pressure ulcers, when bowel care becomes too lengthy, and to overcome incontinence and complications of NBD listed earlier.

Professional guidelines acknowledge their weak evidence base. Interventions are not amenable to testing by randomised controlled trials, and are developed by professional groups deliberating best practice and reaching consensus (National Collaborating Centre for Acute Care 2018). Service user involvement appears limited, with not all appropriate professional groups represented. Stoma Care Clinical Nurse Specialists were not listed as involved in developing any of the guidelines reviewed. Guidelines tend to be physiologically focused, with only passing reference made to wider lifestyle and individual circumstances.

Despite its perception as a last resort, researchers commonly find high satisfaction and a desire to have had it performed earlier (Branagan et al 2003, Coggrave et al 2012, Bolling-Hansen et al 2016). Bowel management becomes quicker and simpler, complications are resolved, and greater independence is possible. Professional attitudes towards colostomy are only slowly shifting in response to these findings. Cooper et al (2019) offer colostomy early only to those professionals consider would benefit. This falls short of offering it to all who may wish to consider it.

Existing studies describe the benefit and positive experiences but have not fully explored why people might desire a colostomy earlier. None have described those with a new SCI making an active choice to have one, as has been observed and made the object of unique research in this spinal injury unit.

RESEARCH QUESTION AND AIMS

The research question and aims were constructed from exploring literature and reflecting on the previously undescribed phenomenon of individuals choosing a colostomy soon after SCI. This group were seen as distinct from those who chose it much later. From discerning these two distinct groups, the question and aims were developed to seek understanding of how their experiences were similar and differed. They were developed in tandem with consideration of the most appropriate research paradigm. A PEO (Population, Exposure, Outcome) framework helped frame the research question.

Research question:

> ***‘What are the experiences of those living with SCI in relation to choices about bowel management?’***

Research aims:

- ***To explore choices made by patients with SCI about bowel care management***
- ***To explore reasons for the decision to have an early colostomy***
- ***To explore differences in experiences between those who have early or later colostomy***

METHODOLOGY

The research framework was decided based on the exploratory nature of the research, the philosophical perspective of the researcher, and their positionality as an involved professional. Constructivist Grounded Theory was used, an approach which co-constructs knowledge between researcher and researched (Charmaz 2014). The goal is an intimate understanding of participants in their specific setting. This understanding enabled the exploratory research question and aims to be answered and explanatory theory to emerge.

The research design reflected the Grounded Theory process described by Tweed and Charmaz (2012) (Figure 2). Primary data were gathered from semi-structured interviews, with secondary data collected from documentary data. The EQUATOR guidelines for Standards for Reporting Qualitative Research (SRQR) were used (O’Brien et al 2014). Co-construction was achieved by taking codes, categories, and theory which emerged from researcher data analysis back to participants in subsequent interviews. Participants confirmed, rejected, modified, or better-defined aspects of the theory as it emerged and was shaped and reshaped.

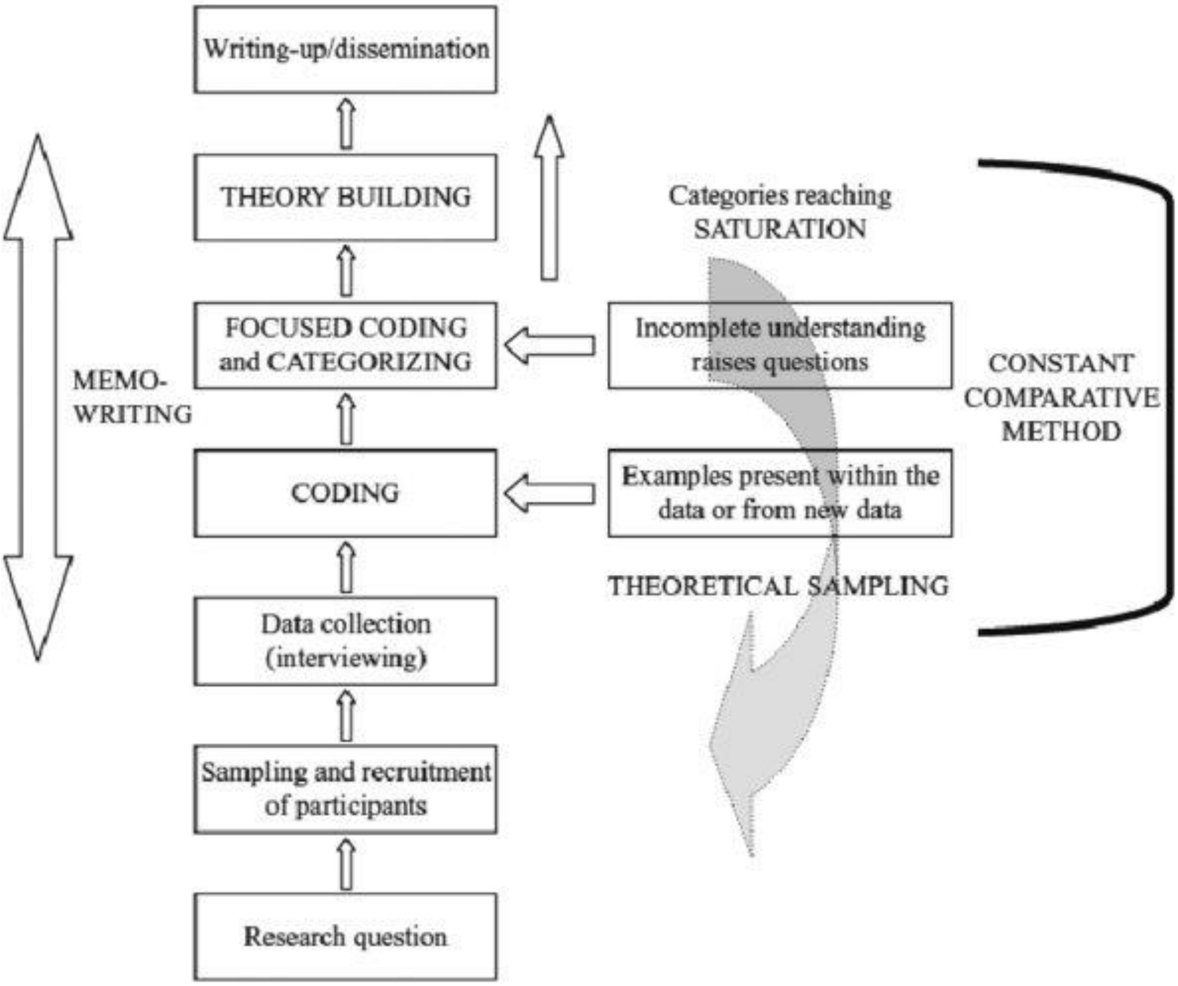

Figure 2: Grounded Theory process (Tweed and Charmaz 2012)

Operational definitions

Observation that some with SCI choose to have a colostomy at an early point whilst others have it much later, led to conceptualising these as two sub-groups. The group who chose colostomy early have not been identified prior to this research. With no existing description available, it was necessary to develop operational definitions to conceptualise the differences between these individuals and those who chose to have colostomy later. They were described as 'early' and 'later' colostomates:

Early Colostomate definition:

Decision to have colostomy made:

- During acute inpatient rehabilitation period

- Prior to continuing traditional bowel care management at home
- Within the first year following SCI

Later Colostomate definition:

Decision to have colostomy made:

- After discharge from acute hospital rehabilitation
- After first utilising other methods of bowel management at home
- More than a year after SCI

Data collection and analysis

Participant interviews were the primary method of data collection, with interviews performed between 2017 - 2019. Consent was gained and semi-structured interviews, using an interview guide, were conducted face to face within the hospital. The interview guide contained ten areas for open-ended questioning. These related to when and how participants first heard about the option of colostomy, who they discussed it with, and the impact it had on their lives. A final question gave opportunity to discuss anything else the participant felt was important or relevant. Relatives or carers were present if desired. Audio recordings were made and transcribed verbatim. Duration of interviews were between half to one hour. Participants were interviewed once, except for one who was interviewed a second time to explore an area of interest they raised.

Secondary documentary data included the researcher's reflexive writing and memoing, and data from hospital databases. During analysis and theory building, and as theoretical questions emerged, further documentary data were sampled from existing literature. Questions were 'asked' by performing literature searches using search terms which emerged from interview analysis.

Interview data were analysed by the single researcher following the Constructivist Grounded Theory process as described by Charmaz (2014). Interviews were transcribed and subjected to systematic manual coding. Initial codes came from line-by-line coding. Each line of transcript was reflected on and given a 'code' which is a label to describe the action or process it contains. From numerous initial codes, focused coding grouped similar codes together and their meaning studied. Codes and focused codes were compared with interview data to check correct interpretation of meaning in the process of constant comparison. Codes from each new interview were checked with previous codes and transcripts, and codes of earlier interviews were searched for in each new interview. Coding and constant comparison were also used when examining documentary data. Other forms of data analysis included free writing, memoing, reflexivity, and diagramming.

The iterative process of data collection and analysis ceased when no new information was being yielded to furnish aspects of theory, and theoretical saturation was reached.

Sampling and recruitment

Purposive sampling was employed to recruit participants from the total population of approximately 200 individuals with SCI who have then had a colostomy in this UK centre. Guided by theoretically informed working definitions of early and later colostomates, similar numbers were sampled of each. As variations in experiences emerged between those who were independent or dependent on others, this feature too was purposively sampled. As a theoretical question emerged during later analysis, two individuals with SCI who did not have a colostomy were also recruited. Men and women were recruited in an approximate 3:1 ratio to reflect SCI incidence. Due to the small total population, there was no attempt to sample different characteristics. Twelve participants were interviewed.

Hospital databases were accessed with permission to discover individuals with SCI and a subsequent colostomy who had an upcoming appointment in the hospital. This convenience sampling minimised inconvenience and increased the likelihood of participation. The sample size was unknown at the start, with sampling stopped once theoretical saturation was reached. Invitation letters and Participant Information Sheets were posted a few weeks before the date of the hospital appointment. It is not known whether participants knew each other.

Inclusion and exclusion criteria

Inclusion criteria were that participants had a SCI and subsequently had a colostomy in the single centre being studied. Excluded were any who had the colostomy because of the injury itself or who had no choice in having it due to e.g., to heal pressure damage.

Ethical considerations

Ethical permission was granted by The East of Scotland Research Ethics Service (REC reference: 16/ES/0144), and permission gained from the sponsoring university and hospital Trust. Understanding was checked and consent obtained before each interview. Of potential concern was the prior nurse-patient relationship with some participants. The risk of misusing trust was mitigated by only making contact by letter and clarifying the researcher's role.

Data were collected, stored, and processed in accordance with relevant data regulations. Each participant was given a pseudonym with only the researcher having access to the securely held single record of patient identities.

Quality and scientific rigour

To ensure quality and scientific rigour in Grounded Theory research, it is appropriate to consider its credibility, originality, resonance, and usefulness (Charmaz 2014). Credibility was ensured through systematic treatment of data and theory building. Constant comparison ensured theory remained true to and anchored in the data. Semi-structured interviews allowed participants to guide the direction these took, and in-vivo codes were used. Clarification of meaning was sought, and emergent themes were checked and explored in subsequent interviews. Researcher reflexivity was a key activity.

Originality is demonstrated in a unique portrayal of experiences of those living with SCI who choose to have a colostomy, and the development of understanding into why it is being chosen earlier. This is not an area thought to have been previously researched. Resonance was ensured by checking meaning and clarifying understanding during interviews. Ongoing professional interactions confirm findings as the flow of patients seeking colostomy continues. The usefulness of the research is demonstrated from innovations in practice, including introducing a regular inpatient information session, and a new clinic and pathway being developed. A recent publication by Johns et al (2021) demonstrates that this research has broadened the perceived role of colostomy in this group.

Reflexive consideration before, during, and after interviews was given to the balance of power between researcher and participants, especially where a prior nurse-patient relationship had existed.

The trust and shared understanding from previous nurse-patient interactions proved positive in facilitating free and frank disclosure of rich information, and care was taken to use this trust with integrity. Where no previous relationship existed, it could take longer to establish rapport in the interview situation, but a similar degree of openness frequently developed.

Participants steered the interview direction. Areas they did not wish to discuss were respected. Twice participants who had a previous nurse-patient relationship were noticed to use their steering power to seek advice on health matters. Where this occurred, the offer was made to discuss the health matter after the interview concluded.

To minimise researcher bias, reflexivity was an essential activity. The 'negative case' was intentionally searched for, which Charmaz (2014) describes as puzzling data which contrasts with major patterns. This was a fruitful journey which enriched theory.

FINDINGS

The participants

There were twelve participants: five early colostomates, five later colostomates, and two without a colostomy. Participant demographics and the participant timeline of when injuries were sustained are shown in Figures 3 & 4.

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 3: Participant demographics *Colostomy enabled some to move from dependence to independence*

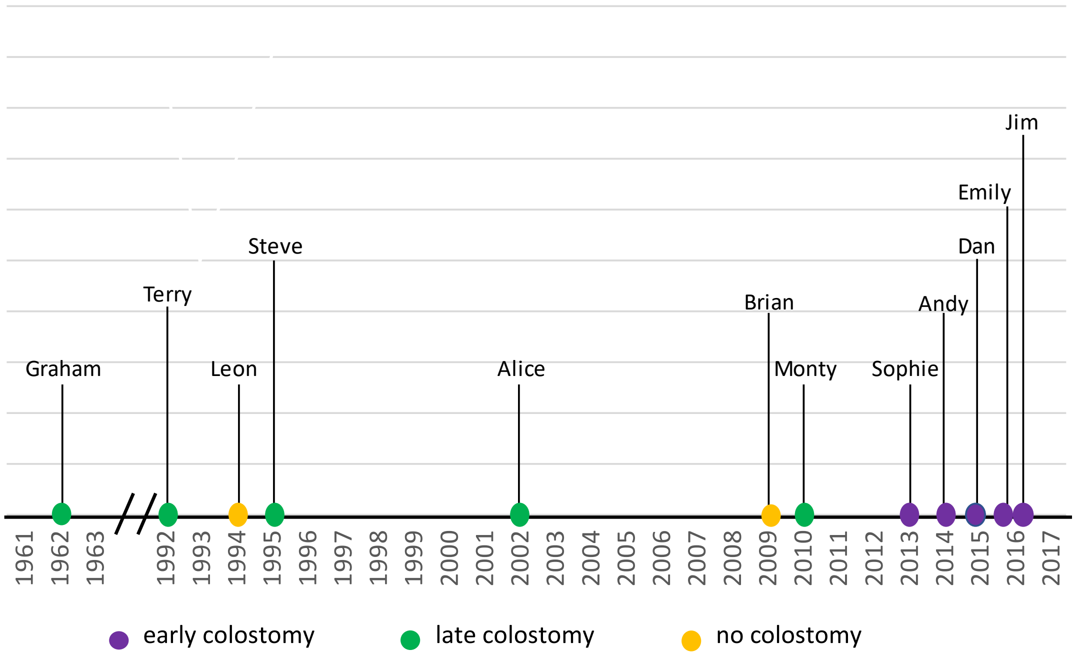

Figure 4: The participant SCI timeline

Participants were sampled from the larger population of approximately 200 individuals with SCI who have had a colostomy in this centre (Figure 5).

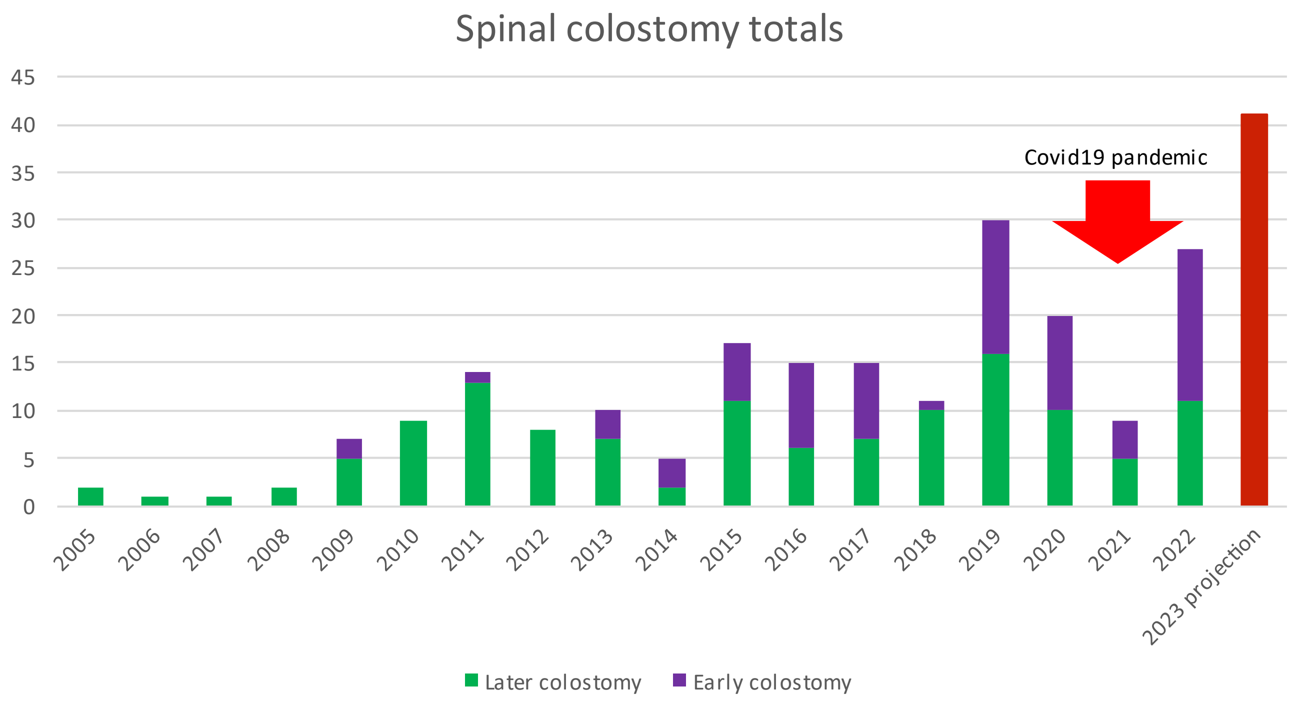

Figure 5: 'Spinal colostomies' performed in the study centre

Experiences of Loss

Experiences of Loss in relation to bowel management following SCI was common to all twelve participants. This included Loss of Control, Loss of Self-determination, and Loss of Dignity.

Loss of Control was experienced most obviously as a loss of physical control over bowel function. Participants were no longer able to empty their bowels intentionally or prevent unpredictable episodes of incontinence. These experiences were described as:

> *"Dreadful. Dreadful. Yeah, it was an awful experience [bowel management when first injured]. It is probably the worst part of becoming a paraplegic." (Graham, later colostomate)*

Loss of control, unpredictability of bowel function, and complications related to it impacted wider lives. Anticipated difficulties pursuing activities was a major reason for choosing a colostomy at an early point. Everyday activities outside the home were fraught with risk and some developed a fatalism about the futility of trying to engage in these:

> *"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." (Dan, early colostomate)*

Added to the loss of physical control was a Loss of Self-Determination in how their bodies were managed. In hospital participants were passive recipients of bowel management routines, and felt they were given little or no information and choice about potential alternatives. This lack of self-determination was most notable in those injured earliest on the participant SCI timeline. These later colostomates would have preferred more information about alternatives at an earlier point. They did not actively seek information and had a colostomy at the point when healthcare professionals advised it rather than when they might in retrospect have chosen it for themselves.

> *"Like I say if I'd found out I would have had the colostomy earlier. Probably much nearer to the beginning." (Steve, later colostomate)*

Those injured earliest accepted the regimes professionals dictated to them, but over the course of the timeline there was a growing desire and expectation to be informed and involved in body management decisions. Those injured more recently had greater involvement in decision making and the balance of power is observed to have shifted. Andy actively asked professionals to perform the colostomy:

> *"I just mentioned it to [the consultant] and [they] seemed to be quite keen once I mentioned it." (Andy, early colostomate)*

A third area in which participants Experienced Loss was through Loss of Dignity. Dignity was lost not only through incontinence, but also through procedures used to manually remove stool. This Loss was acutely felt and untenable for the early colostomates:

> *"They take it out manually, which I thought was terrible…I couldn't…just didn't want to think about going through life with that [manual bowel care]." (Andy, early colostomate)*

The way in which bowel emptying was performed violated norms of privacy and independence. Retaining what dignity they could, for example by having bowel care performed in the bathroom over a toilet rather than on the bed, became important.

From Experiences of Loss which were common to all, a divergence in reaction to these Losses was observed. The later colostomates responded to Losses by Getting Used To them:

> *"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." (Steve, later colostomate)*

Getting Used To unpleasant bowel management interventions appears to be an adaptive response which enabled the later colostomates, given no alternative, to live with their new reality. In contrast, the early colostomates were given, or had an awareness of, alternative methods and Rejected Guidelines:

> *"I thought … there is quite a severe time element involved in this…it would restrict my lifestyle… I was not prepared to spend that number of hours a day in my life. I'm not going to do that." (Jim, early colostomate)*

Secondary data gathered which explored the wider context of experiences gave explanatory insight to these differing reactions as relatable to changes over time in the culture and provision of healthcare services. Those injured in earlier decades experienced healthcare in which professional power and authority was greater and not questioned. The lack of freely available knowledge meant participants were unaware of alternative bowel management methods and had no choice but to Get Used To them. The early colostomates, in contrast, were injured in times with more equal power balance. Cultural and political changes over time mean patients are perceived more as partners in health care. With greater information and freedom to choose, they were able to Reject Guidelines they found unacceptable.

Progression into Suffering

A further divergence occurs as the later colostomates then Progressed into Suffering. This includes Bodily Suffering, Battling with the Body, Shrinking Lifeworld, and the Failure of Care.

Over time, physical complications developed related to bowel function and management, in concurrence with those described earlier in the Background and Introduction. This included haemorrhoids, pressure ulcers, and autonomic dysreflexia. Bodily complications and suffering intensified over time:

> *"It was always uncomfortable, it always set off a certain level of dysreflexia, discomfort. In the latter years that got significant." (Terry, later colostomate)*

Managing bowel function and its complications led to Battling With Their Bodies. Participants struggled with, were let down by, and tried to manipulate their bodies. At times their bodies launched unexpected attacks:

> *"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." (Terry, later colostomate)*

Weapons used to try and manage wayward bodies included the methods and routines advised in professional guidelines. Over time these became less effective. The difficulties they experienced meant pursuing desired activities became fraught with further suffering, and a Determination Through Suffering was observed:

> *"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." (Terry, later colostomate)*

As Battling and Suffering continued, lifeworlds were observed to shrink due to the time and energy which bowel management consumed. For some, this was compounded by ineffective care:

> *"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?" (Monty's wife, later colostomate)*

From a position of Suffering, Battling, and with Lifeworlds Shrinking and Care Failing, the later colostomates Reached the End of the Road:

> *"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." (Steve, later colostomate)*

In fulfilment of the bowel management guidelines, from a place of last resort and feeling they had no other choice, they underwent colostomy formation. This differs starkly from the experiences of the early colostomates. Instead, by Rejecting Guidelines, they made an Active Choice to have the colostomy at a time when they desired it and bypassed the Progression into Suffering.

Understanding of the Failure of Care some experienced was increased by sampling secondary data from existing literature. This led to its development into a third major category.

Failure of Care

Findings discussed so far indicated that contextual conditions were influencing the experiences of participants. As differences in experiences appeared relatable to the Participant SCI Timeline, changes in healthcare provision, culture and society over time were explored. This led to the identification of Ideological, Professional, and Institutional factors as elements of the Failures of Care category. Other influences are likely to exist but did not emerge at this time.

Ideological Failures were discovered from identifying that healthcare ideology has shifted over the span of the participant timeline. At the start of the timeline, in the UK it was dominated by western biomedical health ideology which conceives the body as a machine comprising separate components, with a concern to maintain functional norms (Farre and Rapley 2017). Understanding this explains why professional guidelines have tended to consider bowel management in isolation, and how notions of invasive and conservative interventions have developed. Manual interventions maintain the norm of where stool exists the body and so are conservative. Colostomy distorts bodily norms and is therefore invasive. The influence of this ideology was evident in interviews with those injured earliest:

> *"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." (Terry, later colostomate)*

For participants, interventions are inversely and oppositely experienced to how professionals conceive them. Manual methods are an invasion of a private part of the body. The colostomy, created whilst anaesthetised, is non-invasive as stool passively exits the body and requires only the changing of a pouch attached outside the abdomen once or twice daily. The differing perceptions were observed by participants:

> *"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." (Terry, later colostomate)*

The differing ideological perspectives observed from the findings are summarised in figure 6.

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 interventions as non-invasive	Notions of surgery as non-invasive, manual interventions as invasive
Arise from biomedical perspective	Arise from insider lifeworld perspective

Figure 6: Differences in ideological bowel management perspectives

Those injured longest ago were advised to persist with manual bowel management regimes despite the Suffering and Battling they experienced. Imbibing the ideology which prized the maintenance of bodily norms, they came to the belief of Pain and Suffering as Inevitable, which appears to be an adaptive mechanism to aid acceptance of ongoing Loss and Suffering:

> *"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." (Terry, later colostomate)*

These experiences are reduced or absent in those injured more recently. A shift in the understanding of health is evident in documentary data which demonstrates that over time health is increasingly conceived as more than just the absence of disease, and to extend beyond the physiological to encompass psychological and social elements amongst others. This is reflected in participants injured more recently undergoing colostomy as a first choice rather than a last resort and for reasons which extend beyond physiological management of the body.

Professional Failures of Care were observed. The Loss of Control and disempowerment during hospitalisation following SCI continued at home for those requiring community care provision. Some had lives limited by waiting for caregivers:

> *"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." (Monty's wife, later colostomate)*

Care provision appears to be arranged around performing discrete tasks, organised to suit organisational needs rather than the broader lifeworld needs of those requiring assistance. This led to experiences of Professional Practices Restricting Lives. Monty's care provision meant there was no time for doing anything else in the day as his wife stated: *"It just took over your life, didn't it?"*. This Loss of Time was experienced by others through lengthy and ineffective bowel management regimes that led to complications including incontinence and dysreflexia. When faced with incompetent or absent care, colostomy was chosen to mitigate against this, a choice they may not have otherwise made.

The early colostomates had not experienced community care as they were still hospital inpatients when they chose to have the colostomy. Their words reveal however an awareness of the limitations they were likely to face because of inadequate and untimely care provision. Documentary data demonstrates the structure of community care provision to have changed over time, but it appears to continue to be a restricting factor in the lives of those requiring assistance with bowel management.

Exploration of Institutional Failures of care revealed areas in which society and institutions contributed to experiences. Considering activities outside the home demonstrates how Society Disables People and restricts lives:

> *"If I need to attend to that [bowel function] 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." (Jim, early colostomate)*

These findings point to the Failure of society and organisations to ensure public spaces are accessible and meet the needs of those who require additional space for body management. Disabling environments limit the scope to engage in work and leisure activities. Documentary data gives evidence that much has been achieved by disabled rights movements to redress barriers over the course of the participant timeline, but Jim's statement demonstrates their continued existence.

The Failures of Care arising from Ideology, Professionals and Institutions which cause some to choose to have a colostomy have not been widely discussed, but are demonstrated as crucial elements influencing decision-making. It can be speculated that without these limitations some may not have chosen to have a colostomy. Is it right that Failures of Care are overcome by choosing to have a colostomy, instead of the Failures being redressed? This finding represents an important area to expose and challenge.

Being Alive Again

With the decision to have a colostomy arising from differing experiences, both early and later colostomates found the colostomy transformed their lives, described by the *in vivo* code as like Being Alive Again. Experiences of Loss and Suffering were reversed, and time was regained. A major benefit for all was Regaining of Control, which was experienced differently according to injury level and whether the colostomy was performed early or later.

Those with higher injuries experienced Regaining Control through being able to more easily dictate how care was given:

> *"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." (Andy, early colostomate)*

Colostomy was experienced as a more straightforward method which reduced reliance on caregivers and led to a regaining of independence and liberation from Shrinking Lifeworlds. Some with lower-level injuries were released from dependence on caregivers as the position and ease of the colostomy meant they were now able to manage this themselves:

> *"Because it is that sense of independence and control that you've got back in your life, at least over something." (Emily, early colostomate)*

The nuanced differences and dimensions of Regaining Control are summarised in Figure 7:

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

Figure 7: Dimensions of regaining control

Relief from Suffering was an aspect of Being Alive Again experienced by the later colostomates. Bodies damaged by bowel interventions now healed. Unexpected healing of a persistent pressure ulcer occurred in one individual, which was realised to have been caused by time spent in a shower chair during bowel care.

Both early and later colostomates were observed to Regain Dignity as they were no longer subject to undignified procedures, and they were able to regain continence. Participants could Live with Confidence that their bodies would not let them down. Activities such as travelling became easier and no longer required Determination Through Suffering. Bowel management now consists of changing a disposable pouch on their abdomen once or twice daily, and this fits in with lifestyles rather than dominating them:

> *"The sheer flexibility of it. Being able to change it when I want where I want…Fundamentally you have no restrictions…it's incredible." (Terry, later colostomate)*

The later colostomates were released from Loss of Time and now Had a Day which did not centre around dealing with bowel function. Early colostomates identified this as part of the reason for choosing to have a colostomy, leading to the focused code of colostomy as a Means To An End:

> *"It's all about freeing you up to do what you want." (Dan, early colostomate)*

The early colostomates perceived colostomy as facilitating independence and freedom once discharged home. Sophie saw the colostomy as a means of overcoming barriers:

> *"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?" (Sophie's husband, early colostomate)*

For those with higher level injuries who required caregiver help, an advantage of the colostomy was how Care Becomes Easier. Previous difficulties of variation in caregiver skills and loss of time were overcome. For those able to change the pouch themselves, this was easier due to the location and accessibility of the colostomy.

Findings summary

Findings from the research are summarised in Figure 8. Bowel dysfunction following SCI and the way it is managed leads all to Experience Loss. A dichotomy emerges between the Early Colostomates who were given Information and Choice and made the decision for colostomy at the time they wanted to have it, and the Later Colostomates who did not have Information and Choice.

The Later Colostomates Got Used To losses which resulted from traditional bowel management practices. In the presence of Failures of Care and in the absence of sufficient consideration of individuals' wider lifeworld perspectives, this led to a Progression into Suffering. They had a colostomy as a Continued Lack of Choice in how their bodies were managed. The Information and Choice available to the Early Colostomates gave them greater relative power in deciding how their own health needs would be met. They Rejected Guidelines which did not accommodate their wider lifeworlds and made an Active Choice to have a colostomy.

Both early and later colostomates experienced Being Alive Again following the colostomy, with the early colostomates appearing to have avoided the years lost in suffering experienced by the later colostomates.

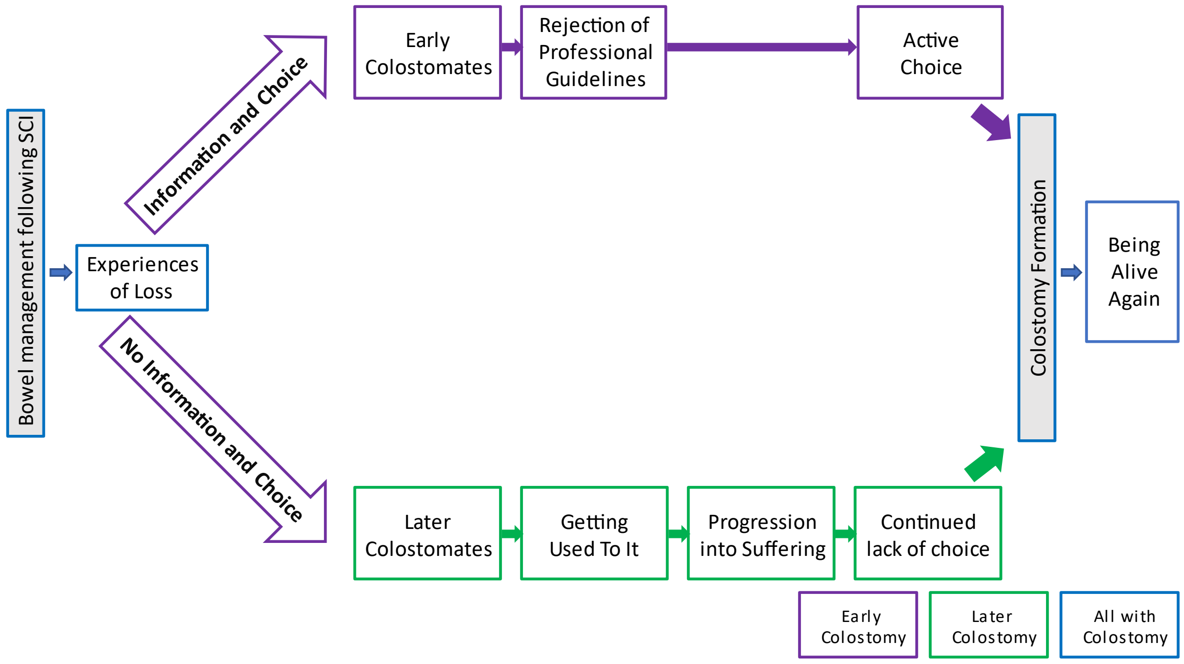

Figure 8: Summary of findings

The Grounded Theory

The use of grounded theory methodology to answer the exploratory question and aims has increased understanding of the motivations and experiences of this patient group. A theoretical explanation for the anomalous phenomenon has emerged to account for findings which can be labelled:

When individuals with SCI have information and choice about how their bowel function is managed, they make decisions in the context of their wider lifeworlds. Losses related to bowel function are reversed, and early colostomates can circumvent the Progression into Suffering experienced by later colostomates. Information and choice received at a later point allows individuals to choose an option which mitigates against further future Losses and Suffering.

Colostomy leads to Being Alive Again: a transforming resurrection-like experience occurs as potential is released for new lives with greater control, independence, and freedom. Information and choice are key to unlocking access to this.

The Failures of Care which have been identified although not definitive, reveal the existence of barriers to Information and Choice in body management. A biomedical ideology with a narrow understanding of colostomy as relevant only to the management of an isolated bodily function has limited what professionals have made available to those living with SCI; services and care provision arranged to meet organisational needs has limited the choice in how and when care needs are met; and disabling environments cause body management decisions to be made which might otherwise not have been.

DISCUSSION

An explanatory Theory has emerged which demonstrates the availability of Information and Choice as key to accessing transformative body management options. Important areas for further discussion have emerged. These include reflection on the importance of Information and Choice, consideration of how bowel management interventions are experienced, colostomy stigma, how bowel management may better be modelled, and the concept of Unmet Need.

The importance of Information and Choice

The ability to make body management choices is contingent on information being available. It was the experience of many participants that it was not. This finding led to the introduction of regular patient information sessions in the researcher's spinal centre to redress this deficit. Others have similarly found that those with SCI are not made aware of the option of colostomy soon enough (Bølling-Hansen et al. 2016). It is not known how unique this centre is in providing regular structured information to newly injured inpatients about alternative methods of bowel management. It is also unknown how many people injured longer ago remain ignorant of alternatives they may benefit from. How information can equitably be made available to all with SCI is a challenge.

A further benefit of having information and choice is the sense of control this brings. Meta-synthesis and systematic review confirm the importance of the sense of control (Waddell et al 2020). Hammel (2007) found that being able to direct others and exert choice is more important than the physical ability to manage the body. This explains how participants unable to move much of their body enjoyed an increased sense of control from making the decision to have a colostomy and being able to instruct others in how this should be managed. These positive benefits confirm the importance of those with long-term health conditions being given sufficient information and the opportunity to play an active role in decision-making concerning their bowel management.

Understanding experiences of bowel management

Experiences of incontinence induce a sense of mortification, loss of trust in the body, and a diminished sense of self (Charmaz and Rosenfeld 2006). This is paid scant attention in existing guidelines. Researchers concur that manual bowel management procedures create a loss of dignity and are experienced as invasive procedures, with some participants likening it to rape (Dickson et al. 2008). Interventions can be dehumanising, perhaps inherently so. Consideration of Todres et al's (2009) theory of humanisation helps identify dehumanising elements of care provision which could be addressed. These include ensuring interventions are performed in a time, manner, and location individuals desire. Unfortunately, limited resources are known and have been demonstrated in this research to impede this.

The later colostomates adapted by Getting Used To dehumanising experiences and it may be argued that given time the early colostomates could have similarly adapted. But *should* they have to do this? If safe, acceptable, more dignified, and potentially transformative alternatives are available for bowel management, should not these be made known and available?

From this, it is critical to further investigate the safety of and complications related to all potential interventions. Many researchers have cited high complication rates for colostomy (Branagan et al 2003). However, examination reveals inconsistencies in what is regarded as a 'complication', with many being resolvable pouch management issues rather than true surgical complications as described on the Clavien-Dindo scale (Clavien et al 2009). The lack of rigour and consistency when citing colostomy complication rates in this population, and the misuse and ambiguity of the term 'complication' has surprisingly not been challenged. This may be due to a lack of understanding of cited complications by non-stoma nurse specialist researchers, or possibly due to unconscious professional bias against colostomy formation, considered later.

Complication rates do not portray the whole picture. Many participants in this research revealed that they had experienced a complication related to the colostomy and yet were Still Glad to Have Had It. Other researchers concur (Bølling-Hansen et al. 2016). This suggests that understanding is required not only of statistical information related to colostomy complications, but also experiences and meanings attached to these. Comparison of these with complications of all bowel management methods would help produce more complete understanding.

Colostomy is presently described as an option of last resort, and yet led to transformative experiences likened to Being Alive Again. In other areas of healthcare, it has similarly been demonstrated how interventions which professionals consider extreme can revolutionise patient lives. There is a disparity in perceptions between professionals and those experiencing interventions. This underlines the importance of listening to patients to gain their lifeworld perspectives, and professionals not paternalistically assuming they know what is best.

Illich (2003) considered over-medicalisation, medical technologies, organisations, and professional behaviours as undermining individual competence and autonomy. The theory developed here challenges this, by demonstrating that avoiding the available technology of a colostomy can *create* dependency on professionals. With bowel dysfunction necessitating some form of intervention, differentiation needs to be made between the degree of harm or loss of autonomy each intervention may bring. Deliberation of which medical technology best meets individual needs and lifegoals, minimises reliance on professionals, and facilitates independence is helpful. It may be surprising to some that colostomy, popularly described as the most invasive option of last resort, is a method which can best meet these aims.

Colostomy stigma

Analysing literature data, evidence was found that amongst health professionals there exist possibly unconscious preconceptions of stomas as stigmatizing:

> *"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)

Professional perceptions may influence how and whether colostomy is presented as an option. Considering the transformative benefits this research has demonstrated, professionals must reflect on personal beliefs and prejudices. Failure to do so may contribute to the suppression of information and choice, and the unnecessary continuation of Experiences of Loss and Suffering in relation to bowel management following SCI.

Previous research has explored unconscious professional perceptions, bias in making clinical recommendations, and the stigmatising effect of having a colostomy. Studies have not however explored the extent to which unconscious professional perception of colostomy, or their perceptions of individual patients, influences the nature of information given and choices made available. Future research in this area will be helpful in exposing bias and raising awareness.

Rethinking bowel management guidelines

An important finding is that patients use colostomy as a Means to an End of achieving lifeworld goals, including work, confidence in social circumstances, and freedom to engage in desired activities. In Maslow's (1958) hierarchy of needs (Figure 9), the need to maintain bowel function is a basic physiological need to be met before progression to higher level lifegoals. This is how present bowel management guidelines are perceived.

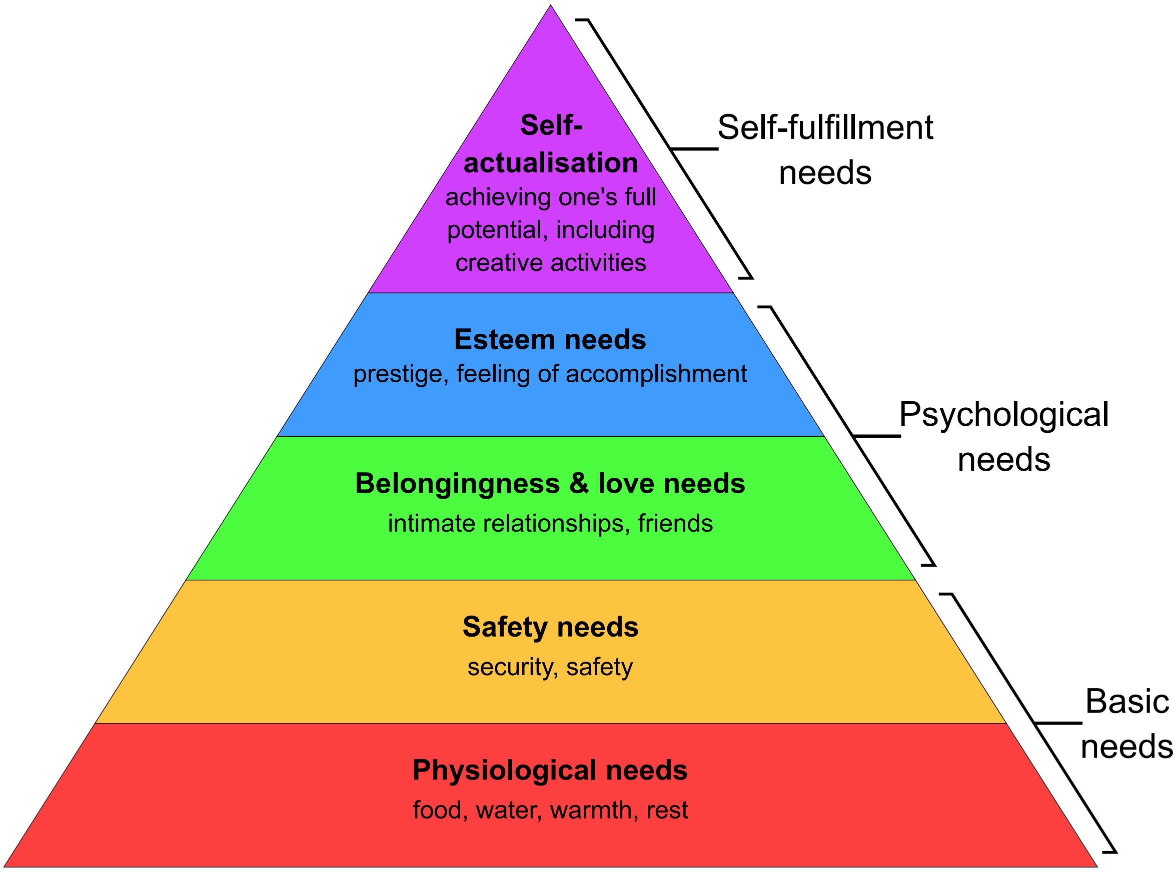

Figure 9: Diagram of Maslow's hierarchy of needs (Androidmarsexpress 2020)

This research demonstrates how this isolated conception of bodily need has limited individuals and prevented them from meeting higher level needs. Guidelines are needed which consider all levels of need *relationally*. Colostomy meets a physiological need but is a tool used to meet higher level lifeworld or self-fulfilment needs. Existing guidelines do not facilitate the assessment of wider lifeworlds or reflect the relational nature of lifegoals and body management decisions. They require individuals to change their lifestyles to accommodate bowel management, rather than considering how this can best fit desired lifestyle. Patients are not placed at the centre of decision-making, but rather decisions are based on professional notions of invasiveness, demonstrated here to be an inversion of patients' experiences.

The Grounded Theory which has been presented and the inadequacy of present guidelines demonstrate the need for these to be reimagined. They must be developed with meaningful patient involvement, incorporate assessment and consideration of wider lifeworlds and life goals, and facilitate safe, acceptable, and dignified management of bowel function following SCI. The structure in Figure 10 is proposed as a starting point for future development of new guidelines, and debate is invited.

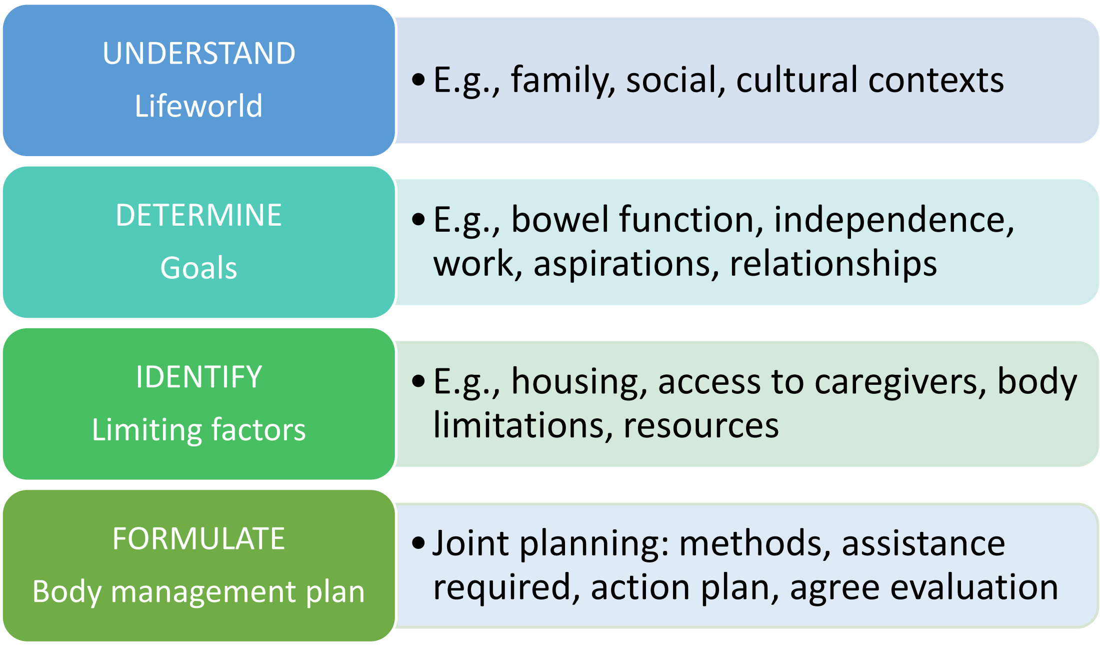

Figure 10: Proposed structure for creating new bowel management guidelines

Unmet need

A final area for consideration in relation to the increasing demand for colostomy formation is the concept of Unmet Need. Limited NHS resources mean that at multiple levels decisions are made about what is and is not available to healthcare users. Primary and secondary care providers act as gatekeepers who may only accept the legitimacy of the request for colostomy when it is deemed a last resort, and not when requested due to deficits in care provision or personal choice. Evidence for this was found in participant interviews, and this demonstrates the disparities in understanding between professionals and those living with SCI.

Unmet Need is found in the waiting list for spinal colostomies where individuals are permitted to proceed, which is lengthening and impacting individuals. The lack of organisational capacity to meet growing demand has been compounded by the Covid19 pandemic. Reflecting on Slasberg et al's (2014) assertion that organisations only recognise need for which there is an established service, the unplanned patient-driven demand for colostomy has created difficulty. As professionals adapt to and even embrace the overthrowing of traditional bowel management guidelines in this organisation and patient demand flourishes, it is not known how and whether the hospital organisation can adapt to meet this new need.

Strengths and limitations of the study

This Grounded Theory study explored the experiences of those with SCI who chose to have a colostomy. Gaps exist in the timeline of those who were interviewed, the filling of which may increase understanding of the wider social context in which body management decisions are made. Although primary data gathering had ceased before the Covid19 pandemic, some theoretical questions did emerge in the later stages of theory development. More interviews may have been helpful to explore categories but were not possible at this time.

The strengths of this research are that findings stem from rigorous explicitly stated and replicable methods, with patient voices central. Constant comparison and checking understanding enhanced the trustworthiness and transferability of findings. Ongoing clinical experience and the continuing flow of patients seeking information and requesting a colostomy confirm and resonate with findings.

Recommendations for further research

Further research is needed to develop and test findings and guide the development of future bowel management guidelines. More needs to be known about colostomy complications and how these are experienced. An evaluation of different bowel management methods would be useful, including acceptability and complications, quality of life, capacity to return to work, caregiver implications, and an economic evaluation.

CONCLUSIONS

This exploratory research has uncovered new knowledge about the bowel management experiences and choices of those with SCI who have a colostomy at either an early or later point. Colostomy is demonstrated to lead to the transformative experience of Being Alive Again, in which Losses and Suffering are reversed, and the attainment of higher priority lifegoals becomes possible. The Grounded Theory demonstrates the importance of providing those with SCI with Information and Choice to unlock access to body management options.

An important discovery has been that some choose to have a colostomy to mitigate Failures which have been identified. These include a deficit in the availability and quality of care provision in the community, and disabling environments which prevent access to public spaces. Exposing these creates a challenge as it is problematic to know how such deficits and barriers can be addressed.

Implications of the research

With new knowledge and understanding from this research of colostomy as a choice made in the context of wider lifeworlds, professionals must reassess their assumptions. It can no longer be assumed what is best for and how patients experience interventions without consulting them. The need for greater patient involvement and the creation of new guidelines is demonstrated.

There is a moral imperative to ensure information and choice are available to all living with SCI, not just to those that professionals deem would functionally benefit from it, so that a potentially transformative option is not denied to those who might choose it. Uncomfortable underlying Failures of Care have been exposed, which are influencing body management decisions, requiring further investigation and action.

The growing demand for earlier colostomy is a patient-led trend. Whilst accommodated within this healthcare organisation thus far, service provision need to be reassessed. Professionals have had to adapt to meet rising demand, creating a new clinic and information sessions, and increasing educational input for staff. With operating lists continuing to be affected in the wake of the Covid19 pandemic, the capacity to continue meeting rising demand is a challenge likely to intensify over time, and no present solution to this problem is conceived.

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