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# Restoring embodied control following surgical treatment for colorectal cancer: A longitudinal qualitative study

Claire Taylor[a,*], Alison Richardson[b], Sarah Cowley[c]

[a] Kings College, London, Florence Nightingale School of Nursing and Midwifery, Burdett Institute, St Marks' Hospital, Harrow HA1 3UJ, United Kingdom
[b] Southampton University Hospitals NHS Trust and the University of University, Southampton General Hospital, Mailpoint 11, Tremona Road, Southampton, SO16 6YD, United Kingdom
[c] Florence Nightingale School of Nursing and Midwifery, King's College London, James Clerk Maxwell Building, 57 Waterloo Road, London SE1 8WA, United Kingdom

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## ABSTRACT

*Background:* This article presents the findings of a study about recovery following surgery for colorectal cancer. Most patients diagnosed with this cancer are treated with surgery. Few studies have employed a qualitative approach to examine their experiences and perceptions of recovering from this treatment.
*Objectives:* The purpose of this study was to discover the process of recovery for individuals following curative surgery for colorectal cancer.
*Design:* This qualitative study drew on grounded theory methods and used a prospective longitudinal design.
*Settings:* Ethical approval was granted by three Local Research Ethics Committees enabling patients to be recruited from three different hospitals in the South of England.
*Participants:* Purposive sampling was used to identify patients diagnosed with colorectal cancer who had had surgery with curative intent.
*Methods:* Each participant was interviewed up to four times following their surgery: at 6 weeks then at 3, 6 and 12 months. Sixty-two interviews were conducted. Emerging concepts from the analysis defined further data collection. Relevant literature was theoretically sampled and all data analysed using constant comparison. Theoretical saturation was achieved.
*Results:* Sixteen participants were recruited. Analysis of study data identified four conceptual stages representing the main phases individuals can experience during their recovery. They are: disembodiment, restoring embodiment, reclaiming control and managing embodied control. These occur in a stepwise progression, reflecting the emotional, physical and social processes involved in restoring perceived control over the body. They reflect the difficulty individuals can experience in understanding and self-managing their bodies. There is a desire to regain confidence and certainty over body function but this is threatened by fears about future health.
*Conclusions:* Achieving a sense of control of one's body, after surgery for colorectal cancer, proves to be a major challenge. Greater recognition of the consequences of cancer and its treatment upon the body and individualised management is required. Addressing how individuals can regain embodied control during their recovery needs to be integral within post-treatment support.

### What is already known about the topic?

- Surgical resection of a colorectal cancer induces acute physical stress upon the body.

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* Corresponding author.
*E-mail address:* gillian.taylor@kcl.ac.uk (C. Taylor).

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- It can take at least 6 months for most acute surgical side-effects such as pain, fatigue and altered bowel function to lessen.
- Overall, the literature suggests that most patients do return to near their pre-diagnosis status although individual recovery trajectories vary.

**What this paper adds**

- The study illustrates how this treatment experience can precipitate a significant change in how the body is perceived which has emotional and physical consequences.
- It draws upon the sociological literature to make particular reference to how loss of normal bodily functions during recovery creates difficulty in re-establishing a sense of mastery, confidence and certainty over the body.
- This altered relationship with the body challenges notions of recovery.

## 1. Background

Over the last decade a greater range of chemotherapy treatment options for colorectal cancer have become available (Cancer Research, 2009). Nevertheless surgery remains the cornerstone of treatment within oncological regimes in offering the greatest likelihood of cure for this cancer. In the UK, individuals diagnosed with early stage cancers (T.N.M. Stage I and IIa) may be treated by surgery alone, although those at higher risk of developing recurrent disease are recommended for adjuvant chemotherapy, +/− radiotherapy if a rectal cancer (see Mayer, 2004).

Recent surgical colorectal cancer research has been orientated to recording and subsequently reducing the associated physical side-effects, which can include: incisional pain, surgical complications such as anastomotic leaks, wound infections, sexual and urinary dysfunction, stoma-related concerns as well as risk of cancer recurrence (e.g. Hendren and O'Connor, 2005; Maurer, 2005). These studies put much significance on physiological healing and to a lesser extent achievement of physical independence, as markers of recovery. This perspective has relevance in early recovery but once immediate corrective work is achieved and homeostasis restored, then the goals of recovery shift beyond physical limitations.

The recovery literature ignores the emotional, financial and social effects of recuperating and renewing the body following this surgery. Few examine how this major abdominal operation for cancer affects individuals more personally and what significance this may have upon quality of life in the longer term. Since recovery is seen as a fundamental and multidimensional process which requires a 'total human response' (Dorsett, 1991, p. 178) the individual context of recovery is significant. Evidence from other cancer sites, namely breast cancer would suggest that there are emotional, spiritual and social factors associated with this cancer treatment, which may equally impact on recovery (e.g. Ganz et al., 1996; Shimozuma et al., 1999).

In studies where qualitative methodologies are used the orientation is generally patient experience during the first 3 months following treatment (e.g. Galloway and Graydon, 1996; Barsevick et al., 1995). Such studies can provide valuable insights into the early phase of recovery, for instance highlighting that altered bowel function including urgency and frequency of bowel action, soiling and faecal incontinence lead to body image issues and fear of intimacy (DeSnoo and Faithfull, 2005). However, many individuals take longer than a few weeks to achieve recovery (Schroevers et al., 2006; Knowles et al., 2007). Simpson and Whyte's (2006) one-off interviews with this patient group suggest that even 6 months after finishing treatment patients report residual tiredness which limits resumption of usual roles.

Two prospective longitudinal studies of patient experiences following colorectal cancer treatment have been conducted. The first is Shaha and Cox's (2003) phenomenological investigation which involved frequent points of data collection over several months with a heterogeneous sample of seven colorectal cancer patients, to describe how this diagnosis can become 'omnipresent' within an individual's life. The second was by Ramfelt et al. (2002) who sought to identify the emotional and interactional perspectives following this diagnosis through a one year illness period. Their focus was the complexity of ensuing emotions rather than the effects of cancer treatment received. These studies have begun to articulate the impact colorectal cancer can have upon individual lives. However, none have investigated the process of recovery following surgical treatment or sought to describe holistic adaptation over time.

Studies investigating the impact of colorectal surgery which involves formation of a permanent stoma highlight how this change in body image and function can affect quality of life (e.g. Sprangers et al., 1995; Wade, 1990; McVey et al., 2001; Thorpe et al., 2009). Aside from these studies, the recovery literature makes little reference to the outcomes of surgical treatment upon the body as a whole. This is surprising as the lived body lays the foundation for human suffering (Frank, 1995). Sociological and psychological discourses of body alteration and effect do however exist in other subject areas such as chronic disease (Seymour, 1989; Williams, 1997) and since correlations to cancer can be made, their relevance is suggested. This body of work articulates how conceptions of the body are influenced by cultural norms, social roles and individual responsibilities (Seymour, 1998). A study of recovery using an approach which enables these variables to be taken into account is required.

## 2. The study

The main purpose of this study was to understand how individuals recover following colorectal cancer surgery. A grounded theory study of recovery was conceived with the intention of creating a theoretical framework which might simplify the processes occurring and accommodate different explanatory variables. The research question was: 'What is the process of recovery for individuals following curative surgery for colorectal cancer?'

The lack of evidence regarding this process justifies an exploratory longitudinal study designed to capture changes in health over time. In exploring what this process means to individuals, it was hoped that discovery of how they adapt and respond, not only to the diagnosis, but also this treatment would be revealed, and any difficulties that they may experience during the first year following colorectal cancer surgery discerned. By exploring the effect such treatment has upon an individual, our appreciation of the post-operative experience following colorectal cancer surgery can be enhanced.

## 3. Study design

A grounded theory approach was used to inform this longitudinal, qualitative study design because its pursuit of theoretical understanding over description offers greater relevance and potential for generalisability (Glaser and Strauss, 1967). It is appropriate for investigating the practical problems and real-life situations that individuals may experience in their recovery and supports inclusion of varied data sources allowing the complexity of a process such as recovery to be captured. By using this approach, what proves meaningful during recovery can be elicited as well as any perceived difficulties in understanding and action (see also Glaser, 1978, 1992, 1998, 2001).

## 4. The setting

Three hospitals in Greater London were selected for their differing characteristics to provide contrast in patients' treatment experience: a tertiary referral centre for colorectal disorders—Site 1, a small urban hospital—Site 2, and a district general hospital in a more rural location—Site 3, and to enable enough patients to be sampled and followed through the recovery period.

## 5. The participants

Theoretical sampling is the method of choice in grounded theory, but in this study, participants needed to be recruited purposefully in order to focus on recovery from surgery with curative intent for individuals diagnosed with colon or rectal cancer. Patients diagnosed with incurable disease were excluded from sampling because the study was concerned with recovery. Additionally, patients recovering from permanent stoma formation were excluded since their experiences are comparatively well researched.

## 6. Data collection

A prospective longitudinal design was designed with four data collection points at 6 weeks, 3 months, 6–9 months and 1 year from surgery, to track this process of recovery and portray moments in time (Charmaz, 1999). Data were primarily collected by semi-structured interviews, chosen for their interactive and generative potential (Mason, 2002). Data collection points were determined at the outset of the study to provide some consistency across cases; with specific time periods selected according to known recovery points (see Table 1).

All interviews were tape-recorded and conducted by one researcher, a nurse with experience in qualitative interviewing. The interview guide for the first and final interviews is shown in Table 2. Questions on these topics were only asked once participants had been allowed to talk freely about their experiences of recovery.

These interview guides were developed by the researcher, based on findings from a previous study (Taylor, 2001). In the second and third interviews, participants were asked how they were now feeling and what had changed since the last interview. Further questioning was employed to clarify any inconsistencies or complete gaps in their accounts over time.

The researcher ensured she was thoroughly mindful of each participant's previous interview data and attentive to the study's evolving analysis during each interview. Field notes recorded these thoughts, as well as reflections on interview technique and 'the conditions of it being told' (Glaser, 2001, p. 145).

The third data collection point was a telephone interview at 6–8 months post-operatively. It was selected over a face-face interview for logistical reasons (Holbrook et al., 2003). The telephone interviews lasted approximately 15 min, compared to an average of 60 min (range 50–90 min) for the face-to-face interviews. Two of the 16 participants chose not to be interviewed at this time, believing this would make for an improved final interview at one year. Although several participants stated they enjoyed the ease and convenience of this method, deeper exploration of ideas was limited.

**Table 1**
Interview time points and associated rationale.

| Data collection method | Time following surgery | Rationale |
|---|---|---|
| Interview 1: Face-to-face | 6 weeks | Diagnostic and surgical experience still vivid (Taylor, 2001). Patient will have discussed staging and option of further treatment. Tiredness should have lessened to allow sufficient stamina for interview. |
| Interview 2: Face-to-face | 3 months | Acute physical symptoms have often settled (Miller et al., 1995; Williamson et al., 1995). In resuming activities associated with normal living, psychosocial difficulties may arise (McQuellon et al., 1998: |
| Interview 3: Telephone | 6–9 months | Hospital check-ups are now less frequent, if at all. Decisions about holidays, work and life priorities may become important. Anxiety regarding survival may increase (Knowles et al., 1999) |
| Interview 4: Face-to-face | 12 months | The first anniversary of the surgery and cancer diagnosis may be significant. Post-operative complications can be maintained >1 year and may determine their chronicity (Camilleri-Brennan and Steele, 1998). |

**Table 2**
Interview guide at the first and final interview.

| Interview (time point) | Interview 1 (6 weeks) | Interview 4 (12 months) |
|---|---|---|
| Interview content | 1) How have you reacted to this diagnosis? | 1) Looking back, can you summarise what this year has been like for you? |
| | 2) Describe your recovery experiences in hospital. | 2) What a) promoted and b) hindered your recovery? |
| | 3) What changes in your health have you experienced over time? | 3) What impact did your recovery have on you? |
| | 4) How have you adjusted to these changes? | 4) Are there any lasting effects? |
| | 5) What support did you expect and receive? | 5) What were the key features of the whole experience? |

## 7. Ethical issues

Ethical approval for this study was gained from the appropriate Local Research Ethics Committees (LREC). All potential participants were approached by their local colorectal cancer nurse specialist who offered a patient information sheet (PIS), and then those who were willing to talk about their experiences were invited to participate.

The face-to-face interviews were conducted in participants' own homes to enhance their comfort and limit a sense of formality. The researcher answered the participant's questions and reiterated the purpose, scope and format of the interviews before written consent was obtained. Potential eventualities which might occur during 12 months of data collection were anticipated and an action plan agreed. The time spent in these preparations proved important in increasing the participants' confidence and willingness to share their experiences on tape.

The participants' consent was continuously negotiated. Participants were also given on-going opportunities to withdraw from the study, reminding them that if they choose to do so, their medical treatment would not be affected. Each interview was numerically coded and any names and locations mentioned were deleted throughout the data, to protect the participants' confidentiality. Ultimately, ethical practice was achieved through a moral integrity to do the subject of inquiry justice, a responsibility to the participants and a conscience to be faithful to the research method.

## 8. Data analysis

Initial data analysis involved the researcher examining and interpreting data from each interview to elicit codes which represented basic units of meaning. This is demonstrated in the following small section of one interview transcript. The bold type indicates the initial coding applied to the preceding piece of italic text: '*I slowly became aware of what was going on within my body (*body listening*), the effects as they felt to me* (body feeling). . .*particularly once the physiotherapists started giving me an incredibly hard time* (pushing body)'.

Each code was formulated in words closely resembling those used by the participants to maintain the semantics of the data. Next, the new codes were compared to all existing codes, and concepts begin to emerge which described the data in a more abstract way (Glaser, 1998). For instance, the codes body feeling and body awareness formed into the concept of 'body listening'. Moreover, from an early stage of analysis, the concept of the body was prominent and seemed significant and had the most data attached to it. N-Vivo proved invaluable in supporting simultaneous development of different theoretical phases; sorting of codes (420 in total) occurred whilst also facilitating the addition of new codes and labeling of properties to provisional categories.

The longitudinal nature of the data required the assiduous deployment of constant comparative analysis that is repeatedly returning to each incident and code, comparing chronological components of participant data to develop and modify the emerging concepts (Creswell, 1998). Similarities, differences and degrees of consistency between participants' accounts were confronted and recorded as memos. Memos were made in N-Vivo, which represented the study's audit trail and could later be accessed to advance understanding and insights emerging from the analysis. The following is an excerpt from one memo, illustrating their potential to progress the analysis: "although no participant has talked about the concept of loss, there are many references to the word loss: 'loss of control', 'loss of choice', 'loss of trust', 'loss of independence', feeling 'at a loss', loss such as weight, appetite and so forth and blood loss. This suggests a possible category 'Loss adjustment." (Memo number 23)

After approximately three-quarters of interviews were completed all data were revisited to test out the provisional categories (Charmaz, 1983) and add explanatory detail. This was both a deductive and inductive process, reinforcing interpretations that the concept 'embodiment' made meaningful sense of the wholeness of this bodily experience and improved articulation of the changes happening to these participants' bodies.

There was also confidence in a second concept 'control' since it appeared frequently in the data. The causes, contexts and consequences of control were compared to those of the other categories which explained associated patterns of behaviour; such as the difference in 'telling others' about the cancer. Further analysis discovered the relationship between control and embodiment proved significant and created the main purpose of recovery. From this, a core category was discovered – restoring embodied control – as it helped to connect the categories that had emerged.

Literature was now selectively sampled pertinent to the evolving concepts (Glaser, 1998). The data were comparatively analysed with the primary data using described coding procedures (Charmaz, 1994). This served to focus and delimit the final phase of data analysis. The categories that ultimately emerged developed into a logical set of interrelationships which became integrated into stages to

**Table 3**
Sample characteristics.

| Participant number | Sex | Age | Surgery | Dukes stage | L.R.E.C site | No. of interviews |
|---|---|---|---|---|---|---|
| 1 | F | 77 | Right Hemicolectomy | B | 1 | 4 |
| 2 | M | 65 | Left Hemicolectomy | B | 3 | 4 |
| 3 | F | 82 | Local excision of rectal cancer | B | 1 | 4 |
| 4 | F | 87 | Right Hemicolectomy | B | 1 | 4 |
| 5 | M | 60 | Anterior resection and temp. stoma | A | 2 | 4 |
| 6 | M | 80 | Sigmoid colectomy | B | 1 | 4 |
| 7 | F | 58 | Left hemicolectomy | B | 2 | 4 |
| 8 | M | 67 | Sigmoid colectomy | B | 1 | 4 |
| 9 | M | 73 | Sigmoid colectomy | B | 1 | 3 |
| 10 | F | 51 | Anterior resection | B | 1 | 4 |
| 11 | M | 75 | Right Hemicolectomy | B | 3 | 3 |
| 12 | F | 54 | Right Hemicolectomy | B | 2 | 4 |
| 13 | F | 62 | Right Hemicolectomy | A | 3 | 4 |
| 14 | M | 66 | Anterior resection and temp. stoma | B | 2 | 4 |
| 15 | M | 63 | Anterior resection and temp. stoma | B | 1 | 4 |
| 16 | M | 52 | Anterior resection and temp. stoma | B | 2 | 4 |

form the process of restoring embodied control. Outlining these different stages put 'the fractured data back together', (Glaser, 1978, p. 116), the last stage in the grounded theory research process. As a result of these inductive and deductive processes, theoretical saturation was achieved within the main four stages - an important factor in establishing trustworthiness.

The review at one year post-surgery seemed an appropriate end point and by the final interview, the researcher interpreted that each participant's story of recovery had unfolded sufficiently to understand its significance within their everyday lives. As primary data collection concluded, it was paradoxical that although the researcher had been careful not to be intrusive in these participants lives, withdrawing contact proved difficult. Nearly all expressed benefit in talking about their experiences and since three wished to continue communications, they were asked for feedback on analytical memos. Member checking was also conducted with two colorectal cancer support groups associated with Sites 1 and 2. These served to confirm rather than change any of the emerging categories. All participants were thanked in writing and sent the study's findings.

## 9. Findings

Sixteen participants were recruited. The characteristics of the sample are indicated in Table 3.

All had received histology results confirming early stage cancer (TNM Stage T1/T2/T3, NO, MO) and did not require, or had been offered and chosen not to have, any chemotherapy or radiotherapy before or after surgery.

The process of restoring embodied control is a tentative explanation of recovery. It embraces four stages: disembodiment, restoring embodiment, reclaiming control and managing embodied control. Although the first three stages do follow a progressive, one-way direction until embodied control is reclaimed, more variation and movement between the final stages can occur, as indicated in Fig. 1 by the two-way arrows.

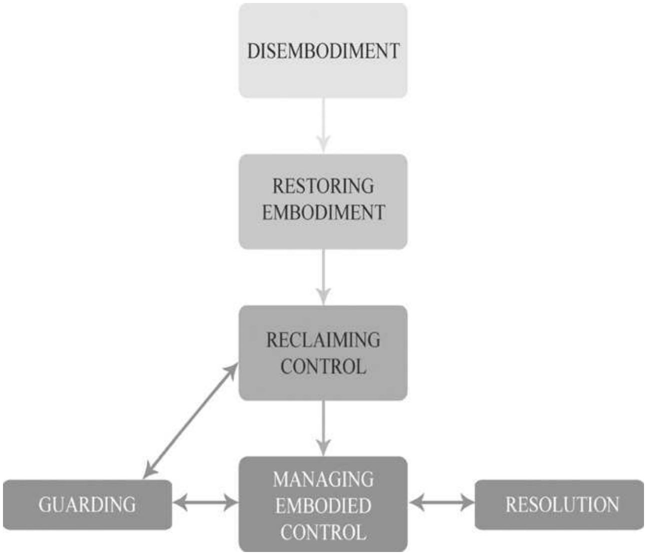

**Fig. 1.** Illustration of the process of restoring embodied control.

These defined stages are associated with unique demands which all participants faced – to varying degrees and in differing timescales – when working through recovery. In seeking to explain the main difficulties these individuals experienced during their recovery – namely the realization that a disconnection with their body has occurred and control over its management lost – the stage 'disembodiment' will be discussed. Due to word limitations the other stages in this process will not be individually delineated in this paper but instead an overview of recovery as a process of 'restoring embodied control' is described. The implications of these findings for practice are then discussed.

## 10. Disembodiment—a loss of body connection and control

Participants made reference throughout the interviews to receiving the diagnosis of colorectal cancer and indicated its significance within their recovery. Much of their early recovery was characterized by shock and disbelief in accepting that this cancer has unknowingly grown within them. Several participants also expressed distress that such a serious disease could cause such minor bowel symptoms and accordingly, created difficulty in detecting and interpreting bodily irregularity.

> 'The worst part of it was when they first break the news to you. It was devastating really. Well I think mainly because you hear so many bad stories about the big C . . . you are always hear the news about the ones that were not cured and you don't hear very much about all the ones that were. I mean I knew I had some problems but it never entered my head that it would anything like that . . . you know. It depresses you.' (P9 Interview 2)

In responding to the immediate threat the cancer and subsequent surgery presents, the bowel and then later the body, may become objectified and disassociated from the self-representing a state of disembodiment. Disembodiment was most evident when participants recounted their first few post-operative days although it was still often discernible, a couple of weeks after discharge. By divorcing their self from bodily events too unpleasant to contemplate, a way of coping with this stressful situation is found.

Several factors proved influential in amplifying a loss of body connection at this stage. They include the numerous diagnostic tests – generally considered unpleasant and personally-invasive but which had to be tolerated. These investigations cause distinct embarrassment in requiring exposure of private parts and possible contamination with faeces, which the patient can do little about. Whilst participants understood that necessary procedures must be endured, there was on occasion a feeling that one's 'self' took second place to the task at hand, particularly when the potential indignity of this experience is inadvertently overlooked by the professional. Such experiences endorsed a lack of involvement in the care experience and disconnection from the body.

> 'You lay on the couch facing the wall with a cushion under your backside and your trousers around your knees. He comes in to the treatment room or whatever you call it, looks into your anus etc., and then he's out and gone.' (P11 Interview 1)

Hospital experiences begin to constrain individual expression, minimize sense of body ownership and impose a new culture of social control upon the individual. A didactic format of surgical consultation was occasionally cited, which provoked a low level of involvement when deciding the surgical plan.

> 'Well he gave me no choice, he was quite emphatic. He said that it had to come out within the month.' (P3 Interview 4)

In symbolically handing their bodies over to the treating team, the 'patient role' is subconsciously adopted and a new identity assumed. Their identity was instead demarcated by implicit rules for patient behaviour, stimulated by hospital experiences and caring encounters. A reliance upon those able to provide skilled surgical management generates feelings of incapacity and/or inadequacy and reinforces notions of personal un-control.

> 'I was in a tremendous amount of pain so she said she would give me something else. She gave me some sort of injection in the bottom.' (P13 Interview 1)

As practitioners fragment the body into parts to be examined, excised and evaluated, disembodiment is promoted. In the quote below this lady indicates how the wound became the focus of her attention. Her ignorance and inability to self-manage this part of her body created fear and dependency. It was then preferable to give someone else the responsibility for fixing it.

> 'After the leaking that went on, I was terrified that it (the wound) might burst open and I didn't know what to do about it so I just didn't move until they came to me.' (P8 Interview 1)

The operation's effects further disarm and temporarily disable the body as acute surgical care causes loss of suppleness, strength and stamina making performing everyday activities difficult. The majority of participants' experienced functional problems after surgery, namely gastrointestinal, but urinary and sexual complications were also reported (see Table 4).

These effects collectively led to a perception of loss – as the body that once existed, was no longer – corresponding to the impact and perceived impermanence of these symptoms. In the first few weeks of recovery, the loss of normal bowel function precipitated most distress.

**Table 4**
Symptoms experienced whilst in-patients.

| | | |
|---|---|---|
| •Hiccups | •Bowel frequency | •Anorexia |
| •Hallucinations | •Bowel urgency | •Stoma Bag leaks |
| •Abdominal tenderness | •Feacal incontinence | •Night sweats |
| •Tiredness | •Nausea | •Urinary retention |

A particular concern after colorectal surgery is that as the bowel begins to function again post-operatively, it can behave more erratically and vigorously than expected, releasing wind or motion without warning. Indeed several participants experienced incontinence post-operatively. The gentleman cited below rated this as the most unpleasant experience in his whole recovery trajectory:

> 'I was having quite extreme diarrhoea and, I must admit I had an accident on the way to the toilet. I had it all down my legs, you know. Quite how that could be handled in a different way, I don't know, but that was quite a problem.' (P11 Interview 1)

Even those participants who had not been incontinent found it distressing not to have a certainty of containment, with fears of an unpredictable release of odour and sound. For those with stomas, the possibility of the stoma bag leaking was a daily consideration, sometimes preoccupation. As a consequence there was a clear tendency to view their temporary stomas as apart from their self. They could then be viewed as a temporary surgical complication of the physical body, unrelated to self and thus less problematic to the psyche.

> 'It made me appreciate that in some ways I've been lucky, haven't I. Since I think there's an awful lot of discomfort and the inconvenience for some people who have these bags.' (P12 Interview 2)

This section has outlined a variety of reasons why a state of disembodiment can develop following surgery for colorectal cancer. As a consequence individual understandings of what the body is, can do, or normally feels like are affected. Yet, disembodiment clearly served a positive function, in enabling patients to submit to otherwise unthinkable bodily insults and deal with their embarrassment. Nonetheless this creates work for recovery because the normal bodily relationship has been upset and the body has to varying degrees become fragmented, deconstructed and disowned. The next section articulates how individual begin to regain connection and control over their bodies as their health improves.

## 11. A process of restoring embodied control

Recovery could start in earnest following discharge from hospital. For most, this was less than a week after their bowel resection. The surgical stay was perceived to occur at speed, leaving little opportunity to fully appreciate the implications of this diagnosis. Once home, participants found the solitude and comfort restorative, most retiring to their beds for several days. Whilst resting, there was opportunity to rethink their bodies, to reflect on what had been endured and the nature of the losses sustained. All participants sought to reconnect with their body (albeit generally at a subconscious level) and consider how to recover their health.

The immediate concerns they faced were physical effects of surgery such as loss of body weight, strength and stamina, alongside the bruises and abdominal scars, which made the body frail, awkward and less like self.

> 'Well I lost a stone and a half, I never lost that much in all my life. My clothes again were hanging off . . . I can wear the same clothes now from twenty years ago. I had arms and legs that I didn't recognize as my own.' (P12 Interview 1)

A desire for the return of a familiar body made regaining a sense of their body's current limitations as well as future potential a deliberate recovery endeavour. This second stage in the process of restoring embodied control therefore involved three important approaches: listening to the body, nurturing it and stretching the body's current capability to improve its future function. As participants engaged with these tasks they began to renew their relationship with their bodies and accept some of the ensuing treatment effects.

> 'I think when I went into the operation my mind was in front of my body because it was my mind that was dragging my body through it a little.' (P15 Interview 1)

Becoming embodied required listening to the body to discover and understand its responses to surgery. Listening to the body involved studying the patterns, frequency and intensity of a particular symptom, to establish meaning and make sense of what is happening before deliberate response. This active attention to the body improves expectance and confidence. Detectible improvements in the body's ability also create optimism regarding its returning health. Signs that the body can again be strong, synchronized and satisfying, will slowly banish dismay over bodily deficiencies and surgical damage. Over time, as cumulative evidence indicates that the body can be trusted again, faith in the body starts to return.

In discerning what resources would be required to nurture and recuperate the body, the surgical team were perceived to be distant but nonetheless instructive to the participants' recovery. In reality, there was little professional intervention unless a body crisis occurred. Family and friends were instead relied upon to provide practical and emotional support, allowing participants to conserve their energy reserves and commit to rediscovery of the body. Achieving an adequate nutritional intake and appropriate balance of rest and activity were considered essential in the in the first few weeks following hospital discharge.

As the body began to grow in strength, the resumption of actions and daily routines soon became the participants' major focus. Although important for meeting basic needs, since practical support from others began to diminish, it served a much more important function in regaining trust and confidence in the body. As these usual activities became easier, further and more ambitious goals – or milestones – were often identified. This was a way of testing the body's capability and confirming recovery progress.

Fig. 2 illustrates these milestones: the left column (1st milestone) displays early recovery milestones achievable during the first fortnight following surgery; the next column (2nd milestone) indicates a growing desire for

**Fig. 2.** Changing milestones post-surgery.

independence – commonly expressed between 6 weeks and 3 months; the final column (3rd milestone) captures more ambitious activities achieved 3–6 months post-surgery.

Most participants were able to resume their usual roles and responsibilities over time and fitness levels generally returned within 2–6 months. However, during this time some experienced a lack of consistency in the way their body behaved; energy levels could oscillate, pain might settle into a daily pattern and then suddenly alter, and bowel habits often continued to be erratic. Thus reclaiming notions of control over body function proved problematic

> ‘There’s many diverse reasons why my bowel might be upset after an operation like this. So it’s a question of saying well, it is being too liquidy I guess this problem isn’t anything abnormal but maybe it should be mentioned just in case.’ (P8 Interview 2)

This participant highlights that although she now feels well, her body is not yet dependable and a harmonious relationship with the body is still sought. Indeed for those whose bowels continued to behave more erratically and vigorously than expected after surgery, regaining controllable and predictable bowel function became a frustrating goal of recovery. The actual loss of bowel control signified an indictment of body control, conveying a dismantling of body boundaries and respectability:

> ‘There’s a feeling in the bowel of . . . I can’t describe it. It feels sort of full and windy. It’s uncomfortable and then you need to rush to the loo . . . (Pause) I didn’t make one time when we out . . . I had to go and sit in the toilet until my daughter could get back with a clean pair of pants.’ (Participant 13, Interview 2)

The humiliation suffered as a consequence of this experience made the above participant reluctant to venture outside her front door again for several weeks. Even if faecal incontinence was not experienced, those with symptoms of bowel frequency and urgency found it distressing not to have certainty of containment. For those with stomas, the possibility of the stoma bag leaking was a daily consideration, sometimes preoccupation. Hence even having to entertain a hypothetical loss of bodily control was detrimental to perceptions of recovery.

There were doubts about what should be considered ‘normal’ during the different stages of recovery and how best to resolve any body complaints. There appeared to be minimal instruction from health care professionals on how to manage the body, participants generally discovering through trial and error how to alleviate their symptoms.

Two participants displayed much greater self-confidence and self-efficacy in their rehabilitation. They adopted a more regimented approach to their recovery and quickly assumed a sense of personal mastery by working with, rather than against their bodies.

> ‘I mean your body does dictate to you but you can dictate back and say, well, I’m not stopping to go the loo now and you can jolly well wait.’ (P15 Interview 2)

> ‘So you’ve got to have that discipline and the mental strength to actually say I can get through this, I will manage this.’ (P5 Interview 3)

Fortunately most functional difficulties did resolve over time although these experiences did leave some participants feeling less self-assured and trusting of their bodies in the longer term.

These are the difficulties encountered in restoring embodiment as individuals struggle to increase functionality and regain familiarity with their bodies again. Embodiment is restored by committing full attention to the body, re-learning how it responds and what it is capable of then slowly increasing body capability through goal setting and engagement in increasingly strenuous activities. The courage to test out the body, a determination to bring the body back into shape and a belief this is possible are fundamental to achieving an autonomous, harmonious and fully functioning body.

## 12. Discussion

Individual reactions to post-operative symptoms must be considered within the context of prior treatment and initial recovery experiences. This study suggests that realising something is seriously wrong with the body; undergoing numerous diagnostic tests considered unpleasant and personally-invasive and then entering into the patient role by accepting major surgery introduces a sense of powerless over their bodies.

Beaver et al. (1999) have questioned why the great majority of colorectal cancer patients react passively when making treatment decisions. Shaha and Cox (2003), suggest they may be happy to surrender to the 'experts' because tumour removal is seen as a positive step. Whilst this may be the case, the individual is as a consequence left distrusting, disempowered and disconnected from their body. This is exacerbated after surgery when the body feels, looks and functions differently. In addition, there is now uncertainty over who is in charge of the body, what it should be like and what it might become. This leads to a loss of certainty, confidence, and perceived control over their body—an experience termed disembodiment.

Disembodiment was discovered to be an important stage in the recovery process since subsequent recovery efforts were orientated to restoring embodiment and the reclaiming of bodily (embodied) control. This concept is scarcely mentioned in the literature, although Ramfelt et al. (2002) discuss a concept akin to disembodiment 'dichotomized embodiment'. They similarly assert that colorectal cancer patients can feel less attached from their bodies after surgery, yet they suggest this state may be precipitated by a loss of temporality. Whilst participants in the study reported here, feared the cancer might '*get them in the end*', there were more immediate concerns and causes of disembodiment associated with loss of bodily connection and functional control.

Loss of body control was particularly noteworthy in some participants' accounts of recovery following colorectal cancer. Whilst only a few actually experienced an episode of personal un-control, in particular faecal incontinence, the potential loss of body integrity was an intolerable prospect. The meanings attributed to this event created an uneasy relationship with the body and added a further challenge to recovery efforts aimed at regaining embodied control.

Whilst working to improve their health, participants expressed shock and distress at how they had taken their inner bodily workings for granted until they started to falter. Leder (1990) illuminates the 'invisibility' of the depths of the body, particularly the visceral organs such as the bowel, which are 'ineluctably hidden from perception' (p. 67). The bowel now had to be acknowledged as a site of significance yet it provoked puzzlement and frustration when its function proved unpredictable and uncontrollable.

There was also the possibility that these symptoms could spiral further out of control at any time (Kleinman, 1988)—a fear which left some participants feeling vulnerable and inadequate in their body's management. The moral imperative to be in control of one's body and uphold social norms of respectability regarding the cleanliness of the presented human body created greater anxieties when moving beyond the confines of their own home (Douglas, 1966). Modification of usual activities and avoidance of social situations was an acceptable short-term coping strategy in response to uncertain bowel control but over time it limited recovery. This highlights the social as well as biological distress that can be precipitated by onset of illness and disability (Corbin and Strauss, 1987).

Thus those recovering from this type of trauma are confronted by the body's own obstacles and difficulties, and their responses to these characterize the early weeks of recovery. The severity of post-operative symptoms has been noted to be a key variable in explaining patients' surgical recovery (Hodgson and Given, 2004) but it is the interpretation of these symptoms and the individual's skill in their management which is critical. Boughton (1997) identifies the significance of such meanings, in acknowledging that we are as humans, to a large extent, biologically determined and constrained by our bodies. Furthermore such recognition exposes the limits of personal control and frailty of the human body. The extent to which the body is perceived as failing or 'broken' (Shilling, 2008), will depend upon how an individual manages what they cannot normally or properly do. During recovery these meanings created difficulty as participants experienced a succession of events that threatened their usual social norms and challenged notions of control.

The concept of control has been associated with recovery only as an investigation of self-efficacy expectancy and preferred involvement (Mondloch et al., 2001; Baker, 1990; Mahler and Kulik, 1990). Indeed seeking control over the body is central to several theories of emotional well-being as a predictor of adjustment (Taylor, 1983; Howell et al., 2003; Ell et al., 1989; Marlow et al., 2003).

Despite embodiment becoming a subject of sociological interest, it has not to date been linked to the concept of control and is this study's unique contribution. Embodied control exists on two levels, firstly as an appreciation of the body's present and required level of control and secondly perceived success in securing appropriate controlling strategies. When the body was deemed dependable, important activities became possible and enjoyable and individuals became able to regain confidence in their body. Cesaretti et al. (2003) confirm this finding that after stoma closure and restoration of bowel function, patients expressed feeling like their old selves again, suggesting that this patient group associated recovery with regaining bowel control.

Clearly symptoms do improve over time but until they do so, patients need greater information and support so that their significance does not cause such a profound perceived loss of bodily control. A model of partnership over authority is advocated, allowing more explicit choice and greater opportunity to engage with care planning within an open and consultative approach (Salkeld et al., 2004). The Enhanced Recovery Programme, a recent introduction to surgical care (Kehlet and Wilmore, 2002), is suggested to in part be delivering such successful patient outcomes because it enables individuals to retain some control over their bodies. Patients are given greater preparation for recovery within this approach; traditionally instruction for self-care is often provided too late and with too much prescription, preventing patients developing the confidence they need prior to discharge.

In addition, these findings indicate pre-operative information-giving for individuals requiring surgery for colorectal cancer should include advising of the changes they may experience within their bodies and that a stage of disembodiment is possible. It can be suggested that during the diagnostic and treatment processes they will lose confidence, connection and confidence in managing their own bodies and reassurance can be given that this is normal.

However whilst disembodiment serves an initial protective function in making it easier to accept traumatic events associated with being diagnosed and treated for cancer, it is not instructive beyond the first few post-operative days and can complicate, even delay the process of recovery. The goal of care should also be to ensure each individual has sufficient knowledge and support to swiftly restore their own sense of embodiment. This requires post-operative support which enables them to renew their familiarity with their bodies, to discover body capability as well as strategies for first-line body-management. Such post-operative care necessitates a cultural shift from 'doing for' a patient to enabling and informing the individual, thereby providing a therapeutic rather than bio-medically prescriptive model of recovery care.

## 13. Issues of rigor

All recorded interviews were carefully transcribed verbatim and entered into the computer package N-Vivo Version 1.2 (Manufactured by QSR International) to ensure efficient data-labelling and data-retrieval. Careful checking of data codes for internal and external consistency was also possible.

In the first interviews nearly all participants gave detailed descriptions of how they reacted to receiving this diagnosis and having the surgery. By the second interview, most participants were comfortable revealing personal concerns and sharing the realities of managing altered body functions. They understood the researcher was independent of their treating team and did not appear to hide their feelings or any difficulties experienced during recovery, thus providing more 'private' accounts of their recovery (Cornwell, 1984). They often expressed great appreciation for the prompt referral process and 'life-saving treatment' received.

This study has found a tentative process of recovery, associated with restoring embodied control. It has not been able to address some issues within this recovery process due to study time constraints such as when the process of recovery is fully complete for those who enter into a state of guarding. Also, some of its findings may not be generalisable to patients who have experienced other treatment trajectories for this cancer such as the addition of post-operative chemotherapy and radiotherapy.

## 14. Conclusions

The study adds a sociological perspective to our understandings of recovery following colorectal cancer surgery. The findings indicate how individuals cope with the disruptions that cancer surgery imposes as they resume daily activities and restore meaning to their lives. Experience of recovery is determined by processes internal to the body but also shaped by meanings attached to health and illness and by the contextual situation in which it occurs.

Recovery after cancer treatment created more complexity and variability than first imagined. Personal vulnerabilities and potential deficits in self-management were exposed. Loss and unpredictability of normal bodily functions deepen perceived loss of control and certainty over the body. These may be overcome by gaining understandings of the changes happening within the body, discovering patterns of predictability and adjusting to the risks presented by this cancer diagnosis. A relationship with the body must be re-established and reformed after illness for recovery to progress and some expectation that achieving bodily dependability will again possible. As a consequence, there is a requirement for the restoration of embodied control, a new way of conceptualising the process of recovery.

## Conflicts of interest

None.

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## Ethical approval

Three local research ethical approvals: Harrow Research Ethics Committee – Ref 2830, Brent Medical Ethics Committee – ref BEC797 and East Hertfordshire Local Research Ethics Committee – EHLREC/9.01/M1139.

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