

# Exploring individuals' perceptions of living with a stoma

**Angie Perrin**, Clinical Lead for Innovation, Salts Healthcare, [angie.perrin@salts.co.uk](mailto:angie.perrin@salts.co.uk), discusses findings from interviews and surveys regarding ostomists' attitudes to their stoma, adjusting to their new reality, and product choice

The NHS *Five-Year Forward View* (NHS England, 2014) set out how the health service needed to change, and emphasised a more engaged relationship with patients, carers and citizens in order to promote wellbeing and prevent ill health. As nurses, we are instrumental in facilitating ownership and responsibility for health, as well as promoting and enhancing an individual's wellbeing or quality of life.

Stoma formation is often the result of a major health concern, recent diagnosis or prolonged illness. For many people, having a stoma formed can significantly affect their quality of life (Burch, 2016). There are approximately 120 000 people in the UK with a stoma—that is equivalent to 1 in every 500 people living in the UK (Colostomy UK, 2019). The most common types of stomas are colostomy, ileostomy and urostomy.

Much has been written about the effects on quality of life following stoma formation. A good or acceptable quality of life will be different for every individual and is defined in the *Encyclopaedia Britannica* as the degree to which an individual is healthy, comfortable, and able to participate in or enjoy life events—such events may include work, hobbies or socialising. Boyles (2010) suggested that, regardless of the reason for stoma formation, the creation of the stoma has a multi-faceted impact on patients and the way they lead their lives. In the Association of Stoma Care Nurses (ASCN) stoma care guidelines (ASCN, 2016) one of the key facts stated is that patients with a stoma may develop complications that are debilitating and life-changing.

Any nurse, irrespective of their specialism, must ensure that people's physical, social and psychological needs are assessed and responded to (Nursing and Midwifery Council, 2018). Undergoing surgery of any magnitude can significantly impact on an individual's wellbeing, both physically and sometimes psychologically, therefore

it is fundamental that each individual who has required stoma formation as a result of surgery is assessed by a qualified stoma care nurse and that a personalised plan of care is prescribed that encompasses all aspects of care (ASCN, 2016). Ongoing support is viewed as one of the key components that can positively affect an individual's ability to cope and manage their stoma. Being able to ask questions or simply being able to voice concerns or anxieties to an experienced stoma care nurse with whom the patient has built up a trusting and collaborative relationship undoubtedly lessens the patient's anxieties. Having any amount of underlying uncertainty in their stoma care routine has been shown to result in a patient finding it more difficult to adapt to having a stoma (Riemenschneider, 2015).

In the first few weeks or months at home following stoma surgery, the patient faces an unfamiliar journey of learning how their stoma functions: when, where and how. Patients often have doubts about their ability to cope at home with the practicalities of managing their stoma (Black, 2009). During these initial few weeks the patient will experience many 'new' firsts. For example, the first time they shower or bath following stoma formation, do they shower with or without the pouch on? The first time they go to the gym or eat out in a restaurant with friends: will the pouch be visible to others or emit odour? All of these activities will challenge the majority of new ostomists, but once conquered, the next time should be easier for them. Unfortunately, most new ostomists may experience a first appliance leak or pouch failure, which will undoubtedly affect their confidence and self-esteem and heighten their anxiety. All of these experiences, both positive and negative, will be made easier if the patient has support, from friends and family as well as from a stoma care nurse.

Support, both short and long term, is vital for the ostomist (ASCN, 2016). In the short

term the stoma care nurse is key with regard to re-assessing the size of the stoma in the first few weeks, providing education and reassurance to the patient, family and carer, as well as reviewing the suitability of stoma products and offering alternatives as appropriate.

## Exploring the patient viewpoint

In 2016 Salts Healthcare, in collaboration with independent researchers, initiated some qualitative and quantitative research exploring some of the practicalities stoma care patients face throughout their journey, as well as trying to understand the emotions they experienced at differing timeframes during their recovery. The objectives were also to determine what influences individuals to make certain decisions regarding their choice of product: was it solely based on functionality of the product or were there other factors that were considered important?

Recruitment was undertaken via a Salts Medilink database from a variety of locations through the UK. The qualitative research was carried out in two modes. The first consisted of qualitative mini groups with a maximum of 6 participants per group to allow detailed and dedicated conversation. Each mini group was allocated 2 hours allowing adequate time to hear each person's 'story'. The mini group sessions were held in a local hotel or a specially designed room within a research facility. This room had a one-way mirror that enabled viewing. Participants gave their consent for this activity.

The second mode involved intensive in-depth interviews with individuals to explore attitudes and experiences. Included within this cohort were patients who were unable to attend a group or who felt uncomfortable discussing personal details in front of others. The in-depth interviews were held in patients' own homes and were allocated 1.5 hours each.

In total, 32 patients were interviewed; it is acknowledged that this is a relatively small

sample in respect of the total population of ostomists in the UK. Nonetheless, despite the small cohort of patients the results extrapolated from the data were analogous with current literature.

The quantitative research was undertaken as a planned follow-up to the qualitative study. This phase of the project took the form of a combined postal and online quantitative survey, which was completed by 257 respondents. The demographics for the quantitative study were as follows: 58% (149) female, 42% (106) male; two questionnaires were incomplete, therefore they were excluded from the results. Concerning stoma type, 56% (143) of participants had a colostomy, 40% (102) had an ileostomy, 7% (18) had a urostomy (some respondents had two types of stoma).

### Living with a stoma

Some of the evidence from this complete study suggests that attitudes towards stomas are dependent on reasons for needing one, whether it is pre-planned and whether they experience any subsequent problems, particularly leakage (Claessens et al, 2015). There was an overwhelming negative attitude from patients who had undergone emergency surgery who had been unaware of the possibility of stoma formation prior to surgery. Such patients had not adapted well to living with their stoma and several had largely become isolated. This is a view supported by McKenzie et al (2006), who found that patients avoided social and leisure activities, especially if a pouch change would be necessary while away from their home.

The responses to the survey highlighted that 30% of individuals were still reportedly experiencing problems with leaks, but despite this, 83% patients stated that they felt comfortable with day-to-day management of their stoma.

Some participants admitted to be struggling to come to terms with their stoma even though their operation took place more than 3 years ago. This situation is not infrequent. How an individual copes with their stoma is greatly influenced by whether it is temporary or permanent (Black, 2000), elective or emergency, and if they have received preoperative information, both verbal and written (Borwell, 2009).

Similarly, there were patients within the cohort who reflected on this as a very unsettling time, having to deal with major health issues or facing death, meaning that

dealing with a stoma was part of a much wider picture and they accepted the change more positively; 87% agreed that their stoma 'is what it is' and that they just needed to get on with life and felt grateful to be alive and generally considered that their stoma had greatly improved their quality of life. Many acknowledged that living with a stoma takes some getting used to but for most becomes a manageable part of daily life.

The study highlighted that the presence of health professionals, particularly a stoma care nurse, greatly influenced the patients after surgery. Similarly, it also emphasised that if there is little or no support then the patients' feelings towards having a stoma were much more likely to be negative. In Wade's (1989) influential study the benefits of support from a stoma care nurse were highlighted, this has subsequently been ratified by Porrett and McGrath (2005), Waller et al (2009) and Burch (2017). In our study 86% of the questionnaire responses said that they felt fully supported by their stoma care nurse. It is evident that stoma care nurses must play a significant role in the new ostomy patient's recovery and beyond, and by doing so can positively influence their patient's ability to cope and adapt to life with a stoma.

As the proverb says: 'If at first you don't succeed, try, try, try again'. It is logical for patients to feel apprehensive when learning the new skill of changing their pouch. Some patients in the study indicated that, for them, reality started to set in on discharge from hospital and they had concerns about how they were going to manage on a daily basis on their own at home. Initially bag changes for some individuals were taking hours, and there was a growing concern that this was how it would be forever. This is reflected in the results from our study that show one-third of the patients, mostly those who had had their stoma for 12 months or less, said that they were still coming to terms with their stoma and that they tried to keep the presence of it a secret. This point was backed up by some of the in-depth interviews.

### The question of choice

If an individual has a limited knowledge within any specialist area, it would be necessary for them to seek information from the expert within that specialist area for help and advice. Some patients commented that they were given an initial postoperative appliance and that they were happy with this, as they were

recovering from surgery and still a complete novice regarding stoma care. This was a product selected by the stoma care nurse following careful and thorough assessment of the individual's stoma and its care needs. Other patients stated that they were offered a choice by their stoma care nurse, but relied on the expert opinion of their nurse to guide them into making a decision regarding postoperative product selection. It is vital component of the nurse specialist role to empower patients to make the right decision for themselves. Interestingly, 43% of those who completed the survey were still using the product that they were using on discharge from hospital. This significant number could suggest that the expert nurse, by using the high-level autonomous decision-making skills they possess, has implemented the correct prescription; or perhaps it could simply mean the patient has resigned themselves to that one particular product and has no desire to look for anything different as it works well for them.

Choice suggests the opportunity or privilege of choosing freely. For ostomy patients in the UK having a choice of product is something that is accessible and appreciated by many. Having a stoma is often not a choice that individuals wish to make; unfortunately, for some it is a choice that favours a more acceptable outcome when faced with an illness or disease. Unsurprisingly the study highlighted several key functional elements that individuals considered vital for any pouch: that the pouch does not leak, controls odour, minimises skin irritation and ballooning and prevents odour. It also revealed that individuals with a stoma likewise felt that it was important to have some less functional, more aesthetic qualities such as the fabric of the product should be rustle/noise free, it should fold up small, should be showerproof or water repellent, have a soft feel fabric, ideally breathable and 'not sweaty'. Some of these elements appeared to influence decisions relating to choice of product the individual ostomists may make. From a quality of life perspective, for some it was important that they should feel comfortable wearing their pouch and it should look aesthetically pleasing, as well being secure. Brown and Randle (2005) highlighted that stoma pouches have an impact on body image that affects relationships, work and psychosocial aspects of life.

The quantitative survey highlighted that 57% of patients, particularly those aged under 50 years, had tried many different pouches

following the ones they were given in hospital, perhaps curious to explore what else is available within the specialist sphere of stoma products that may better fulfil their stoma care needs. This usually started a few weeks or months after discharge. The interviews also highlighted the curiosity among this younger demographic. Younger females were also significantly more likely to mention the benefit of aesthetics, and keen to find products that may co-ordinate with clothes or underwear.

One participant commented that she felt 'it is a risk to try new products, but if I find a better one I will change'. Women were identified as being more likely to change product brand than men; 57% of patients had changed the pouch product they used and 20% had changed more than 5 times—leakage and skin irritations were recorded as common triggers to instigate a change in product.

Rapid developments in information technology and improved accessibility in the past few years has influenced how some patients gather information and make decisions on choice. Recently there has been a focus on numerous social media sites highlighting how ostomists have dealt with their illness and surgery, many of them revealing their surgical scars and subsequent abdomen with pouch on. This is a 21st century reality and it must be acknowledged that social media is an extremely powerful method of communication and information-gathering portal for a wide audience. Frohlich and Zmyslinski-Seeling (2016) discussed the impact of using social media to challenge

some of the stigma that surrounds living with a stoma. It falls within the nurse's remit to help rationalise or balance the information gleaned from the internet or other sources ensuring that it has been interpreted correctly and applied in the correct context to enable the patient to make the right choice. Often some information is misinterpreted by the layperson, which may result in that individual experiencing unnecessary anxiety.

## Conclusion

Although it is acknowledged that this study is limited by its size, it does highlight that nurses are instrumental in enhancing an individual's quality of life after stoma formation by providing valuable specialist support, both short and long term. Attitudes towards the stoma in the study varied, often related to the reasoning behind its formation. Although many recognise that living with a stoma takes some getting used to, for most it does become a manageable part of daily life. Offering choice empowers the individual to be responsible for making their own decisions. Although this can be challenging for some individuals the nurse can provide the safe, supportive environment and offer expert knowledge on key aspects of care if required, facilitating appropriate choices to be made. **BJN**

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