

# Living well with a stoma: a descriptive evaluation

## Abstract

The increasing workloads placed on stoma nurses often puts the focus on the practicalities of living with a stoma with the result being that the emotional impact is overlooked. This research, carried out in the UK and Ireland, attempts to capture the impact of a stoma on an individual's quality of life. Advertisements were placed in the press and online looking for ostomates to assist with research. Respondents contacted the clinical research team and were sent a lifestyle questionnaire to complete. The questionnaire was designed to capture both day-to-day stoma-related issues and the psychological impact that stoma-formation surgery has on individuals. In total, 547 questionnaires were returned, giving a return rate of >90%. Participants ranged from 18–92 years old, with postoperative times ranging from <1 to >30 years. While some describing life since surgery chose positive descriptors, such as better, healthier, happy and free, the vast majority reported some negative feelings, with the predominant words being restricted, embarrassing, difficult and inconvenient. This research highlighted the difficulties associated with predicting the psychological impact of a stoma.

**A**round 24,000 stomas are formed in the UK and Ireland each year; approximately half of which are permanent (High Impact Actions, 2010). Recovery and acceptance following stoma surgery is influenced by many factors, including gender, age, stoma type, reason for surgery and provision of pre- and postoperative care. This journey can also be significantly influenced by postoperative or stoma management complications. This array of complexities makes it difficult for both health professionals and industry to fully understand the impact a stoma has at various stages of a person's life (Burch 2016; Davidson, 2016). The provision of follow-up care varies between countries but this research focuses solely on ostomates in the UK and Ireland.

## Method

With a view to narrowing the identified knowledge gap in understanding the real impact of living with a stoma, an advertisement was placed in print publications and on social media pages for ostomates. This requested volunteers to complete a lifestyle questionnaire.

The study aimed to assess the physical, psychological, social and financial impact of living with a stoma. The questionnaire was designed to provide a comprehensive insight into all these areas. General questions were centred on demographics, product use and associated challenges, with more probing questions on lifestyle and the psychological implications of being an ostomate. The questionnaire was only circulated to ostomates over 18 years' old, irrespective of stoma permanency.

Demographic questions covered gender, age, stoma type, stoma size, output consistency, reason for surgery, time since surgery, likelihood of stoma reversal and occurrence of hernias. Participants were also asked what they found most challenging about having a stoma and to choose three words to describe their life since their stoma operation.

To provide context for the psychological analysis, detailed questions regarding product use and preference were incorporated in the questionnaire. For any technical terminology, explanatory notes were provided to assist respondents to fill in the

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## Key words

- Evaluation
- Online information
- Postoperative complications
- Psychological impact
- Stoma care

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questionnaire. As the study took the form of voluntary questionnaires, seeking ethical approval was not deemed necessary.

## Results

Over 90% (n=547) of those who enquired about the advertisement completed the questionnaire. An almost equal response rate was achieved from men and women, with representation from all age groups (*Figures 1 and 2*). There were respondents with each of the three stoma types, with 10 people having multiple stomas and a few people unclear about their own stoma type (*Figure 3*).

A high proportion (31.8%) of respondents recognised that they had a parastomal hernia, while a significant number (3.8%) were unsure, suggesting a considerable lack of awareness.

Respondents' product use was varied, with flat and convex and one- and two-piece systems all well represented. The predominant flange profile was flat (47%), with an additional 37% using convex and 1% alternating between flat and convex depending on stoma protrusion. A relatively high number of participants (15%) did not answer this question. The great majority of respondents (70%) used one-piece pouches, with 23% using two-piece pouches and 1% using both one- and two-piece products. A lower but still significant proportion (6%) did not respond to this question (*Figures 4 and 5*).

The results showed an ever-increasing use of accessories in the pouching routine, including ostomy seals, flange extenders, adhesive removers and barrier products. The key results in relation to reasons for pouch and/or baseplate changes are summarised in *Figure 6*.

Problems with daily stoma management were unexpectedly common (76%), with leaks and sore skin the most prevalent. Other respondents were found to be living with complex management issues and did not have an appropriate care plan in place, resulting in a disjointed level of care. In some cases, guidance was required on topics including diet and lifestyle, while others needed reassurance that their stoma management was appropriate. Another worrying observation was that some ostomates and health professionals did not know where to find help if required.

Feedback relating to participants' likes and dislikes with their current products covered all aspects of the stoma care routine. There were

particularly insightful responses to questions about what they found most difficult about having a stoma and what three words they would use to describe their life following stoma surgery (*Figure 7*). The reasons for finding living with a stoma difficult were extremely varied, with the most frequently reported being diet, clothing, exercise, travel, discretion, changing in public and fear of leakage. The words used to describe life after surgery by the 93% of participants who answered this question were categorised as either positive, neutral or negative—36% reported a negative outlook, 29% neutral and the remaining 42.8% positive.

The relationship between individuals' outlook and age, gender, stoma type and time since operation are displayed in *Figures 8*. Overall, women reported a more positive outlook than men (44% vs 34%). Some variation was observed across the age ranges, with the most positive response (60%) in the 19–40 age category and the least positive (38%) in the 41–65 age range. For those with a single stoma, ileostomates had the most positive outlook (47%), with colostomates slightly less positive (38%) and urostomates the least positive (32%). Those living with multiple stomas, while few in number (n=10), had a very low positivity rating (11%). Length of time following surgery had a significant impact on the respondents' outlook, with increasing positivity and acceptance over time. In the initial postoperative year, only 24% reported a positive outlook, but this figure increased to 42% through years 1–5 and to 46% for over 5 years.

## Discussion

While it is acknowledged that the sample size is relatively small, all respondents were volunteers. No evidence of bias was observed with respondents not being offered any form of compensation for completion of the questionnaire.

### Demographics

The authors' experience concurs with the results of this study, which showed there is no significant variation between the number of female and male ostomates in the UK and Ireland. While there is some published evidence of the gender split in relation to various conditions that may lead to stoma surgery, there is no comprehensive research regarding the gender split encompassing all potential reasons for stoma creation. However,



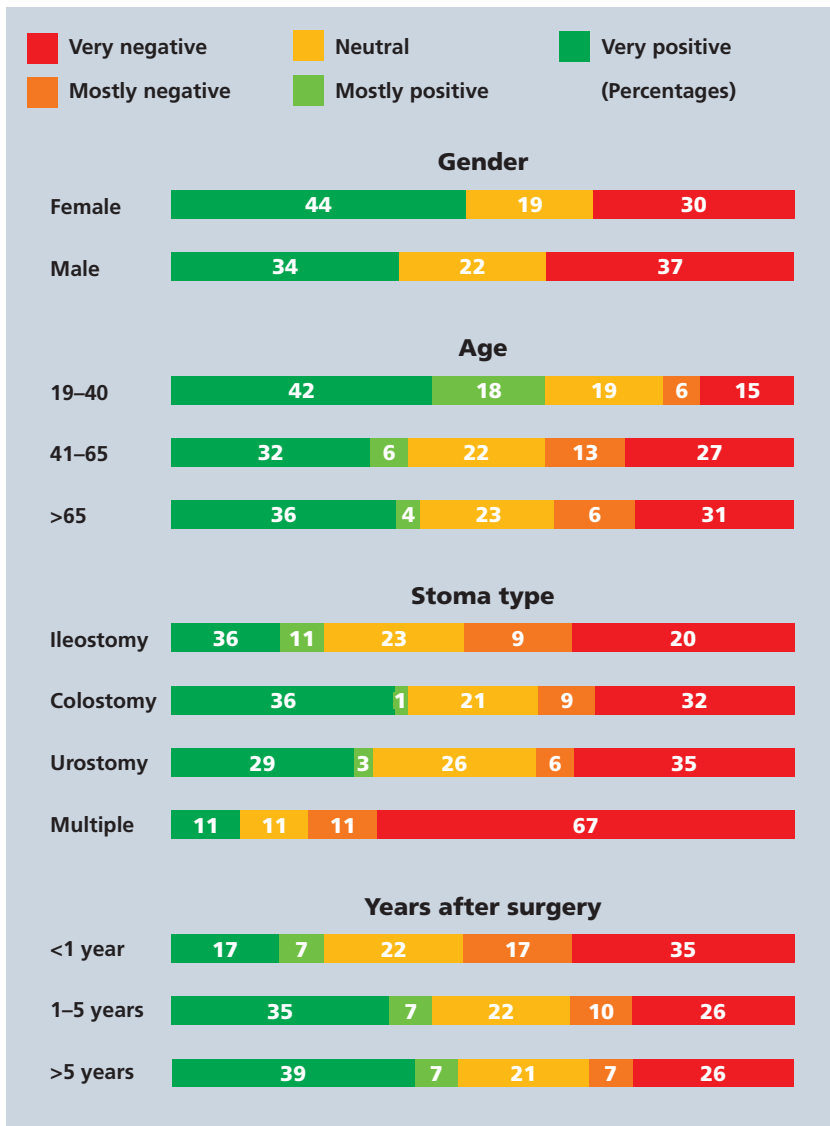


Figure 8. Relationship between demographics and perspective on life after surgery

Stoma type	This study	Black (2009)
Colostomy	42%	49%
Ileostomy	49%	39%
Urostomy	6%	12%

Appliance	This study	PCA data
One-piece	70%	86%
Two-piece	23%	14%

usage, with convex products now representing more than 30% of the ostomy pouch market. The 37% of respondents in this study using a convex appliance corresponds to prescription cost analysis (PCA, 2016) data.

Findings showed lower use of one-piece appliances and a corresponding greater use of two-piece appliances compared with UK PCA data (2016) (Table 2). Regional variations and nurse preferences may account for this anomaly. When ostomy products are free of charge to the end user (UK and Ireland) 2-piece usage tends to be lower as there is not as much incentive to extend pouch wear time as exists in some other, self-funding markets.

The high use of accessory products seen in this study illustrates an often highlighted problem for NHS budgets. Accessories are estimated to have cost the NHS over £53 million in 2012 (Black, 2013).

**Problems**

When asked, 76.6% of respondents reported having problems managing their stoma. While this incidence does appear to be high, other authors have found similar results (Boyles, 2010). Nichols and McPhail (2014) reported that many ostomates were living with extreme problems.

The researchers asked respondents to identify all relevant problems experienced, with 74% overall (96% of those who experienced problems) reporting their current ostomy products leaked at least occasionally. The findings are supported by Erwin-Toth et al (2012), who found leakage to be a common complaint for ostomates. These findings are also supported by Nichols and McPhail (2014), where 87% of respondents from the US, the UK and Italy described how they often worried about leakage, resulting in social isolation for 62% of them. In this study, 18.6% of respondents (24.3% of those who experience problems) reported experiencing sore or itchy skin. It is likely the source of this could be either contact with leaking stoma output or irritation from ingredients contained in stoma care products; the result of which could be silent or frank leakage (Rolstad et al, 2004).

This research also examined respondents' pouch changing routine and the rationale for the timing of pouch changes; 43% reported that they always replaced their pouch on a scheduled basis, with an additional 17% reporting that pouch change can sometimes be scheduled. The remaining respondents reported either always or sometimes changing pouch due to leakage or sore skin, representing 21% and 19% of respondents respectively. When analysing these

results in parallel with problems reported, the frequency of pouch changes relating to leakage or sore skin seem surprisingly low. It is the opinion of the author that it is possible that experienced ostomates develop a routine where they are able to estimate their pouch wear time, thus pre-empting leakage, and as a result they articulate their rationale for pouch change as routine. Hooper (2016) described in great detail the many contributing factors to peristomal skin complications and recognised the levels of under-reporting, under-recognition and lack of treatment.

### Psychological impact

The primary focus of this research was to investigate the psychological impact of stoma surgery (whether temporary or permanent) and how it influences quality of life. It is widely acknowledged that the psychological impact of a stoma cannot be underestimated (Pittman et al, 2009). The freedom of respondents in this research to use their own descriptive words, rather than choosing from a predefined list, provided a wealth of information. With a broad range of pre- and postoperative experiences, individual and personal insights were important to ensure a comprehensive overview of individual journeys.

The high response rate (92.7%) to psychology-related questions is suggestive of ostomates' perception that research in this area is limited. The overall results of 42.8% positive, 28.8% neutral and 36.1% negative were examined in more detail to identify if outlook following surgery is dependent on any of a number of variables, namely age, gender, stoma type, occurrence of problems and time following surgery.

There appears to be some evidence that women cope slightly better than men when living with a stoma, with 44% of women attributing only positive words to their experience, compared with 34% for men. This is a similar finding to Krouse et al (2009), who examined coping strategies of people who had been living with a stoma for at least 5 years. However, they do caution health professionals to be aware of gender variations in coping, as there may be other psychosocial and cultural factors that influence coping mechanisms, such as social roles and responsibilities.

Analysis was carried out on the different attitudes of three age ranges (18–40, 41–

65, 65+); it was observed that the 18–40 age range, while only a small proportion of the overall study, appear to have a more positive outlook than the older age ranges. In the 18–40 age range, 54% of people recorded positive descriptive words, whereas the comparative figures for 41–65 was 38% and for 65+ was 39%. In the lower age range, the positivity could be related to diagnosis or the absence of other comorbidities. Meanwhile diagnosis, treatment plans and age-related comorbidities are more likely to affect those people in the older age ranges in their choice of positive or negative words chosen to describe their situation.

Pittman (2011) found limited evidence to support any correlation between stoma type and the positivity or negativity of how an individual reacts. However, in this study, the examination of stoma type was shown to impact on ostomates' postoperative outlook. Unsurprisingly, people with multiple stomas struggled to describe their experiences with any positive adjectives, with 70% of all words used for this group being negative. People living with a urostomy were found to be the second most likely group of people to describe their life with a stoma in a more negative manner, with 40% using only negative words. It should be acknowledged that a proportion of this study group had their urostomy formed as a result of complications following other surgery. This struggle towards acceptance corresponds with previous studies, which recognised that lack of understanding and preparation for surgery and life with a stoma does have a significant impact on adaptation (Thorpe et al, 2014). This study found a more positive reaction from those living with an ileostomy compared to a colostomy which could be as a result of an improved overall quality of life due to symptom alleviation.

### Stoma care nurse

The impact of a stoma care nurse in the immediate and early stages of a patient's overall recovery is well documented, but it does appear to go further, as it remains an important aspect of longer-term recovery (Persson et al 2005). It is well recognised that the first year following stoma forming surgery is a stressful period and this was backed up with 53% of respondents using mostly/all negative words to describe this time period. It should be noted that ostomates

generally report a more positive outlook as the length of time following surgery increases. Within 1–5 years, only 35% of respondents used any negative words to describe their life following surgery, with this figure dropping further to 33% after 5 years. This aspect of recovery has been examined by Ito et al (2012), who also found that life does continue to improve over the first year following surgery.

In this study, 76% of people reported experiencing problems with their stoma. This is consistent with findings by other authors (Johnson 2012; Davenport 2014). It would be logical to assume that with this extent of problems, respondents would have a negative response when asked to describe their life with a stoma; however, this was not the case. The positively associated words chosen by those with and those without problems were almost identical, suggesting a degree of acceptance that stoma-related problems are an expected by-product of having a stoma.

### Solutions

Where problems were identified, solutions were also sought. Adhering to the Nursing and Midwifery Council (NMC, 2015) Code, each individual respondent was treated with respect, kindness and compassion. Interventions varied, from reconnecting participants with health professionals (not restricted solely to stoma nurses) to recommending more appropriate use of products, while maintaining best practise and clinical experience (Black, 2015). The implications of appropriate product use are known to affect people physically, psychologically, socially and financially. In a climate where pressures are mounting on health budgets, it is essential that all products are used effectively and efficiently. Black (2015) acknowledges that the use of appropriate products can help to ensure a better quality of life for stoma patients.

The role of the stoma care nurse specialist has been an evolving speciality over the last 30 years, with the development of expertise in all aspects of the patient's journey (Association of Stoma Care Nurses UK, 2015). However due to some of the respondents' surgeries predating the implementation of adequate specialist care, some ostomates had never met with a stoma care nurse. The consequence of a lack of follow-up care was that this group of people required some

reassurance that their routine was correct, even though they were not experiencing problems and they had been living with their stoma for many years (Johnson, 2012). Other respondents with more complex needs required re-referral to hospital-based teams.

The collaboration and cooperation that exists in the Northern Ireland Stoma Care Nurse Forum (NISCNF) facilitated these referrals with ease. Davenport (2011) recognised that cooperation between health professionals is key to providing a good service. A significant problem identified was that people did not know where to go for help. At the time, the NISCNF were working with the Northern Ireland medicines management team to develop a formula for appropriate product and accessory use. A map was created, detailing the locations and contact details of where stoma care nurses were based in Northern Ireland. This will be distributed to health centres by the medicine management team for display, which should ensure that stoma care services are easily located.

A common theme found in face-to-face discussions was the need for up-to-date, relevant user information. This information can be delivered through digital platforms. In an evaluation of web-based ostomy patient-support resources, Pittman (2016) recognised that in health-care systems where short hospital stays and fragmented follow-up care is the norm, the availability and accessibility of web-based resources could prove to be valuable in terms of learning and self-management.

As well as the NHS, online support is available from charities, patient support group and product manufacturers. TG Eakin have launched a new stand-alone digital platform for ostomates and their families at [www.abiggerlife.com](http://www.abiggerlife.com). Content is generated by both users and clinical specialists, and stoma-specific information for different time points in a patient's journey is presented in various formats to appeal to individual preferences for learning and absorbing information. A recent review of the site has found that it is meeting the needs of the users. It should be acknowledged that the availability of stoma services is not standardised on a global scale (McQueen, 2014), making it more important for industry to provide clinically robust information and advice on many levels without adding the complexity of direct links to products.



## Conclusion

This study has highlighted that living well with a stoma is dependent on many factors, including age, gender, stoma type, provision of follow-up care and the incidence of complications. Face-to-face contact with ostomates and allowing them to freely describe their experiences of living with a stoma gave a deeper insight into their thoughts and feelings.

Access to up-to-date, relevant information is an ongoing need. This can come from either physical contact with a stoma care nurse or the availability of clinically accurate online information and advice, delivered in short, informative sessions. This type of impartial information delivery supports the information and advice previously given by hospital-based stoma care nurses.

In the UK and Ireland, patients have access to up-to-date ostomy products and follow-up care from stoma care teams; however, the number of people living with stoma-related problems remains high. This study has identified areas that require further research, including a better understanding of why people do not seek help. The author acknowledges the potential limitations of the study, as it is not based on a validated questionnaire. Following review of the available validated questionnaires, the author concluded that, for this study, it was necessary to gain a more basic, real-life understanding of the challenges faced by ostomates. It is the intention of the author to expand this research wider and to consider the use or adaptation of a validated questionnaire, the results of which should help manufacturers provide more targeted support to both nurses and ostomates.

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**Declaration of interest** The authors are employees of TG Eakin

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## CPD reflective questions

- What are the factors that influence ostomates' postoperative quality of life?
- Reflect on how stoma care nurses can assess whether an ostomate is using the most appropriate products for his or her needs
- What are the most helpful online resources available for stoma patients?

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