

From attitudes to materialities: Understanding bowel control for colorectal cancer patients in London

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Abstract

Among the standard biomedical interventions available to treat cancer, surgery stands for the technique with highest curative potential. However, bowel surgery for eligible colorectal cancer patients creates important issues of bowel motility and faecal incontinence, who have to learn how to get acquainted with their modified bodies over time. A fundamental type of body modification occurs when a stoma is temporarily or permanently created. In this chapter, I unpack the socio-material practices that make up the body with stoma in order to complement academic perspectives than understand the challenge of faecal incontinence from the point of view of its effects on the individual's self-image and integration into social dynamics. Drawing on three ethnographic cases, I offer a description of the practices through which the stoma is managed. I shed light on the preconditions of bowel control for people with stomas. By doing that, I complicate the concept of 'adjustment' widely used by clinical practitioners to assess the extent to which a person undergoing stoma formation is able to cope with the demands and consequences of the surgery.

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1 An unproblematic surgical procedure

Planned bowel surgery to resect a malignant tumour requires patients to physically, emotionally, and intellectually prepare for it. A surgeon met Jay, a British man in his thirties of Indian background affected with stage III rectal cancer, to explain the procedure. He would undergo a colectomy, that is, the ‘en bloc resection’ of a large area of the large intestine where the tumour sits, which includes its vascular and lymphatic structures and cancer-free tissue margins. Because of the site and stage of his cancer, measured via scans and colonoscopies at the moment of diagnosis, the multidisciplinary team that oversees patients’ treatments suggested that Jay should have a permanent colostomy – that is, the diversion of the bowel towards a surgical opening on the abdominal wall where the upper end of the bowel is sewn, forming a stoma. Plastic surgery would then be performed to close his excised rectum and anus. Three defining aspects of the body – function, sensation, and image – would permanently change after the stoma formation.

After discussing with the surgeon the main risks of the procedure and fertility preservation options, Jay was given homework to do. He was invited to meet a former patient treated by the same surgeon for the same condition. This way, Jay could see first-hand how someone with a colostomy could get on with life and understand that, regardless of how gruesome the stoma formation might initially feel, people manage to adapt to it over time. Jay was also invited to talk with a bowel cancer specialist nurse to find out what to expect from his bowel function after surgery and to find out how to look after his stoma. Jay’s faecal waste was to be collected in a plastic pouch attached to the left lower side of his abdomen. However, as a large part of the bowel had been resected, bowel outputs would change consistency considerably towards more liquid states. ‘The large intestine is the part of the body that drinks water for us,’ the stoma nurse explained to another patient I was following. That means that without big sections of the large bowel, water and mineral absorption processes that started in the small intestine cannot be completed before they are evacuated. A week before surgery, Jay underwent a clinical pre-assessment, in which a nurse interviewed him to determine his physical and psychological fitness for surgery.

Three days before surgery, Jay received a ‘bowel preparation package’ by post, containing laxative sachets to consume over a few days, on top of the requirement to drastically eliminate his fibre intake before surgery. The aim was to get his intestines as clean and empty as possible in order to make things easier for the surgeons, and to minimise the risk of infection from faecal matter soiling the peritoneum during surgery. As he was undergoing ‘elective’ (pre-booked), rather than emergency, surgery to repair an obstructed or perforated intestine, the surgeons were able to use a procedure called the ‘key-hole technique.’ Instead of a long abdominal cut, this procedure consists of a series of small incisions through which surgical instruments such as miniature cameras and lanterns can be inserted. Everything went according to plan, and Jay recovered in hospital until he could eat a diet of soft foods and pass faecal waste without complications or debilitating pain. Just a few hours after he had fully awoken from the general anaesthetics, a stoma nurse visited him in the ward to teach him how to clean his stoma in practice. His concentration was low and his mind still foggy, but he had all his life to become acquainted with his new body part, and to improve his cleaning technique.

Four years after the first cancer diagnosis, three surgeries, a course of chemotherapy and fertility treatment, Jay is hitting his forties. He is the father of a young boy, the landlord of a flat in London, and the founder of his own estates company. Jay’s ability to get to this point is not only because of his pragmatic attitude and resolution, the loving support of his wife and father, and comfortable finances.

He was also, in some regards, lucky – having access to the benefits of modern surgery as a techno-scientific achievement. Surgical colectomy has been practiced since 1776, but it became a safe procedure only when anatomical knowledge was coupled with effective antiseptic surgical techniques at the beginning of the twentieth century (Cromar 1968). Moreover, Jay benefited from a further technological innovation that took place in 1991 when the laparoscope was created to replace direct contact between surgeon’s hands and patients’ viscera (Jacobs et al. 1991). Jay’s successful experience of laparoscopic surgery confirmed the shorter recovery period it affords in comparison to laparotomy (open surgery). The procedure also minimises post-surgical pain and infection risk (Kuhry et al. 2008).

The current practice of oncological care for intestinal cancer in London is based on colectomies with or without colostomies, standing as the most effective treatment with curative intent for eligible¹ bowel cancer patients (NICE 2011). Complete surgical excision of the cancer growth offers the possibility to some people affected by colorectal cancer to eradicate the disease from their lives. During 18 months of ethnographic field research on everyday experiences of colorectal cancer treatments in London, I quickly realised how significant surgery was for all my research participants. Surgical findings and outcomes structure consecutive clinical procedures, depending on histological analysis of the tissue, the visual corroboration of the tumour spread (including extra-mural invasion and number of lymph nodes involved), and the success in resecting the mass with margins free of mutated cells. Surgery was also vividly narrated by many patients as the single cause for their survival from cancer, notwithstanding the complications they might have endured on the way. Hence, the creation of the artificial anus on one side of the abdominal wall is, from the patients’ point of view, one of the most important features of their treatment experience.

It takes considerable time for the human body to ‘re-learn’ the peristaltic rhythms of the bowel after surgery. As a consequence of the resection, patients like Jay must cope with increased bowel motility. But the stoma does not have a sphincter, and without it, defecation occurs without Jay’s control. Even for patients who did not need a stoma after the surgical resection (i.e. had a colectomy without colostomy), diarrhoea is a debilitating side effect of cancer treatments. It requires people to deal with a metabolic rhythm and a material messiness that all colorectal cancer patients experience but is especially highlighted if their intestines become obstructed. Unlike scholarship highlighting the difficulty for people with stomas to reconstruct their self-image after surgery in order to socially reintegrate (Tao et al. 2014; Thorpe et al. 2009) as the main source of stress post-surgery, my ethnography highlights the importance of its precondition. The management of high-output stomas during cancer treatment in order to regain bowel control is, therefore, an essential task for my research participants. The challenge, I would like to argue, relates to our understanding of what diverted bowels and ostomy pouches afford the person to do, analysing the material conditions that enable cancer patients to be in control of their bowel outputs. The practice of managing bowel motility makes it possible to present an anatomically different body to oneself and to the world. The psycho-social understanding of adjustment, in this vein, could be complemented with an analysis of what happens before the attitudes with which a person relates to his or her stoma, incorporating the multiple materialities at play.

In understanding the practices and materials through which people with stomas are able to carry on with their everyday routines, I wish to depart from symbolic analyses of matters out of place that have

¹Patient fitness for surgery, in consideration to frailty and co-morbidities, is analysed in conjunction with the progression stage with which the tumour is labelled during diagnosis to assess prognosis. Cancer stages are retrieved from imaging techniques and histological samples with standard labelling techniques that include three main components: size of the tumour, nodule involvement, and degree of metastasis (or whether the cancer has spread to other organs). Stages range from stage 0 to stage IV, which are then used to discern the appropriate clinical management of the condition, including the decision for surgery.

permeated anthropological analysis of (in)continence and defecation practices (Douglas 2003; Lea 2001; Lawton 1998; Manderson 2005; van der Geest 2007). Undoubtedly, the symbolic aspects that connote matters out of place are relevant to understand the practices that my interlocutors develop to conceal the stoma and its ‘accidents’ from others. Yet I would like to argue that symbolic approaches to ‘dirt’ miss the perspectives of people with stomas, and make the experience of incontinence something deviant. Writing in the third perspective obscures the struggle of those who are actually breaching the symbolic boundary. An exclusive consideration of the ‘generalised other’s’ view of dirt, namely, the ‘other’ with a normative body, the ‘other’ that acts according to what is desirable, re-victimises the person who suffers from faecal incontinence. In doing so, symbolic analyses about social constructs of ‘dirt’ do not only reproduce a sanitised anthropological practice (Loudon 1975), but also such scholarship neglects to recognise the ways in which the production of such distinctions requires symmetry in the analysis. ‘Matter out of place’ is not only a construct imposed on ‘dirty’ individuals by the ‘pure,’ but also negotiated and informed by those who are made subject to this symbolic category.

Instead of focusing on the symbolic aspects of living with stomas, this chapter takes seriously the material interface that makes waste management possible for my research participants. I would like to offer an alternative, de-normativising view of stoma care that foregrounds the materiality of the body in its engagement with the physical and social surroundings. Following Tilley (2007), I understand materiality as not only incorporating the world of ‘brute’ objects that are oblivious to human actions (such as a standard ostomy pouch), but also the ‘processual significance’ of those materials and its properties for the ‘socio-political relationships’ between people. Tilley proposes a movement away from consideration of the raw materials towards its social significance, for [... materials are] implicated in people’s experiences of the world, ‘providing affordances for thought and action’ (2007:17–19). Following this approach, I would like to examine the material properties of intestines at their interface with ostomy bags in order to tease out the modes through which material adjustment (dis)enable my research participants in their quest for achieving normal routines. Going beyond the body as representation to understand how it is made to work in practice, I suggest that the ability to manage the stoma lies in great part on the privilege of access to material devices and infrastructures tightly related to the social and economic support available to the person. Through the analysis of three different ethnographic cases, this chapter sheds light on two related questions: how do material techniques and infrastructures afford liveable stoma management routines? And, how do those practices afford different emotional states for the person with a body-with-stoma? A fine-tuned understanding of both questions might help to demystify the process through which clinical professionals assess people’s ‘adjustment’ to stoma formations, offering instead a materialist understanding of behaviour change.

2 Colostomies and accidents

When I met Elizabeth, she was sitting in a wheelchair, speaking in Spanish with her sister, while she was waiting for her appointment with the medical oncologist. It was her sixth cycle of chemotherapy after bowel surgery. In a loud tone of voice that disturbed the constrained atmosphere of the clinic, she consented to participate in my research and told me the beginning of her cancer journey. She explained the process to me as follows: the tumour in her bowel was resected only at the third surgical attempt. During the first surgery, Elizabeth suffered a severe reaction to the anaesthesia which caused life-threatening breathing difficulties, known as anaphylaxis. During the second surgery, exactly one month after the first attempt, she haemorrhaged while undergoing laparoscopic surgery. This constituted

a second medical emergency that required the surgeons to cut her abdominal area open to find and stop the internal bleeding. This induced a coma, and the surgical team had to provide blood transfusions to stabilise her. She stayed four days in the intensive care unit until the surgeons were able to resume the operation with a third attempt. A stoma was created to facilitate an optimum recovery, which caused her a great shock. In her words:

The stoma nurse came every day to the ward to help me with the stoma. In the beginning I did not want to know about it, I did not want to see it. It was horrendous, much bigger! I cried a lot, but the nurse comforted me saying that it would get better, that I would learn how to manage it. She taught me and my children how it works, so they could support me. (Elizabeth, age between 50–60 years)

Despite the fright that Elizabeth's children felt, their mother no longer had tumours in her bowel. With a clear histological margin around the area, the surgery had been successful in eradicating the cancer. Elizabeth was emphatic in showing her appreciation for the surgeon's power. Even though she went through severe complications, developing later a voluminous abdominal hernia around the site of the stoma, and long-standing pain in her legs because of nerve damage, she was quick to tell everyone that 'Dr Y saved my life twice' – first by managing the anaphylaxis, and second by completely resecting her tumour. I followed her through seven out of 12 chemotherapy cycles, a partial liver resection, and the reversal of her colostomy after a year from initial surgery. After multiple cases of deep wound infections after every intestinal surgery, she is now recovering at home. She is working to feel physically and emotionally fit to go back to work in the catering industry where her boss waits for her arrival. Before the stoma reversal, she did not feel able to go to work, due to the possibility of leakages from her stoma.

Bowel and waste 'accidents,' the emic concept for leakages, are a common and powerful experience during treatment. Sitting in a coffee shop near the hospital together with her children and a close friend, Elizabeth and I were celebrating that she had received the twelfth and last cycle of chemotherapy after two surgical operations. Going through follow-up plans, she seamlessly started a story about an accident she suffered because of her stoma, with her children already laughing about it. Elizabeth, instead, wanted to convey her frustration to me:

It was the Saturday after chemotherapy [and I had diarrhoea]. I went to celebrate [my daughter] Sandra's birthday to a Chinese restaurant with my family. The stoma bag blew up while sitting on the table. I got the tablecloth dirty together with all my clothes. I went to the toilets area, crying from embarrassment, until one became available. I used wipes to clean myself and took off one of the t-shirts I was wearing too. Once in the bus back home, I was smelling the stinky odour of my faeces again, but my son-in-law convinced me that it was only my mind playing games with me, that he could only smell the lotion I used after changing the bag. Yet Sandra realised that it was not a mind game. The bag was leaking again, the diarrhoea was like water, non-stop [Elizabeth exclaims in the middle of the coffee shop while her children and friend openly laugh]. As soon as we got home, I went to the shower, taking everything off once I was inside the shower.

Although her children did not think of this accident as a serious matter of concern, for it was not the first or last time it would happen to her, Elizabeth was certainly worried. I tried to calm her down and

repeated what I had learned from the specialist nurses and oncologists: ‘After chemo, you will not have so much diarrhoea, so it will become more controllable,’ I said. She instead replied to me that she is afraid to go back to work. ‘Just thinking in the probability of the accident, even if it is less likely [after chemo] makes me panic.’ Joseph, her son, supported her: ‘It is about the possibility, even if the probability is low.’ Defecation can be considered as a cleansing ritual that is essential for any living organism. Yet it seems that its power is conferred only to those who are in control of the act, who can manage the spatio-temporality of its occurrence (Lea 2001). What happens when individuals have no control of their sphincters anymore? I am interested in exploring the productivity of accidents to understand how people with stomas cope with its threat and re-make their bodies through ordinary practices of care. In the next section, I will describe the material properties of the ostomy bag, the single most important material device to achieve bowel continence.

3 The humble but powerful pouch

Resonating with a long history of public stigmatisation against colostomies because of their ‘disgusting consequences’ until the twentieth century (Cromar 1968), Elizabeth’s account of her stoma, and the fear to have accidents, points to the importance of nicely fitting ostomy bags to secure an emotional state that enables people with stoma to go on with their lives. Faecal incontinence was an issue professionally taken up by the incipient training of specialist stoma nurses in the UK back in 1980 (Lewis 1999). Before, people with stomas relied on cotton pads and collecting devices made of tin and silver to stop faecal leakage. Only in 1940 did people with faecal incontinence start using a washable rubber bag tied to the body with strings. While these bags absorbed unpleasant smells, they also caused intestinal prolapses (protrusion of the bowel through the stoma) and painful excoriation of the area. The solution appeared when plastic started to be industrially manufactured and used for stoma care in 1960, and people could resort to disposable pouches. That invention was coupled with the creation of protective barriers for the skin to prevent dermatitis, and hypo-allergenic adhesives originally invented for dentistry were repurposed as care for the skin (Lewis 1999).

While people undergoing colostomies might recover their bowel habits they practiced before surgery, chemotherapy abruptly increases bowel motility and accidents happen with frequency. Clinical professionals recommend that their patients undergoing chemotherapy refrain from intestinal irrigation techniques to manage bowel outputs, a commonly home-based technique that offers the person with stoma between 12 to 24 hours of intestinal emptiness. Instead, my research participants must resort to the continuous use of ostomy bags, which sometimes fill up in a matter of minutes. Ostomy bags delivered by the NHS to my informants are beige, approaching 30 centimetres in length when rolled out and 5 centimetres wide for an adult size. They hold a maximum of 400–500 millimetres of faecal waste before overflowing. Plastic, flexible, and waterproof; the pouch is attached to the skin around the stoma with a flange. Of red-like colour, without innervation, and of variable diameter but usually round, the stoma is the measure against which the inner circle of the pouch flange must be frequently sized by the person to prevent the strangulation of the stoma. The flexibility of the flange not only offers support to the wall but also affords a tight fitting on the belly irrespective of the shape of the abdomen. Such flexibility is essential as people like Elizabeth develop hernias around the stoma, changing, in turn, the topography of the abdomen. Adhesive remover, wipes and skin protectors are used to avoid dermatitis or excoriation on the site in which the flange is glued. In cases of high-output colostomies, such as while the person is on chemotherapy, drainable stoma bags come in handy because watery waste is emptied without the

need to detach the bag from the body. Users simply open the lock and roll closure mechanism at the bottom of the pouch.

Internally, the ostomy bag is coated with an odour-barrier film and contains a charcoal filter to deodorise and allow the escape of gas. However, filters sometimes become blocked with moisture from the faecal output, leading the ostomy bag to ‘balloon’ and even blow-up. It is recommended that users pay attention to diet, practice slow and mindful chewing, and avoid raw vegetables and fizzy drinks that may cause bloating. Ruth, another research participant in her late thirties who was going through treatment for rectal cancer and had a permanent colostomy, knew exactly what foods had caused the stoma accident. On the chemotherapy suit and while having chemotherapy, she once ate a jacket potato with beans for lunch. We said goodbye, and on her way home after the infusion, her stoma ballooned, causing faecal leakage on the bus. The trade-off between adhering to a constipating diet and enjoying the food one eats is a constant tension that does not have a stable solution. Conversely, lack of air and constipation may cause pancaking, which accounts for a second cause of leakages. It happens when the consistency of stools is more solid, and matter sits at the entrance of the bag, collecting around the flange instead of sliding towards the bottom of the pouch. Unlike ballooning, pancaking is a common occurrence for people with stomas exhibiting a more stable bowel function, who are likely to be off chemotherapy. My research participants who were wearing ostomy pouches while on chemotherapy would always carry a case with few spares of each appliance in case they find they have to relieve themselves on the go.

Having described the main features of the surgical procedure and the material qualities inbuilt in ostomy bags, I will now focus on the ways in which it is possible to understand bowel control for people with stomas in their daily lives. In the following section, I will turn to a discussion of the practices that make up stoma care for the research participants in my study. Understanding stoma care through the material arrangements that afford patients bowel continence or mitigate the consequence of leakages during cancer treatment, rather than, say, psychological strength, provides an important point of contrast to discuss research findings on ‘adjustment’ explicitly advanced by clinical professionals. My argument is that psychological adjustment comes only after, not before, physical adjustment: A well-fitting stoma bag over healthy skin might, indeed, solve most of the problem, if conditions are provided. I will illustrate the socio-material conditions that allow people with stomas to achieve a sense of normalcy in their lives after bowel surgery by enacting a body synthesis of heterogeneous material elements.

4 Coping: coordinating a larger body

When I was just starting my PhD fieldwork in 2015, I was kindly received by two bowel cancer support groups in South England (outside London) to discuss how they could help me improve the design of my study. This type of consultation is called Patient Participant Involvement. In different formats, it is currently considered good practice in healthcare research in the UK, and it was promoted by research ethics committees like the one that approved this project. After negotiating access via e-mail, I went to meet with approximately 30 people affected by bowel cancer: they were either bowel cancer patients, people who had gone through bowel cancer treatments, or significant others that accompanied bowel cancer patients until they passed away. I met 8 participants in one group in a common space of a local cancer charity. Together, their average age would have been around 50 years old. The second group was considerably bigger and was holding its regular meeting in the spare room of a local pub. I counted at least 20 smiling but relatively older faces (as a group, they were in average 65 years old). In both

groups, almost everybody except me was British, and most of them were women (even though the second group was relatively more mixed). Seemingly used to receiving researchers, they welcomed my request to approach them. However, as people who have learnt to manage their stomas for years, they thought it was more useful for me to understand the ways in which they were navigating the rhythms of daily life with a changed bowel function, rather than just making comments on a study design in which they would not be able to participate. Knowing what bowel cancer patienthood (and survivorship) looked like in practice, they seemed to suggest, would help me in improving the design of my research project. After realising that the practices that members of both these groups mentioned were very similar to the type of actions and behaviours my research participants used to successfully deal with the effects of surgery, I took wisdom they shared with me and transformed it in a decalogue.

- One's body will never be the same, and it is important to accept that, for even we ask why this happen to us, we must get on with life, for us and for the ones we care about.
- One plans for trips with stops in which a toilet in good conditions is hopefully available.
- One experiments with the design and the opening of the pouch until finding the right one.
- One learns to eat again; low fibre diets and little alcohol are the best to slow down peristalsis.
- One makes sure not to lift anything heavy and do only gentle exercise not to cause hernias and stoma prolapses.
- One finds the daily balance between having diarrhoea or constipation, depending on how much loperamide – thickening tablets – one takes.
- One washes the skin around the stoma with soap and warm water thoroughly to prevent excoriation.
- One reaches out to others in offline or online support groups, for their members will understand what one is going through.
- One reads 'Tidings' the magazine for people with ostomies to find more tips.
- One carries a change of clothes together with the stoma case, especially while on chemotherapy cycles.

The members of the support groups I attended were emphatic when explaining that the fear of 'accidents' seems to take one's life away, one's ability to go about with life until one finds balance amidst the unpredictability of one's bowel movements. As the decalogue shows, balancing means tinkering with different material elements over time, such as food intake, their own bodies, public infrastructure, thickening tablets, bowel movement consistencies, clothes, and ostomy bags. By tinkering with the material forms of one's own body and its surroundings, one can gradually learn how to deal with an erratic and sometimes explosive bowel function during cancer treatments; this 'tinkering' will also slowly help the patient come to accept his or her body after surgery. Adjusting to the stoma is premised in the coordination of socio-material practices that can make bowel motility happen in a controlled way. Following Mol and Law (2004), I suggest that the way in which my research participants aim to continue with their lives despite and beyond cancer treatment depends on the enactment of a different and larger body, a body-with-stoma. The analysis must focus then on 'the body we do' in opposition to the 'body we have' or 'the body we are.' In other words, it is through the productive coordination of different material practices that one produces a body that is substantially different from both the anatomical body that is objectified

by the medical gaze and our own representation of it as a component of our self-image. Undoubtedly, enacting ‘the body we do’ requires work, constituting an achievement when we are successful in keeping it coherent (Mol and Law 2004). Gaining ‘coherence’ enables one’s bowel function and mitigates the inherent tensions embedded in managing one’s life.

Managing the different materialities in the construction of the body with stoma requires time, and my research suggests that people are only able to ‘accept’ their body after such coordination is achieved. The process of tinkering or experimenting with materials precedes, then, the process of adjustment. Warnier (2001) advances a praxeological approach to understanding the relationship between the co-constitution of the subject and the material culture in which she or he is situated. Similar to Mol and Law’s understanding of the ‘body we do,’ Warnier conceptualises the body as a heterogeneous material synthesis. In a more psychological enterprise, Warnier suggests that the subject incorporates experiences arising from its engagement with his material world through sensorimotor practices. Sensorimotoricity, together with speech and images, are mediums through which the new (material) experiences of the world are internalised by the subject. This process of domesticating varying material experiences is what Warnier understands as ‘symbolization’ (2001:14), a process that enables the subject to find meaning in events that are unruly, or that misalign from the stereotypical ordinariness of the day-to-day. Temporality is an important feature implicit in this process of symbolisation that aims at normalising experiences that otherwise would have unexpected consequences. By means of reproducing, and at the same time reshaping, sensorimotor engagements, Warnier proposes that practice acquires meaning for the subject and that such practices are incorporated into a normal sequence of events. Stoma management is, for my participants, exactly this kind of repetitive and creative process of material tinkering that enlarges the body. Highlighting the materiality coordinated in this process bears important implications for our understanding of behaviour change in people who have gone through stoma formations. In the next section, I would like to argue what a material culture approach offers to our understanding of the ways in which people with stomas adjust to their anatomically transformed body.

5 The idealism of adjustment

People with stoma not only go through the struggle of maintaining a sense of the self while their bodies are unbounded, but also must learn and get acquainted to dynamics surrounding faecal incontinence while trying to go on with their lives. Both aspects are said to affect the emotional response that patients develop to the stoma post-surgery: the perceived lack of control or lack of acceptance triggering maladaptive practices that cause emotional distress (Ranchor et al. 2010). The degree of stress that living with diverted bowels generates in the person is what clinical psychologists understand as ‘adjustment to stoma formation’ (Simmons et al. 2007). Operationalised as a concept concerned primarily with the measurement of ‘quality of life’ for people with stomas, adjustment uses standardised metrics to understand the psycho-social burden imposed by the stoma formation. Patients are rated on a scale that has become essential to understand both patients’ needs and how they are supported by clinical professionals. The key explanatory variable usually incorporated is ‘coping,’ which, in turn, depends on two stages of cognitive appraisal. The first stage is about the nature of the stress, and the second is about what the individual thinks they can do to address it. Proponents from health psychology suggest that ‘self-efficacy’ predicts health behaviours (Ashford et al. 2010). However, ‘self-efficacy’ is a difficult behavioural construct to modify. This type of behaviour change is affected not only by external sources of motivation (if they are even available for modification), but also enduring affective states and physiological

conditions (Bandura 1977). Therefore, it is possible to say that cognitive models of adjustment to stoma formations assume that the individual's reaction to estranged body parts depends on the interpretations she or he makes on the basis of the information that is available, and the extent in which she or he believes she or he has the skills to produce the effects (on the body) that are desired. The appraisal process, shaped by one's self-belief, explains how the individual responds to the stoma and its consequences.

The clinical use of 'adjustment' is then predicated upon the transference of control from surgeons and nurse specialists to patients through the clear and compassionate provision of information so they can 'self-manage,' a concept that underpins the responsibility of the individual to take care of their own health, which currently gaining much currency in the NHS in the face of an increasing demand for healthcare services and high work pressure for clinical teams (Foster et al. 2018). The premise is that patients will feel confident enough to manage the consequences of cancer and its treatment if they acquire the relevant knowledge to cope with the disease. Practical knowledge will enable patients to change their behaviours as needed and to make sense of the body-with-stoma as the 'new normal' (McVey et al. 2001). From this perspective, Jay was able to adjust to the stoma formation, partly because his own belief in himself and in his capacity to learn the skills necessary to achieve bowel control, whereas Elizabeth found it more problematic, as she did not feel confident either about what her own body could do or about her future. Through this lens, the achievement of coordinating 'the body we do' through the habituation of embodied skills, draws from absorbing and interpreting information that can, in turn, inform practical skills and changes in behaviour. The challenge, then, is that struggling to manage the pragmatic aspects of the stoma reinforced in Elizabeth a feeling of being out of control. For the colleagues working on psychosocial understandings of cancer survivorship (Foster et al. 2016; Grimmett et al. 2017), the problem for Elizabeth was one of self-efficacy: she was finding difficulty in self-managing her stoma because she did not believe if and how she could do it.

While acknowledging the relevance of people's psychological states to understand how they cope with stoma formations, I would like to argue that adjustment, as defined here, requires a more complex analysis that takes people's struggles seriously. Enacting 'the body we do' demands that one considers both the self-managing agent but also the context in which she or he is situated. Against the ideal of a self-managed patient who is proactive and knowledgeable regardless of the resources available to him or her, my ethnography provides context in which materiality precedes the attitudes of my informants. Regardless of the psychological states of my informants, efforts to help them self-manage the side effects of their cancer treatments must include access to infrastructure and economic support. We must interrogate the material affordances of cancer survivorship, that is, the possibilities for action through which materials allow a successful process of bodily synthesis for the enactment of the body we do. Simon's story is illustrative in making this point. After a bout of uncontrollable abdominal pain, Simon decided to go to A&E, already considering the possibility that something was seriously wrong in his body. The medical doctors quickly referred him to the cancer clinic in which professionals determined that his cancer had already spread to the liver at the moment of the diagnosis. As a result, local surgery was no longer advisable, and chemotherapy was his only viable option. After the second cycle of treatment to deal with a non-resectable advanced sigmoid cancer with liver metastasis, another bout of pain and projectile vomiting overwhelmed him. His bowel had perforated, and emergency surgery was necessary to keep him alive. The procedure resulted in the formation of a temporal colostomy, so like Jay and Elizabeth, he had to learn to live with that. However, unlike Jay and Elizabeth, he did not enjoy the same material conditions or social support. Threatened to be made homeless by members of his family with whom he lived and having lost his zero-hour contract job after the cancer diagnosis, he was left in a very difficult position. The flat in which he was living with his close family belonged to his deceased father, but it had

become the main source of family conflict. The dispute over the father's inheritance reached the county court. Until the judge could make a decision on the case, his mother and sibling determined that Simon was not allowed to use the kitchen for cooking or the washing machine to do the laundry, and he was prevented from using the toilet from midnight to 7:00 a.m. His relatives did not care that Simon had to deal with a stoma and chemotherapy at the same time, challenging him to contain the faecal waste by other means. At 50 years old, Simon was living under a curfew, and as the flat is locked from inside by his mother at night, he feared that an ambulance would not reach him should he require emergency care. His relatives observed strict silence with him – his mother simply did not want him to feel as if the flat was his home. They felt that using the toilet, the kitchen, or the laundry would allow him to feel a sense of ownership of something that was in dispute.

Simon considered his stoma to be the 'worst part of the cancer.' It leaked non-stop. He lacked the ability to do his laundry, to change his stoma bag at night, or prepare more suitable food at home. Moreover, he was suffering from an intestinal prolapse occasioned by carrying his heavy backpack every day. Because he could not trust his relatives in his home, he often carried around his laptop, all his hospital letters, and his medical appliances. During an appointment with the stoma nurse to which both of us went, we found out that his stoma had indeed prolapsed due to the heavy weight of the backpack, and that he was strangulating it because he was not measuring the bags correctly. He was not registered with the GP because his social situation prevented him from having a proof of permanent address, so he found himself recycling the stoma bags that the hospital had given him more than six months ago. In turn, the petroleum-based cream he was using to heal the skin around the stoma provoked an allergic reaction and excoriation, so the bag was not able to stick properly. A year later, the material constraint continued to oppress him; lost his case in court, and he found himself in an even more precarious position. Unlike Jay and Elizabeth, who fortunately did not face serious economic constraints and enjoyed the support of their families, Simon was not always able to produce the larger body-with-stoma and secure its optimum management. Despite his proactivity, he lacked the access to basic infrastructure.

6 Discussion

This chapter has tried to unpack the socio-material practices that make up the body-with-stoma in order to complement academic perspectives that understand the challenge of faecal incontinence from the point of view of its effects on the individual's self-image and integration in social dynamics. Drawing on three main ethnographic cases from colorectal cancer patients undergoing treatment in a teaching hospital in London, a rendering of stoma management has been offered that highlights its material aspects, proposing an analysis that sheds light on the preconditions of bowel control for people with stomas in everyday use. Hence, this approach has been developed to contribute to clinical understandings of processes of adjustment that otherwise tend to idealise proactive attitudes to stoma management under the possible slogan: 'more and better information for a supportive process of behaviour change.' Such an approach, currently used by stoma nurses in the clinical team, transfers responsibility from the clinic to patients irrespective of the material and economic support they find available. Interested in patients' quality of life, clinical professionals aim to give compassionate and informative advice. However, I have argued that the tensions that arise in the enactment of a body with stoma must pay attention to the material surrounding that enable colorectal cancer patients to live their lives despite and beyond treatment. Instead of focusing on patients' perceptions of lack of control, or disregard for the recommendations they receive from clinical professionals, it may be the case that 'maladaptive' behaviours are not just a consequence of individual

attitudes. My ethnography shows, then, that well-fitting stoma bags over healthy skin solve most of my research participants' struggle if basic infrastructure is provided.

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