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THE TREATMENT EXPERIENCES OF PEOPLE LIVING WITH ILEOSTOMIES: AN
INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

Running head: The treatment experiences of people living with ileostomies

Dr Johanna SPIERS, Research Assistant, University of Hull, PhD

Cottingham Road

Hull

HU6 7RX

UK

Phone: 07966 763 364

Email: Johanna.spiers@gmail.com

Twitter: [Johanna Spiers@DrJohannaSpiers](https://twitter.com/DrJohannaSpiers)

(NB Although Dr Spiers undertook this work at the University of Hull, she is now
affiliated with Bristol University)

Professor Jonathan A SMITH, Professor of Psychology, Birkbeck, University of

London, PhD

Dr Phillip SIMPSON, Senior Clinical Psychologist, York Teaching Hospital, Clin,

Psych.D.

Dr Adam R NICHOLLS, Reader in Sports Coaching and Psychology, University of

Hull, PhD

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Abstract

Aims To explore treatment and healthcare experiences of people living with ileostomies, so nurses can build on best practice whilst caring for these patients.

Background Ileostomies, in which the small intestine is re-directed out of a stoma in the abdominal wall so waste is collected using a bag, are used to treat conditions including Inflammatory Bowel Disease. Existing research suggests that although life with a stoma can be challenging, ileostomy patients are largely supported by multi-disciplinary teams. However, more research is needed to understand the nuances of these relationships and experiences of treatment, with a view to improving clinical care.

Design Participants took part in semi-structured interviews consisting of open ended questions about their experiences of life with an ileostomy and their treatments and time in hospital. Points of interest were followed up. Data were collected between July and December of 2014.

Methods The qualitative method Interpretative Phenomenological Analysis was used to analyse interviews with 21 people living with ileostomies.

Findings We present findings from two clinical themes: Issues around treatment and Relationships with multi-disciplinary teams. Surgical complications were common, and several participants reported concerns about addiction to painkillers. Varying

attitudes were found around reversal surgery. Many reported experiencing distressing, dehumanising care, whilst some felt supported by excellent healthcare providers.

Conclusion People living with ileostomies have a very mixed experience of multi-disciplinary teams and treatments, and much could be done to support them more fully. For example, more information about ileostomies could be given to patients and more training given to nurses around stomas.

Summary statement

Why is this research needed?

- There is a dearth of research looking at the treatment and healthcare experiences of people living with ileostomies
- This research can help provide guidance for nurses who are caring for this patient group

What are the key findings?

- Participants reported a number of medical complications following surgery, as well as concerns about becoming overly dependent on painkillers and a variety of differing feelings about pouch surgery. Some participants were keen to revert to a pouch, whilst others felt satisfied with their stomas
- Surprisingly, many participants reported negative relationships with their multi-disciplinary teams, while others reported abusive or negligent care. Despite this, other participants reported supportive, helpful care from both doctors and nurses

How should the findings be used to influence practice?

- We suggest that extra psychological support be offered to people living with ileostomies in order to help them through a potentially challenging time, and that non-judgmental conversations about opioid painkillers are opened up with anyone who might be at risk
- In line with others, we also suggest that more specialist training is needed for nurses to care for or manage people living with ileostomies.

Keywords: Chronic illness; stoma care; health psychology; nursing; patient perspectives; phenomenology; qualitative approaches

Introduction

Ileostomies, in which the small intestine is re-directed out of a stoma in the abdominal wall so that waste is collected using a bag, are used to treat conditions including Inflammatory Bowel Disease (such as Crohn's disease and ulcerative colitis) and bowel cancer. It is estimated that there are around 1.3 million people in the world who have an ostomy, whether that be an ileostomy, a colostomy or a urostomy (Stomaatje.com, 2015). More than 9,000 ileostomy operations are carried out in the UK every year (NHS, 2014), whilst 120,000 ostomy operations are performed in the US annually, with 32.2% of these being ileostomies (Husain and Cataldo, 2008).

Background

Existing research from countries such as Hong Kong, the Netherlands, Australia, Sweden, and India infers that adjusting to an ileostomy can be physically and psychologically demanding (Cheung et al., 2003; Kuijpers and Klok, 2014; Parton et

al., 2015; Persson and Hellström, 2002; Shaffy et al., 2012). Stoma care may be especially challenging in the developing world, where patients may struggle to afford commercial equipment (Buckley et al., 2012). In the case of temporary stomas, there may also be physical and psychological challenges for those who go on to have ileo-anal pouches (known as J Pouches) formed (Notter and Burnard, 2006; Taylor and Morgan, 2011).

It is vital that people living with ileostomies all around the world feel fully supported as they are treated by multi-disciplinary teams. Although treatment experiences are touched on by some authors (Allison et al., 2013; Bray et al., 2012; Brown and Randle, 2005; El-Tawil and Nightingale, 2013; Notter and Burnard, 2006), there is not much work focusing specifically on healthcare experience among people living with ileostomies, which may encompass reactions to surgery and medications and relationships with healthcare providers as well as feelings about the stoma itself. More research is needed to explore how patients experience and respond to care from nurses, so that clinical care can progress (Thorpe et al., 2013).

The Study

Aims

We aim to explore the treatment experiences of people living with ileostomies, using a qualitative method that will deepen nurses' understanding of patient experience and thus improve care (Thorpe et al., 2009). Qualitative methods are useful for researching experiential processes and filling gaps in existing knowledge (Thorpe et al., 2009). Since every person living with an ileostomy requires unique care (Thorpe et al., 2013), qualitative methods, which focus on the individual, seem ideally placed

to explore patient experience.

Design

Interpretative Phenomenological Analysis (IPA, Smith et al., 2009) was selected as the most suitable method to explore the topic in hand. IPA takes a hermeneutic, idiographic, phenomenological stance that allows for a nuanced explication of participants' experiences, and is well suited to subjects that are complex and equivocal (Smith et al., 2009), such as the topic in hand. Participants were interviewed about their experiences over the phone or via Skype, and those interviews were analysed using Interpretative Phenomenological Analysis.

Sample/Participants

Twenty one people living with an ileostomy and who had had experiences of receiving stoma care were recruited. Participants were recruited from three online stoma support groups. They contacted the first author if they wanted to take part, and were then sent an information sheet. If participants wished to go ahead, they gave informed consent to the first author. We recruited a purposive stratified sample with five younger women (aged 23-39), six older women (aged 42-71), four younger men (aged 26-40) and six older men (aged 43-72). Although we suspected that there might be divergences between participant experience based on gender, age and time since surgery, this did not appear to be the case during the inductive analysis process, so all participant experience was considered together. Given IPA's concern with idiography, data saturation was not a useful concept for this paper. Demographic information is given in Table 1, below.

Table 1: Participant demographics

>>>>Insert table one here<<<<<<<<

Inclusion criteria were that the participants were living with an ileostomy in the UK, were over 18 and were native English speakers. Due to the deeply linguistic interpretations that form part of IPA, it is felt that analysing data given in a second language may not fairly represent the participant (Smith et al., 2009). We also excluded participants who did not live in the UK. IPA works with homogeneous samples (Smith et al., 2009), and it was felt that the experiences of participants who were outside of the UK NHS system would be too diverse to render a reasonable comparison with the UK participants. Of course, we would welcome similar research from other countries. All names and identifying details have been changed.

Data collection

Data were collected using a semi-structured interview guide by the first author, between July and December 2014. Four interviews took place in person, five via Skype, and 12 on the phone, due to the geographical spread of the participants. It has previously been suggested (Novick, 2008) that telephone or Skype interviews may be detrimental to qualitative research, since interviewers may miss out on vital body language cues and be unable to establish rapport. However, in line with several other scholars (Novick, 2008; Sturges and Hanrahan, 2004), we would argue that there was no loss of quality for the telephone/Skype interview as opposed to the face to face interviews. Indeed, it may be that the phone and Skype interviews were more convenient for participants and allowed them greater freedom to discuss potentially

difficult topics since the lack of face to face contact has the potential to afford more of a sense of anonymity and confidentiality (Smith, 1989). The semi-structured interviews consisted of open ended questions about life with an ileostomy, including questions about treatment, which is the focus of this paper. These interviews were audio recorded and transcribed verbatim. Interviews lasted between 27 minutes and two hours and 11 minutes. Most interviews lasted around one hour (mean = 64.5 minutes).

Ethical considerations

This study was given ethical clearance by a university ethics committee. Given the sensitive nature of the interviews, it was possible that they may have been upsetting for participants. The option to stop the interview at any time was offered to all, and a list of support services approved by the third author, a clinical psychologist, was also sent out to all participants prior to the interviews. However, feedback to the interviewer indicated that the majority of the participants found the interviews to be a positive experience. One participant became tearful during the interview. The recorder was switched off and the participant given time and space to recover. They were then also happy to continue the interview.

Data analysis

Data were analysed according to the principles of IPA. Due to the idiographic nature of the method, each transcript was analysed in its entirety before moving onto the next. Each transcript was read and re-read. Descriptive, linguistic and conceptual points of note were explored, resulting in a set of themes illustrating key aspects of experience emerging for that participant. These themes were clustered into a table. Once this

stage was reached for all participants, all of the tables of themes were compared, with particular attention paid to examples of convergence and divergence. Analysis continued into the writing up as commonalities and differences between participants became more clear. Six themes arose from the data: Adjustment to stoma; Stoma and others; Impact of illness on sense of self; Issues around treatment; Relationships with multi-disciplinary teams; and Stressors and Strategies. Analysis of these themes comprised a vast quantity of data, so for reasons of brevity and relevance for nurses, this paper focuses on the two most clinical themes: Issues around treatment and Relationships with multi-disciplinary teams.

Rigor

All stages of research, from interview through to writing up, were undertaken with the principles of sensitivity to context, rigour, transparency and impact in mind (Yardley, 2000). Verbatim quotes are included throughout our analysis in order to give the participants a voice, and so that readers can trace back our interpretations, demonstrating sensitivity to context (Smith et al., 2009). We performed a thorough, idiographic analysis of each participant, and our themes are represented by an appropriate number of participants (Smith, 2011), demonstrating a level of rigour (Smith et al., 2009). The first stage of analysis was undertaken by the first author and audited and checked by the second and fourth in order to ensure a rigorous level of iteration. We have been transparent within this method section, outlining each stage of the research process. Finally, we believe that this research demonstrates impact and importance (Yardley, 2000) by tackling a currently under-researched yet key area within health psychology; the treatment experiences of people living with ileostomies.

Findings

The 21 participants ranged in age from 23 to 72. Data arising from all 21 interviews were analysed. As mentioned earlier, six themes arose from the data. However, we here present the two themes most concerned with clinical practice, with the aim of supporting nurses in their work: Issues around treatment and Relationships with multi-disciplinary teams.

Issues around treatment

Thirteen of the 21 participants talked about various issues around being treated for the conditions that had led to their ileostomy surgery. These included surgical complications, concerns about medication and thoughts about reversal surgery, sub-themes that extend beyond the scope of stoma formation.

Surgical issues and complications

Several participants experienced complications following ileostomy surgery. Barney had to go back into hospital for further operations. He discusses one of those traumatic complications:

One night went out (pause) with friends to go to the cinema and, erm (pause) started suffering excruciating pain again. Got, re-admitted, err again, um (pause) and then, ugh, they noticed that, um, my, stoma had actually um, died. It had gone black and necrotic and they had to, re-operate to, re-form my stoma then.

This is a dramatic image, combining as it does extreme physical pain and the horror of seeing a part of one's own body (albeit it a surgically constructed part) die.

Barney's hesitant speech, coupled with his exclamation ('ugh') shows the level of his distaste for what happened to him.

Laura's wound took many months to heal. She describes how this delayed her ability to adjust to the ileostomy:

The stoma (pause) [...] was just a side act, to this massive wound. I didn't really have any way of properly (pause) dealing with the stoma, because, it was just something else that had to be done when the wound dressing was changed, the stoma bag would have to be dealt with, and so it was (pause). I don't really think I got, to think about what it would be like living with the stoma, first in hospital, at all.

We can see here that the complications Laura suffered meant her ileostomy was just one small piece in a larger puzzle of distressing illness, delaying her ability to adjust to it. These surgical complications, which made Laura bed bound for months following her release from hospital, had an impact on her mental health:

Most nights I went to sleep wishing I wouldn't wake up in the morning. It was horrendous. [...] ^a Everything that they tried didn't work to fix this wound.

^a [...] indicates editorial elision

The constant hopelessness that Laura felt during her prolonged period of healing resulted in suicidal feelings. She felt powerless to heal her wound, and is reliant on her multi-disciplinary team ('they'); however, they too are powerless here.

Marianne describes tangible physical complications following dehydration after the first of a two-stage operation to create a J Pouch:

That's effected my kidneys, which, they said at the time, that will sort itself out and it hasn't, so now I have a level of permanent kidney damage as well.

These extracts demonstrate that surgery is not the end of the story for these participants, in terms of treatment and psychological challenges.

Issues around medication

Richard and Harry had concerns around their opiate painkillers. Richard talks about this in a contradictory manner:

*I had a real problem with pain killers, I got stuck on pain killers. [...]
Almost like an addiction problem.*

On the one hand, Richard presents himself as being 'stuck' on the tablets, seemingly implying dependency. On the other, he distances himself from addiction by using the word 'almost'.

Harry expresses concerns around his ongoing painkiller consumption:

I know that it's highly addictive, you know, I'm very conscious of these kind of things (pause) but it's almost a part of me that (sigh), I don't know, it's almost like self-neglect or something like that, that just kind of says well, you know, if you're not gonna give a toss about me, then why should I, really?

Harry has experienced poor treatment from his multi-disciplinary team, which has had a negative impact on his self-esteem and his ability to care for himself. It is also noteworthy that it is he who has to consider this; no doctor has expressed concern about his medication use.

Reversal surgery

Several participants were on track to have their stomas reversed. Howard was fully committed to the idea of reversing his ileostomy, but felt anxious that the surgery may not go ahead:

I've got this (pause) very (pause) strong anxiety in the back of my mind. I mean rationally, I think, I've got a sort of 99 percent chance to be alright. [...] If they said to me, well no, you've got this for life now, and I kind of slightly, emotionally, preparing myself, just in case that happens. I'm hoping that [...] even if they did say that, I wouldn't fall to pieces. But it would be a huge blow.

There is a sense of internal conflict here as Howard presents himself as being adjusted enough to the stoma for keeping it to be ok (although note his hesitant language as he makes this point), but also acknowledges that this would be very difficult for him. His language ('strong anxiety', 'huge blow') emphasises the depths of his anxiety that the surgery may not go ahead.

Marianne expresses ambiguity around her planned reversal surgery:

*I now have a higher risk of failure than perhaps most people do at this point. But it's more about people's, reactions to, why I'm doing it? [...]
All the people who haven't got a stoma, it's like well of course you'd do that. [...] You'd be mad not to. So that, almost in some ways contradicts (pause) some of the support they've been given, because, they're saying, you're alright, and then they're saying [...] put yourself through hell and get rid of it. [...] And then (pause) I feel, but it's a feeling rather than any reality (pause) that people who, don't have that option, to get rid of it (pause) you know, I feel slightly uncomfortable with talking about it, getting rid of it because it's a bit like me saying, well I don't like what you've got.*

There are several complex factors for Marianne. On one hand, she isn't an ideal surgical candidate. On the other hand, she is concerned about the opinions of others, which in turn leads to irritation with those others for their seemingly interchangeable attitudes, fear about the surgery itself and guilt at leaving others with ostomies behind. It could be that the reactions of others (some of which are imaginary) mirror her own

conflicting concerns. It feels as though Marianne can't win; no matter what she decides, she will still be left asking if the other option would have been a better choice.

Like Marianne, Rita also feels some ambiguity:

I said to the surgeon, you know (pause) part of me feels, like saying well, life's gone back to normal now and, I'm happy as I am. And he was like well wouldn't you want to try life without the bag and I'm like, I would (pause) but it's going into the unknown again. [...] Emotionally I'm thinking oh, I've got to go through all that [surgery] again (pause) and it almost seems silly like I'm volunteering myself to go through it?

Rita has accepted her stoma, and so the thought of more surgery at this point feels risky. Lucy, meanwhile, has adjusted well to her ileostomy and so rejects the idea of reversal surgery outright:

It's quite major surgery, there's a 30% failure rate. [...] And with two small children, it was just, not really a possibility and also, my stoma hasn't really affected my life.

Stephen had had a J Pouch following his first temporary stoma, which leaked and caused problems for him:

I'll never forget, during this whole period saying to my wife, god, there are times, I just wish to god, I'd just kept the bag.

Following the return of his bowel cancer, Stephen now has an ileostomy once again, and says:

When I woke up in ICU, the first time (pause) it was basically almost like seeing an old friend. It probably sounds weird, but (laughs), it was actually a bit of a relief!

We can see here that Stephen's imperfect experience of life with a pouch resulted in warm feelings towards his ileostomy.

Relationships with multi-disciplinary teams

Eighteen of the 21 participants talked about their relationships with and experiences of multi-disciplinary teams, some of which were negative, and some positive. Again, these experiences extend beyond the scope of stoma formation.

Negative relationships and experiences

Many participants described negative relationships with their multi-disciplinary teams, including dehumanising treatment from nurses. Kim describes a sense of alienation resulting from what felt like automaton care before her operation, which resulted in her being scheduled for the wrong surgery:

I felt like, they weren't dealing with me as a person. [...] I was an operation which they were going to perform. [...] She described the operation [...], and I was thinking, that's not what the [other] nurses said.

But didn't say anything, I really am cross with myself that I didn't say anything. [...] I just assumed that I'd misunderstood.

Kim found this treatment dehumanising and lacking concern for her well-being or individuality. Her hesitant, repetitive speech suggests that she felt she was not given the respect or confidence to speak up and ask questions, leaving her feeling like less of a person, and doubting her faith in her own knowledge.

Rita felt belittled during an incident following some bleeding when a nurse expressed disgust at her symptoms:

A big clot come out, so she showed it to the next nurse, and the nurse's reaction was oh, god no, put it away. And I seen her do that. And I felt quite frustrated, I thought, that's your job. [...] It was sort of very (pause) you know, just disregarding.

Rita perceived the nurse's reaction to be one of disgust, negatively impacting on her self-worth and hence dehumanising her.

Several participants described incidents of what appeared to be negligent care from nurses or doctors. Natalie had a young baby who she was breast feeding during her recovery from surgery. A nurse tried to give her a medication that a doctor had told her wasn't for breast feeding mothers:

She goes, well how old's the baby? I said well he's 10 months, she goes (uptight voice) oh my goodness gracious me, why on earth are you still breast feeding him now? She said there's more nutrients in cow's milk for that age than there is in breast milk. And (pause, sigh) had I not just had major surgery and had I not been a bit of an emotional wreck, from all that had happened over the previous couple of weeks (pause) I would have gone through her like a dose of salt and (pause) put her on the correct path.

There is a sense here that Natalie, who was in a position of exhausted vulnerability, felt dictated to by this nurse. She also reports that the nurse negligently gave the wrong advice about breast feeding (Victora et al., 2015), leading to feelings of anger; however, Natalie was too tired following surgery to respond.

Marianne describes a negligent incident when she was in the vulnerable position of recovering from surgery and dealing with a DVT:

A doctor came and I said look, I'm not elevating, and it's really swollen and, you know, it's uncomfortable and he asked the nurse to get me a stool. So that I could elevate it. [...] And, he went away, and the nurse said, well just cos some, doctor asked me to get a stool, doesn't mean I'm actually going to do it.

Harry describes low quality care following reversal surgery for a J Pouch, which later failed in an appalling fashion, with unknown, alien matter emerging from his rectum and causing him to go back into hospital. Harry says:

Doctor came round with a few other people, with him the following morning, and had a bit of a look (pause) said oh, ok, not sure what that is, gave it a bit of a tug, and it came out and off. And I've no idea what it was. [...] He didn't get it tested, he just basically, it got (pause) thrown away or whatever. My surgeon was never, consulted about it.

Harry's symptoms were alarming and intimate, yet he was treated by a crowd of unknown people (doctor plus 'a few others') dispassionately looking at his body and seemingly disregarding any impact this incident might have had – psychologically or medically – on Harry.

Positive relationships and experiences

Several participants talked about the helpful support they received from multi-disciplinary teams. Laura describes how the district nurses caring for her made her long recovery easier:

They'd go och, it's fine! There's a guy round the corner, and his is, and he's got, and you're like (pause) but (pause) they brought in a level of, relativity, they would say, we've seen things like this, or, we know how to deal with this.

The downward comparison used by the nurses helped Laura contextualise her illness, which reassured Laura and boosted her sense of well-being.

Amy describes a tactic employed by her surgeon when he was talking to her about the need for ileostomy surgery:

He gave me the option of, think about a hemi colectomy which won't last. Or a stoma. [...] But you'll need a stoma eventually and I thought oh, I don't want to go through it twice so, and he said that's the right decision cos I can't do a hemi colectomy. So I said so why did you offer me one? He said because if I'd told you you needed the stoma, you'd have run a mile (laughs). [...] Clever man!

Amy is appreciative of the sense of choice she was offered by her surgeon around the difficult decision to go ahead with stoma surgery, even after she realises this was an illusion. This demonstrates the understanding her surgeon had of her, and shows evidence of a positive, close relationship.

George highlights the importance of trust in relationships with multi-disciplinary teams:

I did often see the same people. [...] So yeah, I did feel that thing about trust.

The consistency within his multi-disciplinary team allowed George to feel trusting of them and as though he was safe in their hands.

Discussion

Issues around treatment

Participants described complications following surgery, and their consequences on well-being. One participant (Laura) described feeling suicidal whilst waiting for her wound to heal. Some extant research also reported both physical (Allison et al., 2013; Kuijpers and Klok, 2014; Nordstrom and Nyman, 1991; Notter and Burnard, 2006; Paquette et al., 2013) and psychological (Cheung et al., 2003) complications following stoma surgery, including suicidal feelings (Erwin-Toth, 1999). The nuances within our study highlight the depth of emotional impact these complications cause, suggesting a need for extra support. This social support could be provided in counselling sessions or facilitation of peer support. In addition to this, stoma nurses may be utilised by people living with ileostomies as expert resources, so that they are fully informed of the potential complications of living with an ileostomy and the healthcare that inevitably goes along with that life.

The concerns of Richard and Harry about painkiller dependence following ileostomy surgery appear to be relatively novel. Dependence on opioid painkillers as a result of

chronic pain is not a new finding (Dowell et al., 2013; Juurlink and Dhalla, 2012; Pade et al., 2012; Passik et al., 2011), but literature searches only revealed one case study detailing this dependence in an ileostomy patient, observed when he was in hospital (Porter-Williamson et al., 2003). Our findings add to this picture by showing that some ileostomy patients may feel concerned about their intake of painkillers without discussing this with their multi-disciplinary team. Non-judgmental discussion with healthcare professionals about potential addiction may be beneficial for at risk patients immediately after their operation (Dowell et al., 2013).

Participants' feelings about and experiences of reversal surgery were mixed. Whilst early findings (Salter, 1992) suggested that reversal surgery was an unmitigated improvement, recent research illustrates that pouch formation surgery carries a set of stressors all of its own (Taylor and Bradshaw, 2013; Taylor and Morgan, 2011). Some patients perceived life with a pouch as being worse than they had been led to believe. Indeed, Taylor and Bradshaw (2013) called for more education and pre-surgery counselling. Our findings document a range of complex feelings among patients whilst considering reversal surgery. Again, stoma nurses are ideally placed to be able to discuss the potential benefits and disadvantages of living with a pouch with people who may be considering this option. Perhaps future research could explore this avenue more fully.

Relationships with multi-disciplinary teams

Many participants reported poor relationships with their multi-disciplinary teams among our sample. Research into doctor patient relationships for chronically ill patients has painted a mixed picture, with some studies suggesting that patients tend

to be very happy with those relationships (Hudon et al., 2013) and others suggesting that there is room for improvement (Schoen et al., 2009).

Research specifically into ostomy patient experience has tended to report positive relationships with supportive and helpful multi-disciplinary teams (Allison et al., 2013; Bray et al., 2012; Brown and Randle, 2005; El-Tawil and Nightingale, 2013; Notter and Burnard, 2006). We found only two reports of potentially abusive care reported in the literature. In the first (Kelly, 1992), a woman with an ileostomy described an incident in which a nurse grimaced and walked away when she was meant to be bathing her. In the second (Thorpe et al., 2013), a participant described being told off by a nurse when her bag leaked. Although these two incidents pave the way for the findings in our article, they are isolated incidents. As such, the high number of negative and seemingly abusive incidents reported by participants is somewhat unexpected. This highlights the usefulness of idiographic qualitative research within medical settings and suggests that care that is perceived to be abusive might be more common than previously thought (Kelly, 1992; Thorpe et al., 2013).

It remains unclear why the participants in this study experienced such difficulty with their care. One possible explanation is the understaffing of specialist stoma nurses within the United Kingdom, where our participants come from, or the USA, meaning that the demands placed on these nurses results in feelings of pressure and stress, and a diminished capacity to fulfil the demands of the job (NAWCCB, 2015; Notter and Burnard, 2006). It has been noted that there is a lack of standardised training for stoma nurses across Europe (Eucomed Medical Technology, 2015), showing that this is an international issue. It has been posited that non-specialist nurses should receive

more training around stomas (Brown and Randle, 2005; Notter and Burnard, 2006), and that those non-specialist nurses who do have some stoma knowledge can also be more supportive (Thorpe et al., 2013). We would support the recommendation that more nurses receive training in stoma care in order to help these patients. A third explanation for our findings within the United Kingdom may be a consequence of NHS funding reductions (Thorpe et al., 2009). If multi-disciplinary teams are finding themselves working longer hours, with less support and less staff members, this will inevitably have an impact on the quality of care they are able to deliver, which is reflected in the accounts of the participants. Additional research examining the experiences of nurses is required to explore these ideas.

In line with some of our findings, scholars also reported that multi-disciplinary teams provide positive support to people living with ostomies (Allison et al., 2013; Thorpe et al., 2013). In particular, specialist stoma nurses are cited as being knowledgeable and supportive experts (Bray et al., 2012; Brown and Randle, 2005; Notter and Burnard, 2006), and it is suggested that those who don't have access to a specialist stoma nurse may be more prone to depression and anxiety (Brown and Randle, 2005; Cheung et al., 2001). As George noted, trust is essential in building positive relationships with multi-disciplinary teams (Thorpe et al., 2013).

Limitations

Despite the promising findings in this study, it does have some limitations. We purposively recruited a stratified sample based on age, gender, and length of time since surgery, tentatively thinking that there may be some divergence between these groups. However, we instead found patient experience was comparable for all

participants, and so analysed our findings in one reasonably homogeneous sample, as suggested by the principles of IPA (Smith et al., 2009). However, the fact that two of our participants had had surgery a very long time before interview (one 29 years previously and one 53) threatens the homogeneity principle of IPA (Smith et al., 2009). Despite this, it is felt that patient experience was comparable enough to provide a coherent and resonant account.

It is also the case that, due to methodological concerns, we only spoke to Native English speakers living in the UK, so it may be that these findings are not internationally applicable. We would encourage future research with different cultural groups, so that patient experience can help inform clinical care all around the world.

Conclusion

We set out to explore and resonantly illuminate the experiences of people living with and being treated for the conditions leading to ileostomy. Our findings have succeeded in illustrating the mixed healthcare and treatment experiences of ileostomy patients. We can see that these experiences may be challenging in terms of medication, surgical complications and relationships with their multi-disciplinary team. Based on these findings and the consequent situating of them within the literature, we concur with the existing recommendation that extra psychological support should be offered to patients who experience surgical complications, that physicians open non-judgmental conversations with patients taking opioid steroids about their usage, that more training is needed around stomas for all nurses, and that multi-disciplinary teams provide clear information about life with a stoma, possible complications from stoma surgery, and life with a pouch.

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Table 1: UK sample distribution according to demographic data

Name	Age	Year of surgery	Years elapsed between surgery and interview
Laura	39	2011	3
Natalie	32	2013	1
Rita	33	2013	1
Harry	40	2011/2014	3/1 ^b
Barney	29	2013	1
Nancy	58	2012/2013	4/3
Diana	42	2011	3
Kim	65	2013	1
Richard	57	2014	0
William	43	2014	0
Howard	71	2014	0
Heide	23	2010	4
Lucy	32	2009	5
Jack	26	2006	8
Simon	27	2009/2013	11
Marianne	43	2010	4
Amy	58	2010	4
Iris	71	1961	53
Stephen	72	2006/2010	8/4
George	69	1985	29
Oliver	52	2006	8

^b Two numbers indicates that participants had a temporary ileostomy which was later replaced with a permanent one