Patients’ experiences of treatment and care after ileostomy

Keywords Stoma care/ileostomy/ Patient experience/Coping strategies

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● Outcomes of interviews with 21 patients living with an ileostomy
● How nurses can improve care for people after an ileostomy
● Understanding patient experiences of nursing care

A round 9,000 ileostomy procedures are performed annually in the UK (Bit.ly/NHSChoicesIleostomy). Having an ileostomy (Box 1) can negatively affect patients’ body image and intimate relationships; some may also perceive themselves to be older than their years (Smith et al, 2017). Nurses play an important role in maximising wellbeing among this patient group (Nicholls et al, 2016).

Thorpe et al (2014) called for more research to document patients’ experiences, but there is still little research available. To address this, we conducted a small-scale qualitative study exploring the treatment experiences of people with an ileostomy, their emotional reactions to surgery and medication, and their relationships with medical staff (Spiers et al, 2016).

Method We recruited 21 participants aged 18 years or over living with an ileostomy, and conducted semi-structured interviews with them, either in person, over the phone or via instant messenger applications such as Skype. Most interviews lasted around an hour. Each was recorded, transcribed verbatim and subjected to interpretative phenomenological analysis (IPA) (Smith et al, 2009). Each transcript was read and re-read in its entirety, and descriptive, linguistic and conceptual notes were made. These notes informed the creation of themes for each participant. We then explored similarities and differences between participants.

We chose IPA because its initial stages explore individual experiences, while its subsequent stages identify patterns within groups of individuals (Smith et al, 2007). We felt this approach was well suited to the aim of the study (to provide a better understanding of the treatment experiences of people who undergo ileostomy).

Results

Surgical complications
Some of the 21 participants experienced surgical complications – for example, stoma necrosis, wounds failing to heal or kidney problems due to dehydration – and
Negative relationships
Many participants described negative encounters and relationships with nurses often perceived as dehumanising. For example, one participant felt that she was not being treated as a person, and that she received conflicting information about the operation, but was too afraid to ask for clarification. There were also instances in which nurses appeared to react in disgust when examining stomas that had blood clots, which negatively affected participants’ self-worth.

Participants reported having received negligent or inadequate care. One woman who was breastfeeding had been told by a doctor that a particular medicine was inappropriate for breastfeeding mothers, but then a nurse tried to give her that medicine. The nurse also encouraged her to stop breastfeeding, stating that cow’s milk is more nutritious than breast milk.

Another instance of negligent care was reported by a participant who was at risk of developing deep vein thrombosis. During a consultation, a doctor asked a nurse to get a stool so the participant could elevate her leg. However, she reported that when the doctor left the ward, the nurse refused to provide her with a stool.

Dependency on opiates
Two participants described a perceived dependency on opiates. One described this as a severe problem, using the word ‘addicted’. The other was taking opiate-based painkillers as a form of self-neglect, partly because he did not feel supported. He felt that, if the medical team did not care about him, why should he care about himself? He was consciously taking excessive doses of opiates, but reported this was never questioned by doctors or nurses.

Implications for practice
Ileostomy operations, surgical complications, corrective surgery and reversal surgery appear to cause intense stress and anxiety in some patients. This can be alleviated through good relationships with key medical professionals such as surgeons and nurses. The psychological support provided by specialist stoma nurses to patients who experience surgical complications and undergo additional surgery is crucial, given that this is a time when they are particularly vulnerable to anxiety and low mood. Patients’ relationships with their specialist stoma nurse and/or their multidisciplinary team is therefore of particular importance.

Nurses can support patients by providing coping strategies, mindfulness training and optimism training, which seem to be helpful in this setting (Nicholls et al, 2016). Nurses can ensure that they show empathy – especially immediately before and after surgery – and that they treat patients as individuals. Finally, nurses can reinforce their awareness of the risk of opiate dependency among patients with an ileostomy, and provide advice and support to avoid this.

References

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● Management of stoma complications
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Some found this traumatic. One participant reported feeling suicidal, while others reported low mood and anxiety after experiencing complications that resulted in additional treatment.

Positive relationships
Several participants reported having positive relationships with the multidisciplinary team, which often had a positive effect on their wellbeing. One woman, concerned about her recovery, was reassured by the nurses, who she reported told her that they had seen many people with a stoma and so knew how to manage her stoma and help her cope.

Seeing the same nurses on repeated occasions helped participants build positive relationships. One participant explained that he came to trust his nurses because he got to know them; this also gave him a feeling of safety, as he was confident that he was receiving the correct treatment.

Reversal surgery
Several participants were preparing to have their stomas replaced with an ileo-anal pouch (Box 1) and this was a source of anxiety for some who worried about whether or not reversal surgery would be successful. Some participants also had mixed feelings about having an internal pouch. One participant had been told that having a stoma was acceptable and had adjusted well to it, but now that she was being offered an internal pouch instead, she felt that the medical team no longer viewed the stoma as appropriate.

One participant who previously undergone reversal surgery, but when his bowel cancer returned a new ileostomy had been formed. When he awoke from surgery, he was pleased to see his stoma, as there had been times when he had longed to have it back because of leakage problems with the internal pouch.

Box 1. What is an ileostomy?
An ileostomy is formed to either temporarily or permanently stop digestive waste passing through the full length of the small intestine or colon. The small intestine is diverted through an opening (stoma) in the abdomen, over which a special bag is placed to collect waste products that usually pass through the large intestine, rectum and anus.

An ileostomy may be needed to:
• Allow the small intestine or colon to heal after surgery (for example, removal of a section of bowel in patients with bowel cancer);
• Relieve inflammation of the colon in Crohn’s disease or ulcerative colitis;
• Allow complex surgery to be carried out on the anus or rectum.

In loop ileostomy, a loop of small intestine is pulled out through an incision in the abdomen before being opened up and stitched to the skin to form a stoma. In end ileostomy, the ileum is separated from the colon and brought out through the abdomen to form a stoma. Alternatively, an internal pouch that is connected to the anus (ileo-anal pouch) can be created: in that case, there is no stoma and stools are passed out of the anus in a similar way to normal. End ileostomies and ileo-anal pouches are usually permanent. Loop ileostomies are usually temporary and can be reversed at a later date.

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