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The psychological challenges of living with an ileostomy:

An interpretative phenomenological analysis

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This research was supported by a grant awarded to Adam Nicholls and Jonathan A Smith by the Ileostomy Association (UK).

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Abstract

**Objectives:** Ileostomy, in which the small intestine is re-directed out of an abdominal wall so that waste is collected using a bag, is used to treat conditions including Inflammatory Bowel Disease and colorectal cancer. This paper reports an in depth idiographic analysis of the experience of living with an ileostomy. **Methods:** 21 participants took part in semi-structured interviews about their lives and relationships. Those interviews were transcribed verbatim and analysed using the experiential qualitative methodology Interpretative Phenomenological Analysis (IPA). **Results:** Two super-ordinate themes arose from the data: Ileostomy's intra-personal impact; the impact of ileostomy on relationships with others. We found that ileostomy may destabilise the sense of self, disrupt body image, and alter experience of age and sexuality. Other participants were able to employ their illness to positively reframe the self. Disclosure of ileostomy status was difficult for some. Intimate and friend relationships were often challenged by stoma status, whilst other family relationships were largely characterised as supportive. **Conclusions:** Ileostomy may impact upon both intra and interpersonal aspects of the lives of those who live with it, in both negative and positive ways. Consequently, the sense of self can appear challenged, and relationships with partners, family members and friendships could be causes of distress. On the other hand, some partners were supportive, and children were found to be sources of comfort.

**Keywords:** Ileostomy; phenomenology; qualitative; relationships; self

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Ileostomies, in which the small intestine is re-directed out of an opening in the abdominal wall so that waste is collected in a bag, treat various conditions including Crohn's disease, ulcerative colitis, and bowel cancer. It is estimated that nearly 40,000 ileostomies are performed in the US every year, (Husain & Cataldo, 2008), while more than 9,000 ileostomy operations are carried out in the UK annually (NHS, 2014).

Prior research has explored life with a range of related procedures: ileostomies, colostomies, and urostomies, collectively known as stomas (eg. Bray, Callery, & Kirk, 2012). The confluence of elements that lead to and follow stoma surgery, which often includes severe pre- and occasionally post-operative illness can be psychologically challenging (Thorpe, McArthur, & Richardson, 2009). Studies show people with an ileostomy report shock at the impact of surgery and pay close attention to bodily functions (Kelly, 1992, Ramirez, 2014) An on-line survey found that a stoma bag can challenge existing notions of identity (El-Tawil & Nightingale, 2013). Kelly (1992) and Notter and Burnard (2006) reported surgery can create a tension between public and private selves. Life with a stoma can also present interpersonal difficulties. Partners may struggle to accept the stoma or those living with the stoma may find it hard to feel attractive and continue to enjoy sex (Danielsen, Burcharth, & Rosenberg, 2013b; Ramirez et al., 2014), Manderson, 2005). Conversely, other studies find friends and family provide support for people living with a stoma (Nicholas, Swan, Gerstle, Allan, & Griffiths, 2008).

Several authors have called for more methodologically rigorous, in-depth qualitative research to both explore individual experiences of people living with a stoma and to seek out convergences and divergences across cases (Brown & Randle, 2005; Thorpe et al., 2009). Much existing research has focused on multiple types of stoma (Bray et al., 2012; Thorpe,

McArthur, & Richardson, 2013). In their review, Brown and Randle (2005) point to the fact that this makes comparison across studies more difficult. There is a value in a closer examination of the intra- and inter-personal experiences of people living with specific stoma types. Here we focus on people living with an ileostomy. Subsequent research may explore the experiences of people living with other ostomies.

This study employs interpretative phenomenological analysis (IPA) (Smith, Flowers & Larkin, 2009) which was developed as an experiential qualitative methodology within psychology. IPA offers a detailed, nuanced analysis of the personal lived experience of a phenomenon. It subscribes to a hermeneutic phenomenology where both participant and researcher are recognised as sense making agents. The sense making of the participant becomes central when the taken-for-granted is breached. A major health issue represents such a breach and it can lead the person to attend closely to bodily changes and the impact of those bodily changes on sense of self (Smith et al. 2009). IPA has become one of the most widely used qualitative methods in health psychology (Smith, 2011). This growing presence is manifest, for example, in the number of IPA papers in a recent special issue of *Health Psychology* on qualitative research (Gough & Deatrck, 2015) and in the wide range of health psychology issues now being addressed by IPA, e.g. the impact of pain (Andrews, Strong, Meredith, Gordon & Bagraith, 2015), factors influencing engagement in physical activity (Chatfield & Hallam, 2015), the experience of transplantation (Spiers, Smith & Drage, 2015). IPA is especially valuable where the topic is of existential importance and the issues are complex and affectively laden. It therefore lends itself well to examining the psychological experience of living with ileostomy.

Existing studies have used a range of methodologies. Three which come quite close to ours in terms of research question and orientation are: Danielson et al. (2013a), Ramirez et al. (2014), Kelly (1992), Danielson et al. take a hermeneutic phenomenological nursing

perspective, Ramirez et al. have a medical anthropology frame, Kelly is a medical sociologist adopting a symbolic interactionist framework,. Danielson et al. and Ramirez et al. included participants with an ileostomy or colostomy, Kelly looked exclusively at participants with an ileostomy. Danielson et al. used focus groups while the other two employed individual interviews. This does indeed show the complexity of comparing across studies. We see our work as differing from, but complementing, these three studies in having a more explicitly psychological perspective and employing a specific idiographic experiential qualitative methodology developed in psychology. This paper has come from a mixed-methods study of the psychological impact of ileostomy. The IPA arm came first and provided experiential data to inform the subsequent online educational tool. IPA yielded two foci: a) the psychological impact of ileostomy; b) practical implications for caring for people living with an ileostomy. This paper reports the first of those analyses, the second is published (Authors, 2016). Thus, this paper is a detailed idiographic examination of how participants make sense of the personal experience of living with ileostomy.

## **Method**

*Design and Participants.* This study was designed collectively by the authors following the principles and guidelines of IPA (Smith et al., 2009). Three of the authors are very experienced IPA researchers. IPA is an inductive rather than hypothetico-deductive approach. The research question was framed in an open way consistent with this. The principles of IPA were instantiated at each stage of the project to ensure high quality, trustworthy data collection, analysis and writing up. This was checked at regular intervals through discussion within the team and through team members explicitly checking the research process adhered to this. Participants were recruited from online stoma support

groups. They contacted the second author if they wanted to take part, and were sent an information sheet giving the details of the study. Twenty-one people living with an ileostomy were interviewed. We recruited a purposive stratified sample to ensure a balanced representation of age and gender and thus we have a relatively large sample for an IPA study.

*Ethics and Data collection.* The study was given ethical clearance by the relevant university board. Informed consent was collected and participants were told they were free to stop the interview or withdraw their data should they wish. Interviews were undertaken by the second author either in person, or via Skype/phone. We worked from an interview schedule which included questions on biography, illness, emotions, self and others. Here are the first three questions from our schedule to give the reader an idea of our interview style: *Can you tell me a bit about what the last few years have been like for you? When were you first told that you would need to have an ileostomy? Can you tell me about going into the hospital to have the surgery?* The full schedule is available as supplementary material online. The schedule was used flexibly in line with IPA good practice. The interviewer took opportunities to probe interesting and important issues which arose but these were those initiated by the participant rather than imposed by the interviewer. It has been suggested that telephone or Skype interviews may be detrimental to qualitative research as interviewers may miss body language cues and be unable to establish rapport. However, like several other scholars (Novick, 2008; Sturges & Hanrahan, 2004), we found no notable difference between phone/Skype and face to face interviews. Indeed, phone/Skype interviews may have been more convenient for some participants and allowed them greater freedom to discuss potentially difficult topics as the lack of face to face contact has the potential to give more of a sense of confidentiality (Smith, 1989). Interviews were audio recorded and transcribed

verbatim; field notes were made afterwards. Interviews lasted between 30 minutes and 130 minutes, most were one hour. All data have been anonymised to protect confidentiality.

*Analysis.* Analysis followed the procedures outlined for IPA by Smith et al. (2009). A particular hallmark of IPA is its commitment to the idiographic; the analytic process begins with a detailed examination of each case followed by a search for the patterning of responses across cases. The concern is with both convergence and divergence in the analysis. Transcripts were read line-by-line and analysed by searching for points of descriptive, linguistic, and conceptual note throughout. This first stage of IPA involves maintaining an open mind and an exploratory attitude in order to produce a comprehensive and detailed account of the data. These initial notes were then transformed into emergent experiential themes in the other margin. The themes set out to capture the key elements of each participants' experience framed by the interpretations of the analyst in a resonant and pithy manner. Themes were clustered and super-ordinate themes generated using techniques of abstraction and subsumption (Smith et al., 2009) within case and across participants. The second author took the lead on the initial analytic steps and at each stage the data was audited by the first and fourth authors. This enabled a rigorous search for any ways in which assumptions may have influenced analysis. Only minor modification was required as a result of this auditing. The first two authors took the lead in the later stage of analysis and writing which were conducted as a collaborative process of ideas being shared, challenged and modified. All authors contributed to the writing up and commented on interpretations. These processes are consistent with good practice in hermeneutic phenomenology and help to ensure rigour. In particular, we subscribe to Gadamer's (1960) avowal that significant components of the reflexive interpretative arc only become manifest during analysis and good analysis involves incorporating these new insights in the write up.

## Results

Participants were all native English speakers in the UK. Demographic information is given in Table 1. Table 2 illustrates the structure of the themes found.

### Ileostomy's intra-personal impact

All 21 participants talked about how their ileostomy impacted on their sense of self.

*The destabilizing effect of ileostomy on sense of self.* Twelve participants described ways in which their illness and ileostomy had a debilitating impact on them. Several reported a changed and impaired body image as a result of the stoma. Laura's body image was threatened by her stoma, which appeared in her dreams as an alien force attacking her body:

*I dream that my abdomen's, normal? I'm not (small laugh) I wasn't gonna say flat there, I nearly did and then I thought that that's really telling a lie (both laugh). I dream that my abdomen's (pause) full skin. No scars, no stoma. And then the stoma breaks out. And the scar forms. And, they're horrible, horrible dreams. It seems to be this, this, yeah, it's the unnaturalness of it, the fact that my intestines are on the outside of my body.*

Laura's dream repeatedly replayed the disturbance to her body caused by the stoma. But in the dream the psychologically disturbing aspect of the process is heightened by exaggerating the contrast between the body before and after treatment, by the speed of the transformation and by the visibility of the usually internal organs on the outside of the body. And in the dream the stoma is afforded agency- reminding one of how the organism 'breaks out' from the character's body in the film 'Alien'. This seemed like a strong psychological symbol for the shame and fear she felt. It suggests Laura feels she has become unnatural, scarred, an imperfect 'other' rather than a complete, 'perfect' woman.



For Marianne the process led to a sense of objectification and depersonalization:

*Being in hospital had kind of acclimatised me to some of that and so there had been a point where I'd had to have help to have a shower, even before surgery. So that thing of your body not being your body any more but just being this kind of thing that people do things to, I think that kind of takes over for a bit.*

This was reinforced by intimate and potentially humiliating medical tests:

*Earlier in the year I had some tests of which, part of it involved (small laugh) injecting porridge up my bum (both laugh) and, putting a nappy on me [...]'<sup>1</sup> and asking me to do things like bend over and walk round the room for half an hour and see if I could hold this porridge. [...] So many things like that happen now that you [...] just start to see the funny side of things.*

It is interesting to see how Marianne began to respond to this challenge in an unexpectedly positive manner, becoming desensitised and finding the situation amusing. Maybe she started to separate from her physical sense of self a little, or perhaps she developed a new relationship with her body, in which what had previously been intensely private and bounded was able to become, within the confines of a medical setting, more open and less private. So in a sense, the treatments Marianne endured resulted in her sense of self going beyond her body image.

For both Laura and Marianne, ileostomy is perceived as a process of a self observing uncontrollable things happening to ones' body. However the emotional tenor of the two experiences is markedly different: Laura's dream recounts an experience of horror at a speedy metamorphosis; Marianne feels depersonalized detachment from unrelenting procedures.

Like Marianne, Heide presented a mixed affective reaction to her surgery:

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<sup>1</sup> [...] indicates where a section of text has been omitted.

*It's left like a little tiny bit of like, excess skin around the stomach, and I can't quite tone it? Because of how deep the scar was and it went into the muscle. That's the only thing I hate. [...] If I didn't have that, I would, I would be down the street in a bikini flaunting me stoma. Cos I think it's beautiful.*

The contrast between her aversive reaction to the scar on her body and the affirmation she showed for her stoma is striking.

Several participants found their illnesses resulted in a perception of being older than their years. Howard described the negative impact that his illness had on his feeling of age:

*My wife took a photo of me the other day in a new jumper my grandkids gave me for Christmas. And, when I looked at it [...] I was pretty shocked, kind of, at how, frail and, and weedy, and old (pause) I looked.*

The unrealised impact of his illness on his physical appearance was a nasty shock for Howard, forcing him to see himself as weaker than he had previously. Harry (aged 40) said:

*You do kind of joke 'how old am I, exactly?' [...] There is a certain amount of (sigh) feeling that you're getting a lot older before your time.*

The bodily changes led to a sense of premature aging. They also had the disconcerting effect of confusing the body clock and creating uncertainty over actual age.

The disruption to bodily integrity can have direct psychological consequences. Nancy was dealing with an extremely active stoma which often leaked. Managing the demands of this had diminished her sense of self in a destructive fashion: *It makes you feel useless sometimes.* These leaks had metaphorically leaked into every aspect of Nancy's life, making her doubt her abilities and her sense of self.

Kim described a similar eroding of her sense of self as a result of her stoma, which was also very active and hard to manage. She asked: *Am I as complete a person now as I was before?* She elaborates:

*I don't see myself as being quite such a (pause) whole person, is it? I don't see my, I see myself as being of less value somehow because I've got this thing [...] I can't quite get the level between what I should be able to do. I don't do as much (small laugh) as I used to do. And I can't, and when, sort of, I feel like I should be doing more, and, and I get very cross with myself [...] I suppose I, a lot of my value as a person came from what I did for other people and I what I (pause) what I did, I suppose. Now I can't do as much. I feel less, valued, I suppose.*

Kim is concerned with the literal depletion of her body. Equally importantly, however, that physical reduction stands as marker for psychosocial depletion. Her physical loss has led to personal loss; an inability to complete many of her familiar activities and fulfil her social role.

George's ileostomy had pronounced impact on his sexuality. As a gay man, the removal of his anus during surgery for ulcerative colitis had tangible, permanent effect on his sex life:

*I wouldn't be able to have anal intercourse any more. [...] Although that wasn't kind of the only sexual activity that I had, I mean it was, it's quite important, you know to sort of, again to feel that you're losing a part of your sexuality.*

Some participants found their illness and ileostomy challenged their ways of engaging with the world. Here the impact is less stark but more global psychologically as participants ponder the implications of their changing physical state on their life goals. For example, Richard's feeling able to engage in work was challenged in fluctuating ways. He had had to stop work for a few years and was considering returning. Note the contradictions at play here:

*I've been out of the flow [of work], and you're able to talk about that, with passion, with, you know, people who do the same thing or whatever. [...] and I suppose, that, that has been my whole aim really. Is to get back in the flow.*

*It's been quite a big sort of reconfiguration of my thinking about work and what it means to me. I could quite easily not work, actually [...] Don't need it to feel fulfilled in life.*

Richard firstly talked passionately about his motivation to work. His metaphor of 'the flow' depicts illness as having stranded him on the shore, and a return to work as being an attempt to swim back into the more populated current of life. This contrasts sharply with the later quote stating he could remain fulfilled not working. This new, relaxed way of thinking about work followed a conscious 'reconfiguration' of Richard's options. The second extract makes it appear as though the change to his sense of self as being someone who does not have to work is complete. However, taken in conjunction with the first extract, it could be the challenge to Richard's sense of self is ongoing, arousing different thinking at different times.

William's ileostomy had relieved him of his long-term symptom of fatigue. However, this left him no longer knowing how to engage with his life, as the parameters had changed:

*The burden, has gone from me where I'm (pause) that, that tired. [...] I could actually think that, oh (pause) what shall I do now (laughs)?*

Simon experienced a similar dissonance following a prolonged hospital stay:

*Being in hospital felt normal, whereas being at home felt out of the ordinary. I almost didn't know what to do with myself so like, I'd spent the last seven or eight weeks saying to myself in hospital I'm bored stiff. And then when I finally*

*did get out, it's like I've just spent the last eight weeks laying in a bed doing nothing and I, yeah, I just didn't know what to do with myself.*

Although Simon was keen to leave behind the monotony of hospital, he found this sense of self as an inert patient difficult to change. He could not initially return to engaging with 'normal' life; the new, warped normal, imposed by his illness, was hard to shake off.

*Employing illness to positively reframe sense of self.* Eleven of the 21 participants successfully found ways to allow their illness to positively reframe the ways they thought about themselves. Jack reconstrued the idea of difference:

*Sometimes, it's quite nice to be a bit different. [...] But at first I was sort of embarrassed, didn't want anyone to know about it, but now don't really care if anyone knows [...] It's just like feels (pause) bit good to be slightly different to everybody else. Gives you something to talk about like with new people.*

Jack saw his ileostomy as a reason to talk to people rather than a stigmatising deficit. Jack's dynamic relationship with his stoma changed from one of insecurity to confidence, suggesting it added to, rather than detracted from, his sense of self.

The stoma also helped to improve Simon's self-confidence:

*In some ways, I'm more confident because, you know, everyone has insecurities but it, it's made the insecurities I had before, less of a big deal, if that makes sense. Cos you know, they're kind of overshadowed by having, having a bag.*

Simon used his current situation with the stoma bag to reconceptualise the previous insecurities that he had. Although the bag is an ongoing, major issue for Simon, it also served to diminish all his old worries and give him an unexpected confidence boost.

Barney made an empowering choice to use the disability label in a positive way:

*If you can identify yourself as having a disability, certainly in terms of employment, it has advantages sometimes in, in assisting you really to ensure that you, you know, you're able to perform at the same level as everybody else.*

Barney positively reclaimed the disability label, which many might see as a negative, allowing it to create a level playing field for him and his colleagues. As a result of his ileostomy, Barney had started campaigning to support others at work who also consider they have a disability. Hence, he used his illness to positively reframe his sense of self.

Lucy used downward comparison with hypothetical others who are not doing so well to give her difficult experience meaning and to frame her sense of self as a supportive teacher rather than merely a patient. This boosted her self-esteem and made it easier to cope:

*I just wanna, just be very open about it and if I can help even just one person come to terms with it or, have a little bit more knowledge about it, or how to deal with it or [audio cut out] then that, that for me is, right, good enough.*

Both Amy and Natalie also saw themselves as campaigners following their surgery:

*I kind of almost see myself on a little bit of a crusade to sort of like give, get people's awareness of actually, inflammatory bowel disease. (Natalie)*

*I want to raise awareness and if you can, talk about it openly then it removes some of the fear, and the taboo. (Amy)*

Both women here used strong, political language ('crusade,' 'raise awareness'). Their illnesses have reassigned them as women doing battle on behalf of a group of patients, rather than as passive members of that group. This new role carried power and agency.

### **The Impact of Ileostomy on Relationships with Others**

All 21 participants talked about their ileostomy in relation to other people.

Disclosure. Eleven of the participants talked about disclosing their status as a person living with an ileostomy. Two described anxiety about disclosure. Kim expressed uncertainty around discussing what could be perceived to be an unseemly topic: *Do I tell people, do I not tell people? You know, do I just keep quiet about it? It's not a very pleasant subject.* Her language here reflected the hesitation she felt around disclosure.

Marianne also expressed uncertainty and anxiety around disclosure, but for her, this was specific to the context of romantic relationships:

*I've got much better at telling people who are my friends. [...] In a relationship situation there's always, just always that fear of how is someone gonna react?*

Marianne demonstrated two different sides of disclosure; an ability to relax about disclosing to friends and yet a constant tension around disclosing to potential partners. There is a sense here that this concern was a source of stress for which Marianne cannot see an end.

Several participants described strategies they had developed to make disclosure work for them, based around being selective with who they talked to. William described protecting himself from an onslaught of questions from his family:

*They're much more picky [...] trying to dig and stuff like that, and they ask lots and lots of questions. [...] That's another reason why I haven't told everyone.*

Disclosing selectively helped protect William against his family's relentless curiosity.

Howard would also pick and choose to whom he disclosed:

*I hate actually talking about the whole thing, cos it's so boring, and everybody asks you how are you doing every time you see them. And you do not want to go*

*through it again and again. [...] One or two other people, film club friends and people, they ask, about what actually is happening, so I might say well yeah, I've got this colostomy.*

Howard described indiscriminate disclosure as impacting tediously on relationships. There is a sense that once people knew about his illness, this became their main topic of conversation; Howard's identity became subsumed by an all-pervasive sick role. He was keen to avoid this, so only told selective people, referring to his ileostomy as a colostomy, a word more people know, so distancing himself from in-depth explanations about his situation.

Finally, Harry talked of the benefits he experienced as a result of disclosing his ileostomy status to his work colleagues, although this was also tempered with a concern:

*It's probably strengthened it because I've kinda laid everything down on the table and said this is me. [...] I've opened myself bare and said, this is what I'm going through. People have respected that I think and the worry is that they've made allowances. And you don't want people to make allowances for you.*

Harry reflected that vulnerability could result in strengthened relationships. However, like Howard, Harry feared the idea of being tarred with the 'sick role' brush, and being pitied as a result of his disclosure, making it a double edged sword for him.

*Intimate relationships.* Twelve participants discussed the impact of ileostomy on partner relationships. Simon expressed concerns around finding a partner:

*I do get quite pessimistic sometimes whether I'll actually be able to find anyone that'll be able to, put up with it and stuff like that.*

Simon's frames the bag as a burden which he felt unsure another would be able to take on.



Like Simon, George initially felt concern over whether partners would accept him: *They've got to take on this (coughs), this sort of, bag.* Note George used similar language to Simon, suggesting the bag is a burden to be 'taken on' by partners. Despite these fears, George's first sexual experience post-op was positive:

*He was incredibly kind, you know, just, I mean it wouldn't have been a terrible thing if he'd said I can't cope with this [...] But he didn't. And, that was, that was very important, getting that kind of, that kind of initial support.*

George suggested he would have coped if the man had reacted badly but the warm response was greatly beneficial. However, George was relating an incident from several decades ago, so it is possible that time has mellowed the impact that rejection may have had. Despite this positive response, the ileostomy continued to affect George's partner relationships:

*My fear was a bigger problem than the actual encounters themselves. But I would say that I became less sexually active than I would have expected to be, if I hadn't had the surgery.*

George's continued fear of rejection resulted in less sexual partners than he would have wanted so he is now partly mourning the loss of an imagined past.

Several of the female participants described being rejected by their male partners. Laura described her partner being phobic of the stoma:

*I'm not gonna be comfortable worrying about the fact that you might come back into the room when I'm having a shower and you might see something you don't want to see. And I know it's not because you're disgusted by it, I know that you just can't see it, sort of thing. I said so, I can't do that, that made me really upset.*

Laura felt a need to protect her husband from the sight of the stoma and to protect herself from his possible reaction to it. Nancy discussed a perceived rejection from her husband:

*I don't sleep with my husband [...] Because I don't want to make a mess on him (small laugh, long pause) so we, we sleep in separate rooms [...] It's upsetting [...] I'm not even sure he'd want to sleep with me anyway, cos he certainly doesn't want to see me stoma.*

There is sadness, confusion and loss in this extract. Nancy's language around potential leaks has connotations of shame. The couple became severely distanced following the surgery, sleeping now not just in separate beds, but separate rooms. Nancy perceived her husband no longer desires her, but did not seem to feel confident enough to talk to him about this.

Finally, two male participants talked about how supportive their female partners were. Barney talked about an incident of being questioned about his bag at an airport:

*My wife came through afterwards and she then heard them both sort of looking at each other a bit bemused, asking each other what I was talking about. [...] And she sort of ended up barking at them about it in the end.*

Barney's use of the word barking here depicted his wife as a protective guard dog, chasing away anyone who might stigmatise him. Stephen's wife was similarly supportive, despite the problems with sexual function he has experienced as a result of his surgery:

*My wife is absolutely wonderful; we've reached a point where we're both happy.*

There is a real sense of team work here, suggesting that Stephen and his wife were united in their acceptance of the ileostomy and the issues it has brought with it. Stephen used unremittingly positive language to describe his supportive wife.

*Relationships with friends.* Ten participants talked about the impact of their ileostomy on relationships with friends. Harry worried about their reaction:

*You worry that people [...] will either feel sorry for you, or feel repulsed by the idea that you've got this appendage that they don't really understand it, especially with ileostomy and stomas, you're talking, effectively incontinence in some ways, you're, talking, ah, toilet behaviour, which people don't talk about.*

Harry felt an internal, defensive conflict around the chance of either pity or revulsion from others. Note that Harry was not talking about an incident that had happened with his friends, this was his internal debate about their possible reactions, suggesting in fact, he may wrestle with questions about his own dignity and self-respect as a result of his ileostomy.

Iris talked about reactions others had to her ileostomy in the past:

*Years ago, older people [...] wouldn't really want to have an awful lot to do with you because, you were different. And they would expect your house to be smelly and all that stuff. [...] To a certain extent some people still think that way. Which is a bit daft [...] I just let it go over my head.*

Like Harry, Iris perceived a potential for stigma. However, Iris brushed off these potentially hurtful reactions in contrast to Harry who continued to struggle with his concerns.

Kim described a disagreement with her friend about her treatment:

*It's a bit upsetting (laughs), honestly! [...] This is one of my best friends, do you know what I mean, and I don't feel sort of like I can talk to her about it.*

Kim perceived her friend's lack of understanding as a barrier to their friendship. While she offsets her upset with laughter, one guesses that she felt judged by her friend's attitude.

So far, we have seen examples of conflict or negativity in the impact of ileostomy on participants' friendships. However, several participants found their ileostomy had a positive impact on friendships. Howard described a practical way in which this had worked:

*We needed to go down to the East Coast and somebody drove me down there which wouldn't have happened, otherwise. Maybe I've been a bit more, I mean I'm, quite a self-sufficient person. But maybe being a bit dependent on other people, also I've been a bit more open about developing friendship.*

Howard had bowel cancer, which caused his friends to rally around him and his wife, and offer practical support. This illness-specific behaviour led Howard to become more open. We can see how the enforced dependence on friends arising from his illness benefitted him.

Heide made the decision to do a presentation at her university about IBD and ileostomies, and disclosed her status as a person living with an ileostomy at the end of the presentation. She felt nervous about how her university friends would react to this, but stated:

*Some of them said that was quite, it quite was admirable, it was quite, brave of you.*

Heide was loathe to call herself admirable, using hesitant speech and retelling the story from her friends' perspective, rather than from her own. The positive feedback she received from her friends was in stark contrast to the critical reaction she thought she might get:

*I was worried that people would look at us and go (pause) urgh, that's a bit unhygienic. That's a bit (pause) that's a bit disgusting.*

Family relationships. Eight of the participants talked about positive reactions from their children. Lucy had concerns about her stoma impacting on her children, yet said:

*It was really sweet the other day cos he helped me change my bag for the first time, you know, he helped pass the bits to me and stuff like that and, that was a real turning point for me, I feel quite tearful talking about that.*

Lucy's strong emotional reaction to her son's acceptance of her bag showed the depth of her relief that her unusual toilet habits, necessitated by the stoma, haven't impacted on him.

William's children also unquestioningly accepted his stoma bag:

*They know, what I had. And since, what it looks like (laughs). And, you know, barging in [...] They've been great. They've just like, I'm normal, you know, it's just like well, nothing's changed. Dad's here, right, let's drive him mad!*

It could be suggested that the reaction of William's children normalised the bag for him, and detracted from any possible 'Other' status imposed by the ileostomy.

Not all participants felt supported by their families. Amy, who has been ill with many conditions which have required surgery, described her family's reaction to her ileostomy:

*My cousin was telling me to go to a psychiatrist and it was a really upsetting time [...] They thought I had some mental illness where I wanted surgery.*

Amy's family's disbelief of her need for surgery created massive conflict for her resulting in her withdrawing from family life to a certain extent. Amy found support by creating a new 'family' for herself via online support groups: *I thought yes, you're in a, a new kind of family.*

### Discussion

More than half of the participants talked of the disruptive intrapersonal impact of the ileostomy. This took a number of forms: debilitated body image, impaired sense of self, perception of premature aging, challenges in engaging with the world. Our work complements and extends previous research which suggested people with an ileostomy report post-operative pain, shock at the physical impact of surgery, vigilance with regard to bodily functions and the working of the appliance (Danielsen et. al., 2013a; Kelly, 1992; Ramirez, 2014; Notter & Burnard, 2006). What our analysis adds is: closer analysis of participants' explicit attendance to changing sense of self, more detailed delineation of some of the psychological processes involved and consideration of the range of possible impacts on identity. We think these different emphases arise, in part, from the differences in the perspectives taken. Previous researchers have tended to be from nursing, sociology or anthropology and have often used non-specific thematic methods. We are psychologists using an idiographic hermeneutic phenomenologically informed method developed in psychology.

Several of the participants in the current study described an uncomfortable process of observing a changed body image. This relates to the claims of some previous researchers (e.g. Beitz, 1999; Salter, 1992). However our idiographic and psychological focus enables detailed instantiation of the nuanced patterning of how this process can happen in different individuals and close scrutiny of the psychological dynamic associated with this process. Laura's threatening dreams graphically show her still grappling with the impact of the ileostomy. Marianne's ability to assimilate the challenges to her body image and shift her sense of somatic boundaries so that treatment changes from being humiliating to a cause for humour shows a possible strategy for reaching a place of equilibrium following such challenges.

Two men described feeling old before their time, suggesting that body image issues can be challenging for men living with an ileostomy as well as women, thus building on existing

literature (Brown & Randle, 2005). Howard saw himself as weaker following his surgery, whilst Harry expressed uncertainty around his age. The impact of stoma formation on the masculine body image is further explored in a mixed methods paper about veterans living with ostomies (Symms et al., 2008). Their qualitative findings showed intimacy as a big problem as the men's stomas provoked feelings of shame and disgust. Stoma surgery can impact on sexual functioning for men (Symms et al., 2008) further compounding the issue.

Both Nancy and Kim described a destabilization via an erosion of self, resulting from life with an ileostomy, a finding that is also reflected in the literature; a female participant in another study (Ramirez et al., 2014) described not feeling like a whole person many years after her surgery. The current findings further add to the picture of the ways in which ileostomy surgery may challenge sense of self, since they include the embodied experiences of a gay man living with a stoma. Surgery for IBD often involves removal of the rectum, as it did for George. This can restrict sexual activity for many people, especially gay men. There seems to be little research in this area, with one author mentioning this challenge in passing in a longer piece about sexuality following ostomy surgery (Turnbull, 2001). Future researchers may consider exploring further the experiences of gay men with ileostomies.

In addition, some participants described ways in which their ileostomy destabilized them by challenging their ways of engaging with the world. Previous research suggests 15% of people living with a stoma must make changes to their working life (Brown & Randle, 2005). The current study provides resonant detail of how this challenge affects Richard. The current study also shows how relief from symptoms may lead to existential uncertainty or cognitive dissonance as patients shift from the sick role back to the world of good health. This is a useful reminder that change can have a destabilizing impact on the person, whether that change is associated with a worsening or an improvement in physical health.

In contrast, several participants found that their sense of self was impacted in a positive way. Previous authors have reported similar findings. In many cases, ileostomy surgery relieves extreme symptoms, resulting in improved quality of life (Manderson, 2005) and a transition away from the sick role (Brown & Randle, 2005). In several studies, adolescents with ileostomies have reported their stoma experiences making them more compassionate, stronger people (Nicholas et al., 2008). The current study provides greater detail around some of the unexpected ways in which ileostomies can positively impact sense of self. For example, Jack redefined the notion of difference, seeing it as an advantage rather than a disadvantage, while Barney reframed the label of ‘disability’, able to use it to ensure his fair treatment at work, rather than being a limiting and stigmatising label.

It is worth considering participants’ intrapersonal experience in terms of Charmaz’ (1995) model of adaptation to chronic illness. Charmaz considers how chronic illness impacts identity and points out that, as we strive to adapt to chronic illness, we can ignore it, minimize it, struggle against it, feel resigned to it, or embrace it; and that furthermore, we may move between these modes of being. This seems relevant for our participants; the impact of the ileostomy is always apparent, but can take the form of a challenge or an affirmation. For some participants, ileostomy primarily posed an ongoing ordeal; for others, it offered an opportunity to find a valuable purpose arising from their predicament.

All the participants discussed how ileostomies affected interpersonal relationships. Disclosure was an issue for many participants, with some reporting feelings of anxiety and uncertainty around telling others about their ileostomy, while others described the selective strategies they employed in order to limit any psychological hardship. While disclosing stoma status has been likened to ‘coming out’ as gay (Kelly, 1992) or disclosing status as a person living with HIV or with an artificial limb (Ramirez et al., 2014), some adults living with stomas may feel reasonably relaxed about disclosure (Ramirez et al., 2014). One group of



older women agreed disclosure might be harder for young people, but they felt relaxed about it themselves (Ramirez et al., 2014). Thus, the finding that Kim and Marianne felt uncertainty and anxiety around disclosure adds depth to the current picture and highlights potential need for support in this area. The selective disclosure strategies described by William and Howard may be beneficial to others who are struggling in this area.

Extant research on the impact of stomas on intimate relationships focused on the partner's difficulty accepting the stoma, which can lead to rejection (Danielsen et al., 2013b; Manderson, 2005; Notter & Burnard, 2006; Ramirez et al., 2010), and difficulties around sex (Brown & Randle, 2005; Danielsen et al., 2013b; 1999; Kelly, 1992; Manderson, 2005; Ramirez et al., 2010). In addition, scholars described a loss of sexual confidence in people living with an ileostomy, who may then try to hide their bodies from partners (Manderson, 2005; Ramirez et al., 2010; Thorpe et al., 2009). The findings that Laura and Nancy felt rejected by their partners, while Simon and George talked of fear of rejection from potential partners provides further evidence of this. The experiences of Barney and Stephen show that partners can be supportive to those living with an ileostomy.

Friendships were frequently mentioned by the participants, both in terms of their supportive role, and the sense of isolation that could arise when friends were unable to understand participants' situations. Whilst the importance of support from friends is widely recognised (Nicholas et al., 2008), difficulties with friends are less frequently mentioned. The frequency with which participants present psychological issues arising from difficulties with friends suggests this may be a rich area for future research.

Several participants discussed family relationships. In line with extant literature, some found their families supportive (Nicholas et al., 2008). However, Amy's feeling of rejection by her family following her illness, causing her to form a new support network made up of

others living with ostomies, is an unexpected finding, again showing the value of idiographic research and the distress that can occur when family support is lacking

*Reflections* We documented earlier the procedures used to ensure the trustworthiness of our research. In addition we formally checked our work against Smith's (2011) guidelines for high quality IPA. We consider our paper meets the requirements for a good piece of IPA according to those criteria. The research is consistent with the theoretical underpinnings of the approach. The data is rich and the analysis hermeneutic, offering a detailed, coherent account. The paper is well evidenced and draws proportionately on the corpus.

It might be considered that the heterogeneity of the sample (in terms of age, gender and condition leading to ileostomy) contravene IPA's homogeneity principle (Smith et al., 2009). In fact the study was purposively designed to examine possible effects of these factors. However during analysis it transpired there were not significant differences across variables. As a result we have treated the sample as a whole during writing up. We consider our paper successfully combines a concern with convergence and divergence of lived experience.

*Conclusion* IPA was used to examine the psychological experience of living with an ileostomy. The nuanced, detailed findings create a resonance, allowing the reader to get close to the lifeworld of the participant and this is consonant with the aims of IPA. Ileostomies may have both intra- and interpersonal impact and that impact can be negative or positive. For many of the participants, the ileostomy had debilitating consequences for their sense of self. In particular, a number struggled with body image issues arising from their ileostomy and illness. Conversely, other participants found ways to redefine difference and disability in order to boost their self-esteem. Living with an ileostomy also impacts relationships with others: partners, friends and family. For some, ileostomy led to a perception or fear of rejection from other people. Other participants obtained relational support.

### References

- Andrews, NE., Strong, J., Meredith, P., Gordon, K. & Bagraith, K. (2015). "It's very hard to change yourself": an exploration of overactivity in people with chronic pain using interpretative phenomenological analysis. *Pain*, 156, 1215-1231.
- Beitz, J (1992) the lived experience of having an ileoanal reservoir: a phenomenological study. *Journal of Wound, Ostomy and Continence Nursing*, 33, 518-524.
- Bray, L., Callery, P., & Kirk, S. (2012). A qualitative study of the pre-operative preparation of children, young people and their parents' for planned continence surgery: experiences and expectations. *Journal of Clinical Nursing*, 21, 1964–1973.
- Brown, H., & Randle, J. (2005). Living with a stoma: a review of the literature. *Journal of Clinical Nursing*, 14, 74–81.
- Chatfield, S. L., & Hallam, J. S. (2015). Flipping the on switch: Men who became regularly physically active during middle age. *International Journal of Sport and Exercise Psychology*, DOI: 10.1080/1612197X.2015.1036097
- Charmaz, K. (1995) The body, identity and self: adapting to impairment. *Sociological Quarterly*, 36, 657-680,
- Danielsen, A., Burcharth, J., & Rosenberg, J. (2013b). Spouses of patients with a stoma lack information and support and are restricted in their social and sexual life: a systematic review. *International Journal of Colorectal Disease*, 28, 1603–1612.
- Danielsen, A. K., Soerensen, E. E., Burcharth, K., & Rosenberg, J. (2013a). Learning to live with a permanent intestinal ostomy: impact on everyday life and educational needs. *Journal of Wound Ostomy & Continence Nursing*, 40, 407-412.
- El-Tawil, A., & Nightingale, P. (2013). Living with Stoma: Long-term Effects on Patients' Quality of Life. *Journal of Clinical and Cellular Immunology*, DOI: 10.4172/2155-9899.1000145.
- Gadamer, H. (1960/1990) *Truth and Method*. New York: Crossroad (second revised edition).

- Gough, B., & Deatrck, J. (2015). Special Issue: Qualitative Research in Health Psychology. *Health Psychology, 34*(4).
- Husain, S., & Cataldo, T. (2008). Late stomal complications. *Clinics in Colon & Rectal Surgery, 21*, 31-40.
- Kelly, M. (1992). Self, identity and radical surgery. *Sociology of Health & Illness, 14*, 390–415.
- Manderson, J. (2005). Boundary breaches: the body, sex and sexuality after stoma surgery. *Social Science & Medicine, 61*, 405–415.
- NHS (2014). NHS Choices: Ileostomy. From: <http://www.nhs.uk/conditions/Ileostomy/Pages/Introduction.aspx>
- Nicholas, D., Swan, S., Gerstle, T., Allan, T., & Griffiths, A. (2008). Struggles, strengths, and strategies: an ethnographic study exploring the experiences of adolescents living with an ostomy. *Health and Quality of Life Outcomes, 6*, 1-8.
- Notter, J., & Burnard, P. (2006). Preparing for loop ileostomy surgery: women's accounts from a qualitative study. *International Journal of Nursing Studies, 43*, 147–159.
- Novick, G. (2008). Is there a bias against telephone interviews in qualitative research? *Research in Nursing & Health, 31*, 391–398.
- Ramirez, M., Altschuler, A., McMullen, C., Grant, M., Hornbrook, M., & Krouse, R. (2014). "I Didn't Feel Like I Was a Person Anymore": Realigning Full Adult Personhood after Ostomy Surgery. *Medical Anthropology Quarterly, 28*, 242–259.
- Ramirez, M., McMullen, C., Grant, M., Altschuler, A., Hornbrook, M., & Krouse, R. (2010). Figuring out sex in a reconfigured body: experiences of female colorectal cancer survivors with ostomies. *Women & Health, 49*, 608–624.
- Salter, M. (1992). What are the differences in body image between patients with a conventional stoma compared with those who have had a conventional stoma followed by a continent pouch? *Journal of Advanced Nursing, 17*, 841-848.

- Smith, J.A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health, 11*, 261–271.
- Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review, 5*, 9–27.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage.
- Smith, M. (1989). Woman abuse: the case for surveys by telephone. *Journal of Interpersonal Violence, 4*, 308–324.
- Spiers, J., Smith, J.A., & Drage, M. (2015). A longitudinal interpretative phenomenological analysis of the process of kidney recipients' resolution of complex ambiguities within relationships with their living donors. *Journal of health psychology*. DOI: 10.1177/1359105315581070
- Sturges, J., & Hanrahan, K. (2004). Comparing telephone and face-to-face qualitative interviewing: a research note. *Qualitative Research, 4*, 107-118.
- Symms, M. R., Rawl, S. M., Grant, M., Wendel, C. S., Coons, S. J., Hickey, S. & Krouse, R. S. (2008). Sexual health and quality of life among male veterans with intestinal ostomies. *Clinical Nurse Specialist, 22*, 30-40.
- Thorpe, G., McArthur, M., & Richardson, B. (2009). Bodily change following faecal stoma formation: qualitative interpretive synthesis. *Journal of Advanced Nursing, 65*, 1778–89.
- Thorpe, G., McArthur, M., & Richardson, B. (2014). Healthcare experiences of patients following faecal output stoma-forming surgery: A qualitative exploration. *International journal of nursing studies, 51*, 379-389.
- Turnbull, G. (2001). Sexual counseling: the forgotten aspect of ostomy rehabilitation. *Journal of Sex Education and Therapy, 26*, 189–195.

**Table 1: Participant demographics**

<b>Name</b>	<b>Gender</b>	<b>Age</b>	<b>Date of surgery</b>	<b>Condition</b>
Laura	F	39	2011	Crohn's
Natalie	F	32	2013	U.C. <sup>a</sup>
Rita	F	33	2013	U.C.
Harry	M	40	2011/2014	U.C.
Barney	M	29	2013	U.C.
Nancy	F	58	2012/2013	U.C.
Diana	F	42	2011	U.C.
Kim	F	65	2013	Bowel cancer
Richard	M	57	2014	U.C.
William	M	43	2014	U.C.
Howard	M	71	2014	Bowel cancer
Heide	F	23	2010	Crohn's
Lucy	F	32	2009	Other condition
Jack	M	26	2006	Crohn's
Simon	M	27	2009/2013	Crohn's
Marianne	F	43	2010	U.C.
Amy	F	58	2010	Other condition
Iris	F	71	1961	U.C.
Stephen	M	72	2006/2010	Bowel cancer
George	M	69	1985	Crohn's
Oliver	M	52	2006	U.C.

<sup>a</sup> U.C. = ulcerative colitis

**Table two: Super-ordinate themes with their constituent themes**

**Super-ordinate theme 1: Ileostomy's intra-personal impact**

The destabilizing effect of ileostomy on sense of self  
Employing illness to positively reframe sense of self

**Super-ordinate theme 2: The impact of ileostomy on relationships with others**

Disclosure  
Intimate relationships  
Relationships with friends  
Family relationships