Quality of life, wellbeing and care needs of Irish ostomates

Fiona Davidson

ABSTRACT
Having a stoma can reduce a person’s quality of life and cause distress. A survey of people in Ireland who have had a stoma for an average of 15 years found that, while they now have a similar quality of life to the general population, they have poorer mental health and a higher level of sexual dysfunction. Respondents want to talk about their experiences and may benefit from more opportunities to talk to others with a stoma or to stoma care nurses. While most patient information suggests that patients can return to their usual diet and their clothes, a majority of ostomates have to make changes in these areas; some dietary changes have implications for their health. Ostomates in Ireland experience continuing problems with leakages and peristomal skin. These issues show there is a need for routine, regular follow up of ostomates by stoma care nurses. Although most patients found follow up by a community stoma care nurse helpful, the provision of this type of service varies.

Key words: Stoma ■ Quality of life ■ Wellbeing ■ Mental health ■ Stoma care nurse ■ Patient information

Having a stoma can cause distress and negatively affect a person's quality of life so that they have difficulties in maintaining their roles in society (Martins et al, 2015).

Quality of life (QoL) can be defined as ‘the general well-being of a person or society, defined in terms of health and happiness, rather than wealth’ (Collins, 2015). In more detail, the World Health Organization (WHO) (1997) describes QoL as:

‘A broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, personal beliefs.’

WHO, 1997: 1

There are no published national statistics for stoma surgery in Ireland, and the author estimates that there are approximately 7000 ostomates—people living with a stoma—in the country, from comparing Ireland's population with that of the UK. It can be reasonably estimated that there are between 1200 and 1400 new stoma patients each year (Irish Stoma Care and Colorectal Nurses Association (ISCCNA), 2009).

Stoma care provision in Ireland varies from hospital to hospital. There are approximately 27 stoma care nurses (SCNs) employed by the Health Service Executive (HSE), with most adhering to the ISCCNA standards of care (2009). There are no sponsored SCN posts; however, many smaller hospitals use a company SCN to fill this role. Most community follow up is carried out by the 18 company SCNs, and the qualifications and experience of these nurses can vary.

Rather than using research from the UK or the USA, the author wanted to understand how ostomates in Ireland felt about their life and what issues, if any, they were experiencing.

Method
Survey design
The survey was designed as a questionnaire with 16 questions related to general demographics and 20 questions specifically concerning the ostomate's adjustment to having a stoma. The final 43 questions were taken from the Modified City of Hope QoL ostomy questionnaire (Grant et al, 2004). This was chosen as it was readily available and had a validated scoring system. Questions relate to physical, psychological, social and spiritual wellbeing.

Ethical approval was granted by the ethics committee at Naas General Hospital, using the national guidelines (HSE, 2011).

Subjects and setting
The 494 members of the Ileostomy Association (IA) in Ireland, all of whom have stomas, were posted the reviewed questionnaire by the association's secretary. No urostomy association or colostomy association was active in Ireland at the time of writing. A further 101 ostomates were sent the questionnaire by five participating SCNs; two of these were HSE staff and three were from Hollister. These patients were chosen by SCNs who were aware that IA members had already received them; it is possible but very unlikely that a few people received the questionnaire more than once.

Results
Responses
Of the potential 595 respondents, 256 people replied. This gave a response rate of 43% and a margin of error of 4.62 with a confidence interval of 95%. Full anonymity was assured. The data were analysed using SAS, v9.2 (SAS Institute, 2002–2008).
Of all the respondents, 39.5% (101) were men and 60.5% (155) women. IA members are predominantly people with ileostomies, and they accounted for 77% (197) of respondents. A total of 20% (53) had colostomies and 1% (3) urostomies, with a further 1% either not knowing or not answering that question. The numbers are broken down in Figure 1.

A diagnosis of cancer was the reason for stoma formation in 22% (55) of those who replied and 51% (129) said that their surgery was due to inflammatory bowel disease. Most of the stomas—92% (233)—were perceived as permanent.

The length of time people had had their stomas ranged from a few months to over 50 years, with the average time being 15 years. Respondents were aged from 18 to 91 years with a mean age of 61.

The author works as a SCN and territory manager with Hollister and has a declared interest in the importance of community follow up. She carried out this research in her own time. Five of the questionnaires were sent to ostomates directly by the author and, although these were anonymously returned, this may have influenced the results from these people.

Reliability
The interim reliability of the data was assessed (Cronhbach’s alpha) on three subsets of the data; wellbeing; social interference; and fulfilment. Cronhbach’s alpha was 0.881, 0.866 and 0.787 respectively.

General questions
The survey asked participants basic questions concerning how having a stoma had affected their lives.

Of those who responded, more than half of respondents (54% ) said they had changed their style of clothing since having their stoma while 46% had not; eight people did not answer.

Similarly, 55% had adjusted their diet and 45% had not; one person did not answer.

A total of 27.6% (69) avoided eating vegetables, 32% (80) did not eat fruit and 49.6% (125) avoided fizzy drinks.

More than half of respondents 59% (146) belonged to a stoma support group, while 41% (102) did not.

Community stoma care
Only 54% (137) of respondents said they had been seen by an SCN at home, leaving 46% (117) who had not. Two people did not answer. Participants were not asked whether they had received follow up at hospital.

Of those seen at home by a community SCN, 95% (127) found this quite or very helpful.

When asked how long it took to feel comfortable with their stoma care, of those who answered, 45% (114) of people said it took over 6 months with 6% (16) stating that they have never felt comfortable with their stoma care (Figure 3).
Mental health

WHO (2016) defines depression as:

‘A common mental disorder, characterised by sadness, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, feelings of tiredness and poor concentration.’

WHO, 2016

Participants were asked whether they had felt depressed in the first 6 months after having their stoma. Fewer than 4% (10) of those who answered said they had felt suicidal because of their stoma. Over 96% (241) said they had not, although 25% (64) had felt somewhat depressed, 19% (48) said seldom and 15% (38) said very depressed 41% and (106) said not depressed. (Figure 4). These figures exclude the five people did not answer this questions.

Participants were also asked how depressed they felt at the time of responding to the survey (Figure 5).

Sexual activity

The ostomates were asked if they were sexually active before and since having their stoma (Table 2).

Of the 138 people who said that they had resumed sexual activity, 81% (110) said it was satisfying, 16% (21) said it was not and 3% (4) answered ‘not applicable’. Three people did not respond.

They were asked later if having a stoma interfered with their ability to be intimate, Figure 6 details the responses. A total of 21 people did not answer the questions.

More than half (53%) of the 101 men surveyed said they experienced problems getting or maintaining an erection; 42% reported they did not (Table 2). Participants were not asked if there had there been a change since having the stoma.

Physical issues

A majority of participants experienced minor or no problems with the skin surrounding the stoma; however, move than one third experienced moderate to severe problems (Figure 7). These figures were broadly similar for problems with leaking from the pouch (Figure 8). More participants reported problems with wind/gas; while 49% reported no or minor problems, 35% said this was a moderate problem and 15% said this was severe (Figure 9).

Overall quality of life

When asked specifically how they rated their own QoL, the majority (69%, 177 respondents) said it was good to excellent, with 25% (63) saying it was moderately good and 6% (15) saying it was poor (Figure 10). One person did not answer.

Discussion

These results are a snapshot only of how people with a stoma felt at the time of answering the questions. It is important to realise that many of the respondents are members of the IA and have had their stoma for a several years, which may positively affect how they remember their ability to cope both physically and emotionally with their stoma.

The few QoL studies available are not based on the same set of criteria, such as types and reason for stoma, which makes it difficult to compare them directly and even more difficult to compare them to the population at large. However, these results are in keeping with Nichols’ (2015) findings in a much larger study of ostomates in the USA, which found that people with a stoma have a similar QoL to those in the general population.
When split into the four domains of physical, psychological, social and spiritual wellbeing, the answers were analysed and found to be consistent with other studies, albeit a limited number of them (Gemmill et al, 2010; Maydick, 2014). This would indicate that the QoL of people in Ireland with a stoma is within the normal limits.

It is interesting to see that much of the information on diet given to patients with a stoma suggests that most people can return to eating a normal diet, with an awareness that different foods have effects on their output (Burch, 2008), this includes company leaflets e.g. Hollister (2011), Salts Healthcare (2016). However, these Irish QoL survey results show that the majority made changes to their diet. Shorter hospital stays, patients being told a lot information in a short space of time, the lack of availability of dietitians and the need for reiteration of information once at home may all affect how people view their diet. With more than 27% of people stating they avoided eating vegetables and 32% not eating fruit, there could be effects on ostomates’ health as the NHS Live Well campaign recommends that people should eat at least five portions of fruit and vegetables a day to reduce the risk of conditions such as heart disease, stroke and certain cancers (Department of Health, 2003).

Similarly, many of the leaflets SCNs give their patients (for example, SecuriCare Medical (2016)) suggest that an ostomate should be able to continue wearing their own clothing, with perhaps only slight changes if at all (Porrett, 2005). The results of this survey show that a majority of people have had to change the style of their clothes and concur with Claessens et al (2015), who found that 57% of participants in their study limited their choice of clothing.

The results show that 46% of people were not followed up at home by a SCN, although 95% of those who received this follow up found it helpful. The respondents to this survey have had their stoma on average for 15 years. However, today, many people are discharged home from hospital in a shorter postoperative time. Initiatives such as enhanced recovery mean people have less time in hospital to come to terms with having a new stoma. As Williams (2007) suggested, the reduced time spent with the hospital SCN is often concerned with getting the patient to manage their stoma care and, as a result, they may have less time to educate patients on the prevention of stoma complications. In addition, as Black (2009) pointed out, it is often when a new ostomate is at home that the full impact of having a stoma is realised. This is supported by Marquis et al (2003), who felt that support in the initial weeks following discharge is critical to patients achieving a good QoL. Porrett (2005) recommended that people are seen at home within the first 48 hours to a week after discharge home to assess how well they are dealing with their new stoma and to act promptly on any potential problems. It has also been suggested that routine home visits, rather than a problem-focused approach, can prevent significant stoma-related morbidity by identifying problems ostomates do not realise they have (Johnson, 2012).

Davenport (2014) expanded on this, suggesting the use of a structured home support system, which would be enhanced if patients were reviewed again at 3 and 6 months after surgery. This home support has been shown to not only benefit people with a new stoma but also cut costs to the health service through reducing readmissions, GP visits, and outpatient appointments and through a decreased waste of products (Davenport, 2014).

The effectiveness of hospital follow up was not part of this
areas have group IA meetings, for others the IA in Ireland may be seen as more of a helpline and a way of getting information through the journal and the biannual national conference. More than half (65%) of respondents said they had had the opportunity to talk with someone else who had a stoma. A comments page was included at the end of the survey so people could add anything they wanted to say and more than a quarter of those who replied left comments, many very detailed and many very positive. This demonstrates that people are more than willing to talk about their experiences and may need an outlet to do so. This reinforces the findings of Danielson et al (2012), who found that people with stomas wanted to get together to learn and to aid self-empowerment. This is similar to the findings Cross et al (2010) who suggested that:

‘Support groups seek to offer an environment that instils hope, promotes understanding and enables acceptance … advice from peers is valuable and may be more readily accepted than counselling from health care professionals who typically have not lived with the disorder faced by the patient.’

Cross et al, 2010: 393

This study shows a higher rate of sexual dysfunction than in the general population in that over half of the men who responded (56%) said they had issues with erectile dysfunction (ED); 186 people (77%) said they were sexually active before getting a stoma and 44 (18%) said they were not. Of those who answered, 70 (30%) had not resumed sexual activity since having their stoma formed (Table 2). Of the 138 people who had, 110 (81%) said that their sexual activity was satisfying, 21 (16%) said it was not.

This is also higher than it was in a similar study, made up of higher number of people with a colostomy, which showed 40% of men had ED (Anaraki et al, 2012). The National Medicines Information Centre (2007) defined ED as the consistent inability to attain or maintain penile erection for satisfactory sexual intercourse and suggested that one in ten Irish men experience the condition. The prevalence in the general population increases with age to 18% of men aged 50–59 and to 38% of men aged 60–69. The mean age of men in this study was 66. Many health factors can be involved in ED, including diabetes and heart disease, and it has been suggested that sexual function can be worse for those who have had a stoma formed owing to colorectal cancer than those who have stomas formed for other reasons (Reese et al, 2014). While it is known that surgery such as an abdomino-perineal excision of the rectum and treatment with radiation can cause nerve damage, only 21 of the 101 men who responded (56%) said they had issues with erectile dysfunction in the general population in that over half of the men who responded (56%) said they had issues with erectile dysfunction (ED); 186 people (77%) said they were sexually active before getting a stoma and 44 (18%) said they were not. Of those who answered, 70 (30%) had not resumed sexual activity since having their stoma formed (Table 2). Of the 138 people who had, 110 (81%) said that their sexual activity was satisfying, 21 (16%) said it was not.

This is also higher than it was in a similar study, made up of higher number of people with a colostomy, which showed 40% of men had ED (Anaraki et al, 2012). The National Medicines Information Centre (2007) defined ED as the consistent inability to attain or maintain penile erection for satisfactory sexual intercourse and suggested that one in ten Irish men experience the condition. The prevalence in the general population increases with age to 18% of men aged 50–59 and to 38% of men aged 60–69. The mean age of men in this study was 66. Many health factors can be involved in ED, including diabetes and heart disease, and it has been suggested that sexual function can be worse for those who have had a stoma formed owing to colorectal cancer than those who have stomas formed for other reasons (Reese et al, 2014). While it is known that surgery such as an abdomino-perineal excision of the rectum and treatment with radiation can cause nerve damage, only 21 of the 101 men who responded gave a diagnosis of cancer as the reason for their surgery.

Problems with peristomal skin have been well documented, with Notter and Chalmers (2012) stating that almost two thirds of people have skin soreness or damage. This Irish QoL is in keeping with this, finding 34% of respondents have moderate to severe skin problems and 34% have moderate to severe issues with leakage. This is of concern, as most of the ostomates in the study have had their stomas for a long time. It is difficult to know why so many people have ongoing problems and do...
not contact an SCN. This may be owing to several reasons; for example, as many have had their stoma for a long time, they may not be aware of the availability of SCNs or they perceive these issues to be a normal part of life with a stoma.

A further issue that arose from undertaking the study was that there is no national ethics committee in Ireland for non-clinical research. However, many hospitals use the same forms and criteria. This is under review, with the Health Information and Quality Authority (2012) stating there ‘is a need for standardisation and a single application process’ for such research. The author feels this may have been a contributing factor as to why some HSE SCNs felt unable to facilitate the study and may have limited the access to a wider range of ostomates for the research.

Conclusion
The study showed that, although most people felt they have a good quality of life, it took 45% of people over 6 months to come to terms with their stoma care. It also highlighted the well-documented and ongoing issues people with a stoma have concerning their skin, leakages and odour. Community follow up varies; only just over half of those asked were visited at home by a community SCN although 95% of those found it helpful. Home stoma care nursing has been proven to be cost effective for the health service, beneficial to the ostomate and best nursing practice.

The survey found that the overall quality of life of people in Ireland with a stoma is within normal limits; however, the mental health of Irish ostomates appears to be poorer than the national average. Respondents to this questionnaire desired to talk about their experiences and could benefit from more opportunities to talk to other people with a stoma, such as those in self-help groups. Regular follow up by SCNs may also give ostomates opportunities to discuss their life with a stoma.

Although most of the information leaflets given to patients suggest ostomates should not have to make too many adjustments to what they wear, the results of this survey showed that most people have made changes to their style of clothing. Also, many of the leaflets SCNs give their patients suggest that most people with a stoma should be able to go back to eating their normal diet, yet the results of the survey demonstrate that most people have had to make changes to their diet. Because the majority of ostomates questioned had to make changes to their diet and clothing, this should be reflected in the information they are given and literature they are given.

With regards to sexual activity, ED was found to be a problem in 50% of the men questioned, a higher number than anticipated by a community SCN although 95% of those found it helpful. Home stoma care nursing has been proven to be cost effective for the health service, beneficial to the ostomate and best nursing practice.

A system of national statistics and a national ethical approval system would have been beneficial for this research. However, the findings still have implications for the care and information SCNs give their patients. The results show that people in Ireland with a stoma have continuing leakages and peristomal skin issues. This, together with their poorer mental health, highlights the need for routine, regular, ongoing follow ups of ostomates by SCNs.

BJN

KEY POINTS

- People in Ireland with a stoma have a similar quality of life to those in the general population
- The mental health of ostomates appears to be poorer than the national average, and ostomates experience greater rates of sexual dysfunction
- A majority of people make changes to their diet and clothing after a stoma is formed, and this should be reflected in the information they are given
- To help them adjust to having a stoma, patients should be offered opportunities to talk to other ostomates, possibly through a self-help group, or a stoma care nurse
- Ostomates experience continuing problems with leakages and peristomal skin; why they are not seeking help needs to be addressed
- Follow up support in the community after hospital discharge varies, even though there is a clear need for it and it is valued by patients

Declaration of interest: the author is a stoma care nurse in both the acute and community setting for Hollister Limited

Acknowledgements: thanks to all those who responded to the questionnaire; Catherine Hughes, Director of Nursing at Naas Hospital and the members of the ethics committee for taking the time and energy to consider and give their approval to this research; Cepta Burke, secretary of the IA Ireland for her encouragement and for posting out the survey to her members; SCNs Susan Moore, Mary Quigley, Rosemary Roue and Frances Gargan who assisted with the distribution of the survey; Thom Nichols, biostatistician at Hollister, for his statistical analysis and patience in helping the author to understand the numbers and their significance; Maire Reilly, Hollister Ireland, for funding the printing and posting of the questionnaires; and Geraldine Hogan and Simon Figg for assisting with data entry.

Addis G (2003) The effects of home visits after discharge on patients who have an ileostomy or colostomy. World Council of Enterostomal Ther J 23(1): 26–33

© MA Healthcare Ltd. Downloaded from magonlinelibrary.com by Karin Thumeyer on June 19, 2017. Use for licensed purposes only. No other uses without permission. All rights reserved.
Develop your management and team building skills with this concise, practical book

Jean Bayliss

This book aims to offer an insight into what makes teams work. In this text you are offered the opportunity to reflect on various points as you proceed, and spaces are left for you to write your comments if you wish, or you might prefer to keep a reflective journal. Whether you are a team leader or a team member reflecting on your role and contribution to your care team will help to bring the insight which is critical for the care provided. Topics covered include:

- What is a team
- What goes on in a team
- What makes for effective teamwork and what are the obstacles?
- Leadership and management of a team
- Working with conflict
- Effective negotiation
- Developing as an individual
- Integrating new members
- Enhancing the team’s effectiveness to enhance patient care


Order your copies by visiting www.quaybooks.co.uk or call our Hotline +44 (0) 333 800 1900*

Working in a team

A workbook to successful dynamics

Jean Bayliss

and psychometric testing of the City of Hope Quality of Life-Ostomy Questionnaire. Qual Life Res 13(8): 1445–57
Health Service Executive (2011) Standard Application Form For The Ethical Review of Health-Related Research Studies, which are not Clinical Trials of Medicinal Products: For Human Use as defined in S.I. 190/2004 (accessed 19 August 2016)