

Social adaptation following intestinal stoma formation in people living at home: a longitudinal phenomenological study

Abstract

Purpose: Intestinal stoma formation profoundly changes the relationship between a person and their social world. The aim of this study was to understand the experience of living with a new stoma; this paper explores the theme ‘disrupted social world,’ highlighting how stoma-forming surgery impacts on individuals’ abilities to participate and interact socially over time.

Method: A longitudinal phenomenological approach. Twelve participants with a new stoma were recruited using purposeful sampling. Data were collected at three, nine and fifteen months following surgery through in-depth, unstructured interviews and analysed using a bespoke iterative framework.

Results: Three categories were identified: participation in the social environment; interpersonal relationships: changes and challenges; and setting and achieving goals.

Conclusions: Stoma-forming surgery changes the ways people relate to their social environment and connect with others, creating self-consciousness and impeding social confidence and autonomy. Understanding the social implications of stoma-forming surgery can help clinicians to provide responsive and appropriate support to facilitate social rehabilitation.

Introduction

The body provides the means through which an individual experiences and understands the world. When a body undergoes significant change, such as following stoma formation (an opening into a hollow organ in the body), it is likely to change powerfully the relationship between the individual and the world in which they live. This is a significant issue as over 100,000 people live with an excretory stoma in the UK, with approximately 21,000 stoma-forming procedures undertaken each year [1]. Stoma-forming colorectal surgery is undertaken to manage a range of clinical conditions, with colorectal cancer, diverticular disease, ulcerative colitis and Crohn's Disease the most common [2]. In the intestine, an ileostomy is a stoma into the distal small bowel (ileum) and a colostomy is a stoma into the large bowel (colon) [2].

People who have had stoma-forming surgery face changes in bodily appearance, function and sensation, which can impact on all areas of their lives [3, 4]. This change in the relationship between a person and their world has far reaching implications as environment and interpersonal relationships are the basis of how an individual relates to the world around them, together constituting their 'social world' [5]. Kelly [6] and Annells [7] found that individuals can experience a tension in trying to return to social 'normality,' feeling a sense of obligation or a desire to present an everyday face to the world, which may not reflect their inner thoughts. Issues relating to disclosure about their stoma can be central to a person's approach to regaining this social normality. Some people with a stoma will voluntarily tell family, friends and/or colleagues about their stoma [8, 9] but negotiating the balance between revelation and concealment of their stoma is made more complex by the possibility that its presence may be inadvertently revealed through appliance failure and leakage and is therefore not entirely within their control [10]. As a consequence,

some individuals with a stoma may feel compelled to withdraw from their social world because of fear that the stoma could be visible through clothing or reveal itself in another way, thus avoiding the potential humiliation of such an occurrence [6, 11].

Feelings associated with disclosure about their stoma relate to individuals' perceptions of the reactions and opinions of other people as "the anticipated negative reaction of others can become an almost obsessive concern" [6, p.407]. Many hold an underlying belief that they are sexually unattractive, not just in terms of outward bodily appearance, but also in how stoma formation disturbs confidence in the sexual self [6, 10, 12]. Relationships with other people with a stoma can provide a sense of shared experience that individuals are unable to find elsewhere [13] and relieve feelings that they are the only person with a stoma [9]. Supportive family relationships and friendships are also important to the process of adjustment for individuals with a stoma, giving opportunity to share problems and concerns and receive practical support [8, 9, 13].

Although several phenomenological studies have been conducted to explore elements of the experience of living with a stoma, and include findings relating to bodily change and social adaptation [7, 9, 14, 15, 16], this study aimed to provide new insight by elucidating and exploring the experience of adapting to life with a stoma over time. This exploration captured two distinct lenses within individuals' experiences of living with a new stoma: looking inward to capture changes to the embodied self and looking outward to highlight participants' altered embodiment within their social worlds. While findings relating to changes to the embodied self are reported elsewhere [4], this paper explores the outward focus on a disrupted social world, highlighting how stoma-forming surgery impacts on individuals' abilities to participate and interact socially and how these experiences can change over time. These findings contribute to a larger study, which included healthcare professionals' experiences of caring for individuals with a new stoma [17].

Design & Methods

An open, exploratory research focus was considered more likely to capture wider aspects of the experience and enable connections to be made highlighting to what extent living with a stoma can impact on all areas of an individual's life. Hence, this study used existential phenomenology to capture a more universal understanding of participants' embodied experiences of adapting to life with a new stoma [5] and ultimately identify the essential structures of the experience of living with a stoma [18, 19].

A maximum variation, purposive sampling strategy facilitated the recruitment of twelve individuals with a variety of diagnoses, illness histories and modes of presentation [17, 20] who underwent stoma-forming surgery at a large district general NHS teaching hospital in the UK. Interview time-points of three, nine and fifteen months following stoma formation enabled exploration of adjustment to a new stoma over time [17]. Selection criteria were designed to provide a study population that would reflect variety within the stories of people with a new stoma and to capture the social, in-depth experiences of living with a stoma. People were eligible to be included who: had a diagnosis of Dukes A-C1 staged colorectal cancer, diverticular disease, ulcerative colitis or Crohn's disease requiring intestinal stoma forming surgery; expected to have a stoma for more than nine months; were aged over 18 years at the time of their surgery; had comprehensive use of the English language and were capable of sharing and communicating personal experiences; had their stoma-forming surgery less than two months prior to being approached. Exclusion criteria were a diagnosis of advanced cancer (Dukes C2/D) and a history of stoma formation.

Insert Table 1 here

Table 1: Characteristics of recruited participants

Informed consent was obtained prior to each interview. A one-to-one, open-ended, conversational interview approach was used [20], with a single question, “please can you tell me about your experience of living with a stoma?” Exploratory open questioning using just information provided by participants enabled them to direct the interview [21]. Reflections, pre-suppositions, and observations pertinent to the research process and emerging interpretations of the data were recorded in a research diary and discussed with the research team during data analysis. All participants chose to be interviewed in their own home, although alternative locations were offered. The study was conducted between October 2007 and August 2011. Interviews were of 40 to 90 minutes duration, digitally audio-recorded and transcribed verbatim using pseudonyms to protect confidentiality.

A six-stage iterative framework was adapted from the methods of Colaizzi [22], van Manen [18] and Smith and Osborn [23] and encompassed the following stages: capturing a sense of each individual’s whole experience (stage one), scrutinising the data in-depth to identify the distinct characteristics of each experience (stage two), engaging with a process of abstraction through which codes (stage three), categories (stage four) and essential themes (stage five) emerged. Particular attention to divergence in participants’ experiences helped to refine this process. Data analysis was undertaken by GT, with a random sample of transcripts co-analysed by MM. The sample size and longitudinal data collection approach provided the breadth and depth needed to identify the essence of the experience of living with a new stoma. Essential themes were shared with participants to facilitate transparency and to give them an opportunity to provide feedback on interpretations made (stage six). Participant feedback confirmed the essential themes identified.

Ethical approval

This study was approved by the Research Governance Committee of the research site (2007GSUR04S) and Local Research Ethics Committee (07/H0310/94).

Findings

The essential structure elucidating a disrupted social world after stoma formation comprises three broad categories: participation in the social environment; interpersonal relationships: changes and challenges; and setting and achieving goals (figure 1). Quotations used to illustrate variations in experiences are identified by the participant pseudonym (e.g. Andrew) and the time point of the interview from which it is derived in terms of months following stoma formation (e.g. 3m, 9m or 15m).

Insert Figure 1 here

Figure 1: Disrupted social world: overview of categorisation

Variations in the experience

Variation within the experience of a disrupted social world was captured in how individual participants' embodiment within their social worlds altered as a result of the bodily changes instigated by their stoma-forming surgery. Stoma formation was seen to impact on the way in which participants engaged with and experienced their social environment, both in the familiarity and safety of home and in wider social settings. Interpersonal relationships were identified as crucial to social adaptation, with variations in experiences of others directly determining levels of self-acceptance and social participation. Setting and achieving goals represented an important way in which participants measured their own social adaptation.

Participation in social the environment

Separation from their social environments occurred for participants either due to the pre-operative symptoms of their underlying condition such as pain, diarrhoea and/or intense fatigue, or by the sudden immobilisation and confinement caused by their surgical admission. Few viewed positively the experience of being in hospital, whether their surgery was elective or unplanned. Many spoke of their lack of familiarity with the hospital environment:

“it’s like being in a space ship; I spent a lot of time awake at night because I was uncomfortable but the whole place vibrates slightly because there is so much electronic equipment there” (Greta, 3m),

or of feeling confined by it. Going home represented security, familiarity and a reconnection with important relationships: “home meant safety to me, being looked after better, someone there if I called” (Ellen, 3m). Ken demonstrated that separation from the social world can be transferred into the home setting, with home seen as a safe haven, and independent stoma self-care only achievable in this familiar environment:

“I didn’t go anywhere for the first two or three weeks; I didn’t want to be away from here (home) just in case; ...if I’m here, if anything goes wrong [with my stoma] I can try and do something” (Ken, 3m).

Physical debilitation was accepted as part of the recovery process at three months after surgery, with physical exhaustion, sleep disturbance and pain preventing many from undertaking routine activities of living. Laura, who had been fit and well before surgery, highlighted the stark contrast between her pre- and post-operative physical function: “you’re hobbling out of hospital and you think, ‘I went skipping in there!’” (Laura, 3m). In contrast, participants who had endured debilitating pre-operative symptoms quickly felt an improvement in physical function that accelerated their

general recovery and enabled them to cope better with the full impact of their surgery:

“you cannot put your mind on to anything because of what you’ve got and the fact that you’re trapped, and you felt like a caged animal in a way ... and having that operation, within two weeks of that, totally different I felt” (Craig, 3m).

Persistence of post-operative exhaustion at nine and fifteen months created feelings of distress and frustration as expectations did not match reality:

“the worst thing to cope with was the frustration and not being able to do all the things I ought to be able to do, which leads to irritability, which leads to depression, which leads to fatigue and it’s a pretty nasty vicious circle” (Flora, 9m).

Participants’ level of post-operative bodily debilitation influenced the speed with which they felt physically able to participate socially. In addition, bodily confidence was crucial in establishing social self-confidence. The possibility of needing to attend to their stoma made participants apprehensive about going out at all in the initial post-operative period; several participants cancelled or delayed holidays over the first year following their surgery to avoid the need to care for their stoma away from home. As time went on, increased familiarity and routine encouraged participants to venture further from home and re-establish social participation, although lack of confidence about stoma self-care at nine or fifteen months still tended to draw attention to this:

“I’ve lost my confidence, I’m still wary of going out because it (the stoma) doesn’t behave itself” (Hazel, 15m), illustrating the individual nature of adjustment.

Being prepared to attend to stoma self-care when away from home facilitated a sense of control over potential and actual situations in which it could be required. This feeling of control increased participants' confidence in tackling new and potentially challenging social situations:

“I have my little kit (equipment to undertake an appliance change) with me wherever I go, so if anything does happen, if it actually fills up, I can soon nip into the toilet and change it; if the worst came to the worst I could actually do it in the back of the car” (Ellen, 3m).

However, the heightened awareness (of potential stoma function, proximity of toilet facilities, stoma care equipment) required to exercise this control represented a fundamental change to their prior 'normal' relationship with their social world:

“I always make sure I've got spare bags in my bag and think perhaps I just need to go to the toilet and just check; so I think ahead more and plan more; that's probably the only way I would say things aren't normal” (Laura, 15m).

Dietary manipulation was also important in planning social activities. Foods that could make the stoma output less settled and predictable, such as high fibre foods, would not be eaten prior to planned social activity and two participants avoided eating altogether prior to a long journey to minimise the risk of their stoma working:

“I thought 'well if we start off early I'm not going to eat anything' because I just couldn't face having to do anything in the toilet in the train or anything ... so I just didn't eat anything until we got on the last train” (Hazel, 9m).

Anxiety about others being able to see, hear or smell their stoma made some participants question the level of social reintegration they were willing to attempt and their ability to exercise pre-operative levels of social autonomy or meet perceived social expectations. In addition, awareness that the changed shape of their abdomen

could be visible to others heightened feelings of social self-consciousness: “because you know there’s something different you think everybody else has picked up on it” (Laura, 3m), although increased familiarity and acceptance of themselves with a stoma over time diminished feelings of self-consciousness about bodily appearance.

Interpersonal relationships: changes and challenges

Other people influenced the ability and motivation of participants to reconnect with their social world through a variety of social relationships.

Participants’ acceptance of themselves with a stoma and their confidence to rejoin their social world were strongly influenced by an intimate partner’s understanding of changed physical and emotional capacity and their preparedness to adjust themselves to accommodate this change and support their partner. For David, his wife’s acceptance of him with a stoma was central to his own acceptance of his changed body:

“I just couldn’t face having anything to do with it ‘til I knew the wife was all right with it and she was fine with it ... I think if she’d have rejected it or couldn’t look at it or whatever then I don’t know what I would have done” (David, 3m).

Some participants perceived a lack of understanding and adjustment in their spouses’ expectations of them. Bob, when discussing an incident in which his appliance leaked in the night, described how his wife,

“got quite annoyed because I had jumped out of bed and it had shot all over the carpet ... I try to explain it’s not my fault; I don’t deliberately say to the bag let’s empty on the bedroom floor; it’s embarrassing for me” (Bob, 3m).

Ellen’s husband was unable to accept her stoma and as a result prompted in her strong feelings of being personally rejected by him: “I do feel so pushed away; it’s as

though I've got something contagious" (Ellen, 3m). General tensions within spousal relationships at three months mostly diminished over time, except for Ellen and Flora who continued to describe relationship problems at nine and fifteen months.

Experiences of intimate partners' acceptance and understanding in general terms were mirrored in participants' confidence to resume sexual relationships. Those who perceived their partners acceptance of their need for stoma-forming surgery and their changed body with a stoma found that surgery had a minimal impact on their intimate relationship in the long term: "there's been no change to our relationship; in fact that's made us very strong, very close, and there's still a little sex there" (Jack, 3m). Conversely, Ellen and her husband slept in separate bedrooms after her surgery, despite having enjoyed a close intimate relationship pre-operatively:

"that's just like two friends living in a house and getting on at the moment; there's no affection, no nothing and the more he couldn't cope with it [stoma], the more I've put up this barrier that I don't want anything there as well" (Ellen, 9m).

Heightened self-consciousness and a lack of bodily confidence, compounded by a lack of support and acceptance in intimate partners, made some participants feel apprehensive or even distressed at the thought of future intimacy. Two participants who had not been in a relationship at the time of surgery divulged that they lacked the confidence to expose themselves physically and emotionally in an intimate relationship: "I don't think I could [start a relationship with someone] because of the way I am ... I don't think it would ever be possible" (Hazel, 15m).

Experiences of receiving care and support from family members appeared to deepen participants' relationships with them while others found their family's struggle to accept their situation to be a source of anguish and disappointment. Practical support by families encompassed not only general household chores and

transportation, but also stoma management and care: “they are now trying out some new bags and she (daughter) came around the other day and said ‘come on let’s have a look at them’; she really is helpful” (Ellen, 3m). Although most described positively the involvement of their family in their recovery, others highlighted experiences of family relationships that hampered their developing self-confidence. Flora’s son told her to “pull yourself together” (Flora, 9m), which she found profoundly upsetting; Hazel reflected on how her daughter had undermined her confidence: “my daughter said, ‘don’t tell people, it’s not nice’” (Hazel, 9m).

Friends were especially important for those who experienced tension within their other close relationships or who did not have an intimate partner. Friends provided practical and emotional support and gave participants the self-belief and confidence to begin participating in their social worlds again. Maria’s friends questioned whether she needed to have stoma reversal surgery: “a couple of them (friends) I’ve told I can go back into hospital and have it all reversed and they are like ‘do you really want to put yourself through all that? You’re all right as you are’” (Maria, 3m). Andrew and Hazel described how their friends’ positive appraisal of the way they had dealt with their surgery and stoma made them feel more confident. Some who felt unable to ‘face the world’ initially reached a compromise by inviting friends to their home, where they felt safe and able to attend to their stoma if necessary. Here, friends could be tested to see if they behaved differently or reacted in any way to the presence of the stoma:

“when I first went out I had a shirt on and I said ‘now can you notice anything, can you notice anything?’ and [my mates] said, ‘no we can’t notice anything’, ‘are you sure you can’t notice that bag?’, ‘no we can’t notice that bag there’” (David, 3m).

Such reassurance fostered the confidence to tackle greater challenges involving renewed social participation, although most participants felt uncomfortable about freely disclosing to those outside their 'inner circle' of partner, family and close friends that they had undergone stoma-forming surgery: "I've told some friends [about the stoma], but I suppose I've been a bit selective; I'm probably not going to tell every person I meet" (Laura, 3m).

Many activities were either avoided altogether or anticipated anxiously due to the possibility that the stoma could inadvertently reveal itself to others:

"I haven't been able to get myself to church for a nine o'clock communion because what would happen you're in church at the most sanctified moment and I have to gallop off to the back end of the church and go in the loo?" (Flora, 9m).

All found their lack of control over wind to be deeply embarrassing, especially in social situations with people who did not know they had a stoma:

"Sometimes you get these noises from your stomach, which are quite loud and if you're in a pub or a restaurant I would have thought it could be a bit embarrassing" (Andrew, 3m).

Participants described how they coped with this involuntary revelation of the stoma by simply ignoring it or making a joke about it in order to diffuse feelings of self-consciousness: "I'd say 'oh that's all right, it's making a noise, don't worry about it'" (Ken, 9m). Initial concerns were expressed by some that their stoma might smell, but these were generally not repeated in later interviews. Instances of appliance leakage in public were described as highly distressing and embarrassing for participants at all interview time-points, decreasing their confidence to face future social outings and representing to them a backwards step in their adjustment.

Setting and achieving goals

Early recovery goals tended to relate to bodily function and basic activities of living, with uncertainty about what constituted realistic social goals. By nine months, there was increased understanding of achievable social goals and greater confidence and energy to achieve them. Resonating with a drive to return to physical normality, social goals centred on a quest to regain social normality, both in terms of physical capability and developing the confidence to resume social activity and participation.

Information from varied sources enabled participants to identify and set achievable social goals for their recovery. Conversing with another person with a stoma was considered especially helpful:

“I spoke to this lady who’d had the operation at the same age as me two years ago; she’s living life to the full in every way now and it made me believe that there’s light at the end of the tunnel and that helped” (Laura, 3m)

Flora and Greta subscribed to a magazine for individuals with a stoma, and felt reassured by stories and letters from people who had achieved a good quality of life following stoma formation. Jack and Maria had prior experience of caring for others with a stoma, which gave them confidence in managing stoma self-care and an expectation of settled stoma function that would enable them to exercise greater social autonomy in time. Many discussed gaining information and advice from the stoma care specialist nurses, helping them to understand how long they could expect their physical recovery to take, their stoma function to settle, and the potential issues they could face in reconnecting with their social world.

All participants attempted to control the manner and the speed with which they resumed social participation by dividing their social goals into achievable smaller steps. This approach reduced anxiety and increased confidence for participants in

resuming their pre-operative relationships with their social worlds. For example, travelling away from home was separated into smaller steps of staying away for a night somewhere close to home, then venturing further afield for two or more nights, anticipating that this would increase confidence to take a longer holiday in the UK or abroad: “we are thinking about having a weekend away in the beginning of December just to see how it goes” (Andrew, 3m). At fifteen months, Andrew reflected on the success of this strategy in enhancing his confidence to travel away from home, as he had just returned from a two week holiday abroad. At nine months, Flora described this as an important strategy to regain basic physical function,

“I’m hoping that [if I] do a little bit more each week, just walk a little bit further or go the longer way round, I’m hoping that I’ll gain some strength from that”
(Flora, 9m)

Laura agreed with her employer that she could use this approach when returning to work, which she found helpful in enabling her to contribute without taking on more than she felt able to manage at the time. This ‘graded’ approach allowed the body to be tested and to adapt gradually and provided a sense of control over social reintegration as participants were able to plan for potentially challenging social situations and minimise the risk of attempting social activities for which they did not feel mentally or physically ready.

As physical function and social confidence developed, participants talked about feeling closer to achieving their goal of ‘normality,’ viewed as an ability to participate in the social world as they did before: “when I say I’m back to normal, I feel as though I can do the things that I did before the operation” (Andrew, 15m). The ways in which participants defined social normality for themselves were reflected in the goals they set and the recovery milestones for which they were aiming. Travelling away from home represented the ultimate social goal at all time-points. Returning to work,

another major recovery milestone, included paid employment, unpaid physical labour or voluntary work, indicating that rather than being about employment as such, this goal could have more to do with recovering previously held social roles and identity: “I want to get back to work; I’ve felt like it for a little while now because I’m fed up with being at home and I miss [my clients]” (Ken, 3m). At nine months, all participants who undertook paid employment prior to their surgery had returned to work.

The importance of social role and identity was illustrated by participants who explored how these important aspects of self had been challenged by their surgery and stoma, and the extent to which they could be re-established in the fifteen months after stoma formation. Bob discussed his role as husband and provider at home, focusing on how difficult he found it to watch his wife undertake domestic tasks that he had previously performed: “I watch her cutting the grass and I think I should be doing that but I know I can’t ... but I feel guilty that I can’t do it” (Bob, 3m). At nine and fifteen months, many described a resumption of activities that signified re-engagement with the social roles exercised previously, albeit limited by the reduced physical capacity initiated by their surgery:

“I’m back doing the granny things, which is good, and I can pick up the little one (her grandson) more easily now, which is good. I haven’t attempted to carry him very far yet but I can actually pick him up” (Greta, 9m).

Ken and Laura described returning to paid employment as providing a sense of freedom and autonomy. Hazel’s first step towards rebuilding her social identity was to work in a hairdresser’s shop because,

“it was all old people and I thought, well, they have problems and that made me feel safe and it still makes me feel safe if I’m going to deal with old people or children because I feel I won’t mind because they probably have problems like that as well” (Hazel, 15m).

Some gender differences were noted in recovery goal-setting. Regaining their ability to continue to be physically active was a fundamental recovery goal for five out of six male participants, underlining its importance to their social identity and sense of self:

“I potter about; I am not one for sitting around watching TV or anything; I get out the back there; I usually have some old engines I was building out in the back garage, rebuilding and doing stuff like that, gardening” (Andrew, 3m)

For female participants, a positive perception of clothed appearance helped to re-establish social and sexual identity. All female participants discussed clothed appearance at each interview, with consciousness of a disruption to clothed bodily appearance following stoma formation seeming to contribute to a deeper disconnection in female participants' sense of embodied self, and in their embodiment within their social worlds.

Although most had achieved self-set goals by fifteen months, no-one had returned to the 'normal' embodied relationship they had experienced between self and social world prior to their surgery. Only through achieving their goals were they able to grasp that this did not necessarily constitute a return to social normality as they had known it pre-operatively. Over fifteen months, many considered themselves to have returned to a 'normal' relationship with their social world in terms of the activities they were able to undertake, even forgetting about their stoma at times during the day when they were occupied in social activity and their stoma remained inactive.

However, the importance of heightened awareness in enabling participants to exercise bodily autonomy extended into their relationships with their social worlds.

Laura reflected on her changed relationship with her body and her social world as a result of her stoma formation: “I am more in tune with how my body feels because I'm taking more notice of it [than] before” (Laura, 15m). At 15 months, participants had developed, or were developing, a new social normality that incorporated their stoma.

Essential Structure

Stoma-forming surgery changes the way that an individual relates to their social environment and other people. This disruption increases a reflective self-consciousness, which impedes social confidence and autonomy. Ability to exercise bodily, and therefore social, autonomy relates to the ability to participate physically in the social world, to master stoma function and self-care independently and competently, and to have a range of strategies in place to feel prepared for the stoma to need attention away from home. Self-consciousness and discomfort about involuntary exposure of the stoma demonstrates the importance of being accepted by other people in facilitating self-acceptance and the self-confidence to reconnect with their wider social world. These factors, combined with a strategy of graded exposure, enable many to achieve self-set social goals and to re-establish social identity, in turn engendering greater social freedom and confidence. However, a return to 'normal,' pre-reflective social functioning is challenged by a need for heightened awareness to enable individuals to exercise the bodily autonomy required for full social participation. The time-frame for this process of social reconnection varies widely as each individual increases their ability to exercise bodily, and therefore social, autonomy at different times in their recovery journey.

Discussion

Understanding fully the impact of stoma-forming surgery lies in acknowledging the extent to which this bodily change impacts on an individual's ability to interact with and participate in their social world. In the initial post-operative period in particular, individuals' anxieties regarding bodily mastery (that is, competent stoma care skills, appliance security, predictable and settled stoma function), general physical debilitation and the potentially negative reactions of others, can lead to loss of confidence and heightened self-consciousness [17]. Concerns about voluntary and

involuntary revelation or concealment of the stoma may induce a tendency to avoid certain social situations or withdraw from social activities. Tensions between revelation and concealment of the physical presence of a person's stoma [6, 7, 12, 24, 25], and avoidance or withdrawal from situations in which the stoma might reveal itself [8, 10, 26, 27, 28] are widely identified in prior research. However, there is limited discussion of the direct relationship between mastery of the changed body and social self-confidence as demonstrated in this study. A richer, more nuanced understanding of the social impact of living with a new stoma can facilitate the planning and provision of optimal pre- and post-discharge care and support for individuals.

Merleau-Ponty [5] describes freedom of action as an essential feature of a person's relationship with their social world, dependent on their ability to exercise autonomy and competence. For the person with a stoma this is dependent on awareness and mastery of bodily function. As mastery of the body is a vital first step in attaining a balanced unity of body and self and reconnecting with the social world [17, 28], the biggest threat to these achievements is not changed bodily appearance or sensation, but an inability to master bodily function. For an individual to be unconscious of their stoma would involve a lack of awareness that could lead to involuntary disclosure: a visible bulge beneath their clothing as the appliance fills and ultimately to appliance leakage if it is not emptied or changed. Social participation, therefore, not only requires heightened awareness and confidence to master the changed body in social situations, but a need to plan and to be prepared to undertake stoma self-care should such an event occur.

Fears concerning bodily mastery and social self-confidence can be successfully managed by using a graded exposure approach, in which social situations are approached in a measured way to minimise the risk of physical or emotional exposure. Success in this approach instills further confidence to be more socially

adventurous, but even at fifteen months social goals such as travelling abroad or swimming, in which the impact of stoma revelation would be most acutely felt, may not have been attempted. Although recommended as an approach to social reintegration in White's book 'Living with a Stoma' [29], this gradual, considered movement from social withdrawal and avoidance to social participation, with a resultant increase in social confidence, is only described by Taylor et al [30], who focuses on general physical recovery and not adjustment to a new stoma. The longitudinal nature of this study demonstrates how failure to achieve bodily mastery can hamper individuals' reconnection with their social worlds in the longer-term, illustrated by experiences of feeling imprisoned at home by the need to be near a bathroom, or seeing home as a safe haven. McVey et al [13] and Rozmovits and Ziebland [10] identify individuals' recovery from stoma-forming surgery for colorectal cancer as directly related to the extent to which they are able to attain personal control over stoma function and management. For those requiring a stoma for diverticular disease or inflammatory bowel disease, it is clearly a similar experience.

A disrupted social world is further illustrated by changes to interpersonal relationships. Other people's acceptance and support are significant facilitators in the process of reconnecting with the social world, helping to re-establish social identity and accept changes to the embodied self, in turn leading to greater social freedom and confidence. Supporting existing research findings, this study also highlights that lack of support and acceptance by others, including healthcare professionals, can detrimentally affect experiences of accepting self with a stoma and social reintegration [8, 12, 13, 26] and that relationships with other people with a stoma can provide a sense of shared experience and a source of information and advice independent of healthcare professionals [8, 13, 26, 28].

Intimate relationships are profoundly influenced by having a stoma, not just in terms of physical sexual activity but regarding perceptions of sexual self, roles within a

relationship, and spousal support. Intimate relationships which are responsive to the changing needs of individuals with a stoma over time are more likely to encourage adaptation and self-acceptance, endorsing previous research findings that a supportive sexual partner can facilitate adaptation and acceptance in the person with a stoma, and that a sexual partner who is unable to accept the bodily changes that a new stoma brings can damage self-acceptance [8, 10, 24].

Social identity, which provides a mechanism through which people participate in their social world, is challenged by stoma formation. Bodily mastery and adaptation to the changed body are fundamental to re-establishing social identities and roles. Strong influencing factors on social identity include the ability to undertake physical tasks in men and clothed appearance in women. There appears to be a deeper link between social identity and an inner sense of self (as opposed to self-image as a perceived view of how others see self) than is currently recognised [10, 31], drawing further attention to the difficulties individuals with a new stoma may face in maintaining social identities and roles.

Time is central in determining adjustment to and acceptance of self with a new stoma. One year has been proposed as a turning point in this process [32, 33], but it is clear that the success of integrating a new stoma into a redefined sense of embodied self can be a highly individual process that extends for many individuals beyond fifteen months and is dependent on a complex interplay of influencing factors. Throughout the experience of living with a new stoma is the expectation that time will bring renewed bodily strength and functioning, familiarity with new circumstances and confidence to face the world again with a stoma. Many feel uncertain about how and when this might happen, knowing they are making progress, but unsure as to exactly what their ultimate recovery goal should be and when they can expect to achieve it. Uncertainty about or anticipation of the future is identified by McVey et al [13], Persson and Hellstrom [9] and Beaver et al [34], but

they do not focus on the temporal dimension of an unknown future versus a familiar but no longer attainable past. Taylor et al [30] identify a disruption to the familiar body and recovery goals focused on achieving bodily potential in the future but do not explore this in the context of time or social participation and do not separate the experiences of participants with a stoma from the other participants in their study. The importance of time, in addition to its role as a facilitator of adaptation, is demonstrated in the current study in the subtle changes in individuals' perceptions of their experience of living with a new stoma, captured in a pendular movement between looking backwards to life as it was and forwards to an unknown life ahead. Kelly [30] alludes to the importance of time, suggesting that despite the profound nature of the experience of living with a new ileostomy, time allows people gradually to develop a more balanced unity between body and self and between embodied self and world. The existential phenomenological methodology and longitudinal design of this study allow time to be explicitly identified as playing a fundamental role in the experience of living with a new stoma.

Strengths and limitations

This research develops understanding of the experience of social rehabilitation following stoma-forming surgery. Further research might include people with wider diagnoses than those included in this study or a more focused exploration of the experience of unplanned stoma-forming surgery. A longer time frame for data collection could have permitted deeper exploration of social rehabilitation following stoma formation.

A range of strategies were used to address the potential impact of the researcher's position on the research process. As a clinician with prior experience of stoma care, the researcher (GT) was interviewed about her own experience of caring for individuals with a stoma to enable identification and awareness of pre-judgements.

An unstructured interview method minimised opportunity for the researcher to direct the interview content. A reflective and reflexive stance was achieved by use of a methodological log, in which design and interpretation decisions were documented and explained, and a researcher diary to work through personal insights and experiences within the research process.

Triangulation was achieved through investigator collaboration in the process of analysis, in which the interpretation of emerging themes were explored and agreed between the authors, and theoretically in drawing from the philosophical and methodological perspectives of Merleau-Ponty [5], van Manen [18] and Heidegger [36].

Purposeful inclusion of participants who may have their stoma reversed between nine and fifteen months enabled exploration of an alternative trajectory within the phenomenon, while ensuring that they had experienced living with a stoma beyond the initial postoperative period.

Conclusion

Stoma-forming surgery changes the way an individual relates to their social environment and connects with others, creating self-consciousness and impeding social confidence and autonomy. Clinicians can provide responsive and appropriate support to facilitate social rehabilitation by recognising bodily mastery as an essential first step in promoting social adaptation and considering time, body, environment and relationships in a holistic framework for patient assessment and care.

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Declaration of Interest

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