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Bowel Symptom Experiences and Management following Sphincter Saving-Surgery for Rectal Cancer: A Qualitative Perspective

Abstract

Purpose of research: The aim of this research was to explore participants' qualitative perspectives on bowel symptom experiences and management strategies following sphincter saving-surgery for rectal cancer.

Methods and sample: The data presented in this paper were gleaned from a semi-structured question that formed part of a larger multi-site quantitative correlational study. From a sample of 143 participants, a total of 77 (62.6%) males and 46 (37.3%) females provided qualitative comments. Participants aged 30 to 70 and beyond had undergone sphincter saving surgery for rectal cancer in the past 3 to42 months. Data were analysed within the contexts of symptom management theory and the common sense self-regulatory model. .

Key Results*:* The findings illustrated the subjective nature of the bowel symptoms experienced. The findings also highlighted the bowel symptoms that were most problematic and the effect of these symptoms on participants' daily lives. In addition, the self-care strategies that worked best for individual participants in the management of bowel symptoms were identified.

Conclusions: There is a need to educate patients on the short-term temporary as well as the long-term more permanent bowel symptoms experienced following sphincter saving surgery for rectal cancer. Nurses have an important contribution to make in facilitating patients to choose from a range of self-care strategies to help them manage their bowel symptoms postoperatively.

Key Words: Bowel symptoms, colorectal cancer, sphincter saving surgery, symptom experience, self-care strategies.

Introduction

Anterior resection with preservation of the sphincter function has now become the gold standard treatment for rectal cancers (Inoue and Kusunoki, 2010). While this surgical procedure leaves an intact anal sphincter, research has shown that participants suffer a number of problematic bowel symptoms. The main symptoms reported were faecal incontinence, bowel frequency and bowel urgency (Guren et al, 2005; Inoue, and Kusunoki, 2011; Vironen et al, 2006). In addition, longitudinal studies highlighted that diarrhoea and constipation were problematic for participants at 12 months (Schmidt et al, 2005) and at 15 months following surgery (Grumann et al, 2001). Bowel function after sphincter saving surgery depends on a number of factors (Taylor and Morgan, 2011). The level of anastomosis may have relevance and the fact that some participants have a temporary ileostomy during the earlier postoperative period.

However, a dearth of published research exists on the affects of these symptoms on individuals' lives and on the self-care strategies used to manage symptoms.

This knowledge is important for clinicians as there may be a gap between health care professionals' andpatients' perceptions of the nature, duration and consequences of bowel symptoms. Furthermore, it is also possible that some of the strategies adopted by patients to manage bowel symptoms may be ineffective or health damaging. The purpose of this paper is to present findings from qualitative comments provided by participants who participated in a multi-site quantitative study on bowel symptom experiences and symptom management strategies following sphincter saving surgery for rectal cancer. From a sample of 143 participants, a total of 77 (62.6%) males and 46 (37.3%) females provided qualitative comments. Participants were aged 30 to 70 years and over, had undergone sphincter saving surgery for rectal cancer in the past 3-

42 months (Table 1). Most participants (n=91)were married or living with a partner, were employment status varied from unemployed (n=7) retired (n=51) and the level of education achieved ranged from none (n=1) to secondary (n=51) (Table 1).

Methods

The data presented in this paper are drawn from the qualitative analysis of a broad semi-structured question as part of a larger quantitative multi-site study. The semi-structured question sought to identity the bowel symptoms that were most problematic for participants, in terms of the affect of these symptoms on their everyday lives and the management strategies adopted to manage symptoms.

Sample

A convenience sample across a total of 10 sites specialising in colo-rectal cancer in Ireland was chosen for the study. Individuals were eligible for inclusion in the study if they were a minimum of 6 weeks and a maximum of 42 months following sphincter saving surgery for rectal cancer. In addition, individuals were eligible for inclusion if they were not receiving palliative care and did not have recurrence of their disease. Both men and women over the age of 30 were considered for inclusion in the study. A total of 123 eligible participants provided qualitative comments.

Ethical considerations

Ethical approval was obtained from six ethical committees associated with ten hospitals in Ireland. When inviting individual participants to take part in the study by mail, they were provided with an information leaflet about the study and what their involvement would mean. Individuals who agreed to participate completed a consent form. All participants were assured that anonymity and confidentiality would be

maintained. The 123 participants who provided qualitative comments were numbered accordingly.

Data Collection

Qualitative data were collected using a broad semi-structured question. The question sought to identify the bowel symptom most problematic for patients (symptom perception), the effects of bowel symptoms on their daily life, (symptom evaluation and response) and the effectiveness of self-care strategies adopted to manage symptoms (symptom management).

Data analysis

The semi-structured question resulted in vast amounts of data (in excess of 122 pages which included additional typed pages from some participants). The symptom management theory (Dodd et al, 2001; Humphreys et al, 2008) which was the principal theoretical framework for the larger study provided a framework for analysing the qualitative data. The symptom management theory posits that there is a relationship between symptom experience and symptom management strategies. This theory includes the dimensions of perception (awareness of symptoms occurrence), evaluation (cause, severity, and treatability) and responses (psychological, social and physiological). Because patients were not asked to provide qualitative comments on what they believed were the causes of their bowel symptoms, "the cause dimension" was not included as a pre-determined category in this analysis. Three additional dimensions relating to symptom experience (identity, consequences which incorporates severity and timeline) from the Common-Sense Self-Regulatory Model (Leventhal et al, 2003) were included.

Data analysis was guided by the principles of deductive content analysis. In this type of analysis, data is coded according to categories, which have been constructed from prior knowledge (Elo and Kyngas, 2007). In the current study, transcripts were coded using the predetermined categories of the study's theoretical framework. Credibility of findings was established by independent review. A subsample (10%) of responses was read by an independent reviewer to verify the emerging themes and pre-determined categories.

Findings

Symptom Experience

Symptom experience was considered with reference to bowel symptom perception, bowel symptom evaluation, and bowel symptom responses.

Bowel symptom perception

Bowel symptom perception was defined as bowel symptom awareness of bowel symptoms identity and bowel symptoms occurrence.

According to Leventhal et al, 2003), the identity of a symptom is confirmed when the symptom can be named and described. In the current study, bowel symptoms identity refers to the identification of bowel symptoms that patients experience following sphincter saving surgery. The most common symptoms identified by patients in the qualitative data included faecal incontinence, bowel urgency, flatus, diarrhoea, constipation and inadequate evacuation. The semi-structured question

provided an opportunity for participants to express the problematic nature of the bowel symptoms experienced, and which was found to vary among participants as evident in the following quotations: "the most difficult is dealing with incontinence," (Participant: 37).

.

:

"my bowel symptoms are caused by diarrhoea" (Participant: 83).

"constipation is the most problematic symptom" (Participant: 47).

Some participants experienced more than one bowel symptom:

"I find that flatulence and diarrhoea are the most problematic symptoms since my bowel surgery" (Participant: 76).

Bowel symptoms caused additional problems for participants. For example, one participant stated:

"I have discomfort in the back passage at almost all times and this can become very sore during bowel movement especially if somewhat liquidity" (Participant: 89).

For other participants, inadequate evacuation was a problem. As stated by one participant:

"…bowel doesn't empty when I use bathroom" (Participant: 8).

These comments highlighted the varied experiences of patients in terms of3 the bowel symptoms experienced following sphincter saving surgery.

Bowel symptom occurrence was described in terms of bowel symptom frequency. The qualitative data provided by participants suggested that the frequent and often unpredictable nature of the bowel symptoms experienced were a concern for most participants. One participant commented on having diarrhoea on a regular basis:

"when I get diarrhoea it lasts 2 days. I usually get it once a fortnight" (Participant: 19).

In addition, participants reported experiencing bowel problems at night as well as during the day, indicating that participants were never totally free from bowel symptoms. Another participant reported that despite his best efforts he continued to experience irregular bowel pattern:

> "the main issues are that I can go a few times daily and it is very hard to regulate it. My movements are very small & I could have 6 - 7 of these in one hour. Also I get sore from using toilet paper and find it better to shower after movements". (Participant: 24).

A link between unpredictable bowel symptoms such as diarrhoea and specific food types was made by some participants. For example, the affects of foodsconsumed could vary from having no symptoms to having symptoms such as episodes of diarrhoea at other times:

> "the unpredictability (sic) has been most problematic for me, sometimes certain foodstuffs cause no reaction and other times the same food stuff runs through me. I have no confidence in any food stuff being "risk free" (Participant: 05).

Another participant wrote of his experience:

> "somedays I have to go to the toilet frequently..… I may have to go again in 30 minutes1hr. The one thing that I have noticed is how much flatus I am omitting – sometimes the flatus is uncontrollable" (Participant: 109).

Bowel Symptoms Evaluation

Consequences of bowel symptoms

Although a range of bowel symptoms were reported, little is known from research to date about the overall affects of symptoms on individuals following sphincter saving surgery or about how they manage these symptoms on a day to day basis. The consequence dimension reflects not only patients' beliefs about symptoms severity

but also the likely impact of these symptoms on their lifestyles. One participant recounted how his bowel symptoms had major consequences on his daily life:

> "what I found most distressing is that all my daily plans depend on my toilet habit and must plan accordingly …for many months after my 2nd surgery (reversal of stoma), I could not leave the house and became somewhat agoraphobic, I had never experienced this before my 2nd operation"
>
> (Participant: 51).

The affects of bowel symptoms also caused difficulties for participants when undertaking routine tasks with those close to them. As one participant recounted:

> "the biggest problem I have with my bowel is when I walk any distance to go shopping with my wife I will have to be sure there is a toilet somewhere close to clean myself"
>
> (Participant: 50).

However, for some participants, bowel symptoms did not seem to have a major impact on their lives as illustrated in the following comments:

> "most of the time the symptoms do not interfere with my lifestyle"
>
> (Participant: 113).

> "I was one of the lucky people that got over my surgery quickly with little or no side effects of bowel symptoms" (Participant: 59).

Bowel symptom timeline

Timeline was expressed in terms of the enduring or transient nature of bowel symptoms experienced. In the following comment, concern about the enduring nature of bowel symptoms is illustrated by a patient who was 24 months post surgery:

> "I often wonder if I will have these symptoms for the remainder of my life"
>
> (Participant: 21).

For some participants, bowel symptoms had improved over a period of months. Signs of improvement included a decrease in symptoms such as frequency and urgency of bowel motions. For example, one participant stated:

> " I feel very good 6 months after operation and can do a full day's work (12 hours)"
>
> (Participant: 68).

The transient nature of bowel symptoms was also evident in the comments made by participants who had undergone a reversal of a temporary stoma following treatment for rectal cancer. These participants who had a temporary ileostomy following surgery noted that they had experienced short-term bowel symptoms. However, even though altered bowel function was experienced after closure of the stoma, participants reported that symptoms had improved over time. One participant commented on his experience:

> "after removal of stoma bowel symptoms persisted for a while but problems gradually almost disappeared" (Participant: 54).

Another stated:

> "for the first 3 months after my operation for the reversal of the stoma I had very loose movements in my bowel and a lot of pain in my rectum. This improved dramatically to the point where it is now close to normal as possible" (Participant: 18).

In contrast, others did not appear to be overly affected by their symptoms and seemed confident that their bowel symptoms would improve over time, as illustrated in the following comment:

> "no problems really - just notice bowel movements are slower, so a little time and patience needed on going to the toilet" (Participant: 70).

These comments illustrate the varied bowel symptom experiences of participants in terms of timeliness following sphincter saving surgery.

Bowel Symptom Treatability

Bowel symptom treatability refers to the anticipated and perceived ability to control bowel symptoms. Poor bowel control was a problem for participants in the early postoperative period. As one participant commented:

> "… I had surgery in April it was a nightmare for months. I had no control"
>
> (Participant: 99).

The unpredictable nature of the bowel symptoms experienced challenged participants' best efforts to control them. One participant had difficulty controlling diarrhoea:

> "I have tried everything to control it, but most of the time nothing works"
>
> (Participant: 85).

Another participant gave his experience:

> "the one thing that I have noticed is how much flatus I am omitting (sic) – sometimes the flatus is uncontrollable"

Findings also illustrated that over time; participants had gained confidence and had learned to control their bowel symptoms.

For example, one participant stated:

> "in the early days getting control of bowel movements was difficult. Now I may go up to six times a day at times but can delay the need until I find a toilet"
>
> (Participant: 113).

Bowel Symptom Responses

The effects of bowel symptoms on participants' daily lives were also explored in terms of participants' psychological, sociological and physiological responses to

them. The current study highlights patients' overall and ever changing responses to the unpredictable nature of the bowel symptoms experienced.

Psychological Responses

Participants described psychological responses regarding lack of control over their bowel function. For example:

> "Sometimes there is an unfinished feeling which is somewhat distressing" (Participant: 109).

Another participant stated:

"…sometimes the flatus is uncontrollable and this can be embarrassing" (Participant: 109).

Comments also highlighted that participants' fears of faecal incontinence were intensified in social situations, as illustrated in the following comments:

> "during social activities I am anxious that I might have an unpredictable bowel movement". (Participant: 100).

> "after surgery (for 2-3 weeks) I was nervously anxious concerning bowel movements …….. bowel movements were erratic for the first 3-4 weeks & this made me anxious" (Participant: 74).

Social Responses

Social responses concern the adjustments participants made to manage unpredictable bowel function, when out socially. Participants expressed a sense of anticipation with having to constantly know the location of the nearest toilet

One participant's response was that:

> "when I am socialising I find I need to use the toilet far more often than most folk" (Participant: 37).

Some participants commented that because of bowel symptoms, leisure activities were restricted. While there might have been expectations of returning to normal life following surgery, some participants experienced no freedom from the unpredictability of bowel symptoms as illustrated in the following comment:

> "my life has changed and so far my social life is a thing of the past. I have no desire to eat out or the energy or the heart to commit to functions… to sit through a play or a film as to do so means I don't eat beforehand…."
>
> (Participant: 101).

Work life was also affected:

> "the need to visit the toilet a number of times within a short space of time on some occasions. This can be a real nuisance when I am at work"
>
> (Participant: 12).

One participant summed up her experience of what it was like to live with unpredictable bowel symptoms:

> "„all my daily plans depend on my toilet habit and must plan accordingly"
>
> (Participant: 51).

The above comments reflect the social challenges that participants faced following sphincter saving surgery. They also faced difficulties in discussing their problems openly with others:

Needs a quotation to support this claim – OR else DELETe.

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Physiological Responses

Physiological responses relate to the physical effects of bowel symptoms experienced. Even though a disease may be effectively treated, symptoms may

place additional physical demands on patients following treatment. One participant commented:

> "I feel the need to go to the toilet but no excretion occurs this results in frequent visits to the toilet that are really unnecessary" (Participant: 31).

Sleep disturbance was also reported;

> "occasionally sleep was disturbed because of the need to visit the toilet" (Participant: 99).

The physical effects of interrupted sleep were articulated by another participant:

> "… having to go to the toilet a number of times during the night. This affects my sleep patterns and ultimately causes tiredness and fatigue" (Participant: 105).

This in turn affected this participant's ability to carry out his daily activities.

Although participants were hopeful of improvements regarding the physical responses experienced following surgery, there was a realisation that their physical status would never be the same as that prior to surgery:

> "I hope my physical condition will improve but realise it will never be what it was" (Participant: 101).

Self-Care Strategies

Functional self-care strategies

Self-Care strategies were explored from the perspectives of "functional self-care strategies"; "activity related self-care strategies" and "alternative self-care strategies"; "self-care strategies". Functional self-care strategies focus on the strategies participants use to manage bowel movements. These were described by participants as diet and fluid modification, bowel medication such as laxatives and fibre forming preparations, and the wearing of protective pads, or clothing. Relating to diet, many

participants reported that they adhered to specific types of diet. For these participants, it meant avoiding the foods that aggravated symptoms. One participant reported that:

> "in an effort to control flatus ..avoided fizzy drinks and pulses" (Participant: 15).

For others, it meant avoiding sweet foods, for example:

> "When I eat a lot of sweet food – e.g. chocolate, cakes etc. - I get diarrhoea so as a result I avoid these foods" (Participant: 13).

Participants also tried different food types which were effective to some degree. One participant stated that:

"I eat a lot of apples, bananas, puddings like rhubarb I find very good. My visits to the toilet can be 3-4 times a day as bowel don't seem to empty but I manage and hope for the best" (Participant: 17).For others, it was the timing of food intake relative to their social events, for example:

> "toast for breakfast if I was going out early morning & have something later. It is just a matter of trial & error and getting to know what helps food wise"

Another participant stated that he now "limits eating to home" (Participant: 5).

This participant went on to say that he had no confidence in the benefit of any of the foods he consumed:

> "sometimes they work sometimes they don't" (Participant: 5).

Medications were taken by many participants to manage bowel symptoms. The most frequent self-care strategy was medication that participants could administer themselves when they felt it necessary. A number of participants took loperamide to manage diarrhoea. For example, one participant stated that this medication was very helpful:

"I have found imodium (loperamide) to be very effective in controlling the symptom (diarrhoea)" (Participant: 30).

Prophylactic use of anti-diarrhoeal medication also allowed for a good night sleep:,

"inability to stop bowel motions, particularly by night. My surgeon suggested using imodium (loperamide), and I have found this helpful, mainly by enabling me to get an undisturbed night's sleep sometimes" (Participant 14)

The medication chosen was dependent on the type of bowel symptom experienced.

For example, one participant who suffered from constipation stated:

"when constipation occurs I take novicol pres (prescribed) by doctor. I repeat 3-4 days, it is very easy to take and works slowly" (Participant: 18).

Participants' comments indicated that they experienced day to day difficulties with having to live with unpredictable symptoms such as faecal incontinence. Participants wore protective pads to prevent the discomfort associated with faecal incontinence. One participant described this strategy as a way of feeling safe:

"wear pads when away from home it gives peace of mind" (Participant: 32).

Another participant commented on the security of protective pads while she slept:

"I share a house so I have a private store of baby wipes, face cloths and soothing creams so I can always cope with incontinence…..
I sleep with a sanitary pad to avoid soiling" (Participant: 15).

Participants' comments indicated that they tended to draw on experiential knowledge acquired over time in their efforts to manage bowel symptoms. For example, participants had gained an understanding of the nature of their bowel symptoms and when they needed to take precaution to prevent unnecessary embarrassment.

One participant gave her experience:

"The use of pads when not at home gives peace of mind but I don't always wear one as I have learnt which days are going to be problematic – I can tell once I am up & made my first visit to the toilet" (Participant: 33).

Activity Related Self-Care Strategies

Activity related self-care strategies described by participants were the actions that they used to manage bowel symptoms in social situations. Participants were constantly fearful of the risk of becoming incontinent. This was particularly the case in social situations, leisure activities and when at work. As a result, participants took special precautions to prevent accidents occurring when out socially. The time spent outside the home was carefully calculated so that the risk of an episode of incontinence would be prevented. For example, one participant reported that he:

"avoids breakfast to allow for 'safe travel to work" (uses public transport)" (Participant: 11).

The location and availability of a bathroom was an important consideration when participants were away from home. Social events were difficult because of the perceived fear of an episode of incontinence, as one participant recounted:

"when I am socialising I find I need to use the toilet far more often than most folk. However most of my friends know I am recovering from bowel cancer and understand. The most difficult is dealing with incontinence, especially at night when I have to clean up without disturbing the household" (Participant: 15).

Another participant stated that:

"bowel does not seem to be empty, when I use the bathroom may have to use toilet four or five times " (Participant: 17).

The constant anticipation of the next episode of incontinence and the need for immediate access to toilet facilities often prevented people from returning to work. One participant reported that because his work involved travel, he could not return to

his former employment because he was worried that he would not always have access to a toilet. One participant summed up how she manages unpredictable bowel symptoms:

> ".. eliminate deadlines and manage schedules"
> (Participant: 106).

Alternative Self-Care Strategies

Only a small number of participants used alternative or complementary medicines, which were identified as vitamins, herbs, bacterial cultures or bowel cleansing agents in the form of tablets, powders or liquids. Other strategies included maintaining 'a positive mental attitude' bio-energy, spirituality, self-belief and yoga. One participant stated that he

> "used alternative medical "viridian" tablets to aid digestion & control gas. Still experimenting with this approach" (Participant: 54).

Another participant used a number of alternative self-care strategies including:

> "bio-energy therapy, spirituality, self-belief and yoga" (Participant: 21).

Some participants adopted a positive mental attitude which led them to feeling positive and in control about the impact of symptoms on their lives: "since I am a retired person, I do not allow my symptoms rule my life

> and I take each day as it comes, come what may" (Participant: 91).

Participants made considerable effort to integrate the management of their symptoms into their every day lives. Participants' comments demonstrated a determination to live as normal a life as possible while attempting to manage a number of problematic bowel symptoms which in some cases can persist up to three years postoperatively.

Discussion

Symptom experiences and symptom management strategies of patients following sphincter saving surgery for rectal cancer were explored using the dimensions of bowel symptom experiences and symptom management strategies framework. Bowel function after sphincter saving surgery depends on a number of factors including the level of anastomosis (Camillerri–Brennan and Steele, 1998) and the fact that some participants have a temporary ileostomy during the earlier postoperative period (Taylor and Morgan, 2011).

Bowel Symptoms Perception

The qualitative data gleaned from this study suggest that participants experience a number of bowel symptoms following sphincter saving surgery for rectal cancer such as faecal incontinence, flatus, diarrhoea and constipation. Consistent with other studies (Desnoo and Faithfull, 2006; Simpson and Whyte, 2006), faecal incontinence was the most frequently reported symptom in the current study. However, additional symptoms not evident in earlier studies were identified by participants in the current study which included inadequate bowel evacuation, abdominal cramps, tenesmus, anal discomfort and the fact that bowel movements took a long time.

Findings from other studies also highlighted that despite treatment for cancer, patients continue to suffer problematic symptoms postoperatively. For example, Olsson et al (2007) found that patients suffered gastrointestinal (GIT) symptoms such as pain and indigestion at 3 and 12 months post upper GIT surgery that were similar to the symptoms they experienced prior to treatment. However, some participants in the current study commented that they continued to suffer poor bowel control such as irregular bowel pattern and urgency two to three years after their surgery.

Bowel Symptoms Evaluation

The "consequence dimension" reflects patients' beliefs about and the consequences of bowel symptoms on a patients' life. Similar to Bertram et al's (2001) study, which explored patients' perspectives of irritable bowel syndrome, the frequent and unpredictable bowel symptoms experienced by participants in the current study, impacted on lifestyle. For example, one participant recalled how his bowel symptoms had major consequences for him as he was unable to leave his house due to unpredictable bowel function. In contrast, other participants reported that their symptoms did not have a major impact on their lives, highlighting again the individual and often enduring nature of the bowel symptoms reported.

Timeline was expressed in terms of the enduring or transient nature of bowel symptoms experienced. According to Leventhal et al (2003) the timeline is guided by the beliefs held in regard to 'timelines' for the development and duration of the disease and how it is perceived in terms of 'felt time'. Camilleri-Brennan and Steele, (2001) concluded that bowel function gradually returns to normal over a period of a year following sphincter saving surgery. The transient nature of bowel symptoms was evident in the comments made by participants who had a temporary stoma and by those who did not require a stoma postoperatively. Although altered bowel function was experienced by a number of patients after closure of the stoma, most participants reported that their symptoms had improved over time. However, this was not the reality for all participants in the current study some participants indicated that they still continued to experience bowel symptoms 24 months and beyond postoperatively.

In keeping with earlier studies focusing on faecal incontinence (Peden-McAlpine et al, 2008), bowel control was enforced by assessing the level of risk of becoming incontinent when away from home. Findings from the current study demonstrated that over time; many participants had gained confidence and became better able to control their bowel symptoms. Simpson and Whyte, (2006) argue that individual adjustment following sphincter saving surgery is largely dependent on receiving adequate support at time of need. Yet it seems that many patients do not receive the information they required on how the procedure might affect their bowel function postoperatively and for how long they should expect their bowel symptoms to persist.

Bowel Symptoms Responses

Relating to psychological responses, the anxiety experienced due to the fear of becoming incontinent was previously highlighted (Desnoo and Faithfull, 2006, Simpson and Whyte, 2006). In the current study, the erratic and unpredictable nature of some symptoms caused some participants to feel embarrassment and humiliated particularly when in the company of others. Participants commented that this was due mainly to their perceived lack of control over their bowel symptoms. However, other participants reported that they felt distressed and frustrated due to inadequate bowel evacuation. Although most participants had learned to gain some control over bowel function, analysis also highlighted that a small number of participants had become despondent and wondered if bowel function would ever return to normal. According to Desnoo and Faithful (2006), patients may be reluctant to discuss their symptoms with a health care professional. Williams (2007) argues that patients should be made feel less embarrassed by their bowel problems. Normalising patients' bowel symptom

experiences following sphincter saving surgery could be a valuable strategy in assisting individual patients to manage their bowel symptoms more effectively.

From a social perspective, comments highlighted that patients' fears of faecal incontinence were intensified in social situations. This finding corroborates with earlier results of research focusing on patients with chronic faecal incontinence (Collings and Norton, 2004, Hansen et al, 2006; Peden-McAlpline et al, 2008) and on patients following sphincter saving surgery (Desnoo and Faithfull, 2006, Vironen et al, 2006). For example, the sense of urgency that preceded episodes of incontinence meant that participants were unable to plan the day without taking consideration of the need for proximity to a bathroom. However, some participants responded by avoiding, or withdrawing from social situations due to fear of experiencing an acute episode of incontinence and the stress associated with not having access to a bathroom. This may be due to the stigma associated with incontinence, making it more likely that this symptom will be suffered in silence (Desnoo and Faithful, 2006). In keeping with Chatwin et al's (2002) research, which also focused exclusively on patients one year following sphincter saving surgery, incontinence was a major obstacle for some patients in the current study who wanted to return to the workplace.

Regarding physiological responses, it was difficult for some participants to distinguish between some bowel symptoms. The inability to distinguish between symptoms such as bowel urgency and flatus meant many visits to the toilet were often necessary. In accordance with Desnoo and Faithfull's (2006) findings, frequent bowel symptoms caused difficulties for participants especially at night when their sleep was disturbed. The current study further highlighted that the need to go to the toilet a

number of times during the night caused tiredness and fatigue the following day. This in turn impacted on participants' abilities to undertake daily activities. Comments highlighted that symptoms such as fatigue were viewed as an additional physiological burden by some patients because it caused them to have less control over their daily lives.

Self-Care Strategies

Data analysis identified a wide and diverse range of functional self-care strategies that patients use to manage bowel symptoms experienced following sphincter saving surgery. Similar to earlier studies focusing on sphincter- saving surgery (Desnoo and Faithfull, 2006; Nikoletti et al (2008) and on chronic bowel disease (Hansen et al, 2006; Peden-McAlpine et al, 2008), the majority of participants had their own postoperative strategies for diet, eating times and daily schedules to which they adhered to in an effort to control symptoms and to lead as normal a life as possible The practical advice on eating patterns provided by participants could be of use to other patients following sphincter saving surgery. For example, some participants reported that they were only comfortable eating at home. They also learned that eating less and more frequently, eating at the same time every day and not eating late in the evening were helpful strategies in enabling them to gain some control over their bowel symptoms. However, the process of identifying offending foods was laborious and was not always successful for participants.

Nikoletti et al (2008) advised that participants recovering from sphincter saving surgery need specific detailed information about the foods that aggravate their symptoms. They also recommend that the advice of expert practitioners such as dieticians should be sought to assist participants with more comprehensive dietary information such as the interaction of certain foods.

In view of the potential for inappropriate use of bowel medication to result in unwanted side effects, it is important that participants are informed about the correct use of medications to assist with bowel management (Nikoletti et al, 2008). Consistent with Simpson and Whyte's study (2006) some participants wore protective pads to prevent the discomfort associated with faecal incontinence. One participant described this strategy as a way of feeling safe when out socially. Gaining confidence and normality was the fundamental aim of strategies adopted by participants until participants found solutions that gave them control and reassurance they were not able to feel confident (Desnoo and Faithful, 2006). However, none of the above studies (Desnoo and Faithfull, 2006, Simpson and Whyte, 2006, Nikoletti et al 2008) focused on patients who were more than two years following sphincter-saving surgery. As highlighted above, a small number of participants in the current study continued to suffer bowel symptoms two years and beyond.

Implications for nursing

There is a need to help patients feel less stigmatised by their bowel problems. This requires greater public awareness to bowel cancer, to innovations in the treatment of bowel cancer and to the effects of treatment. In particular, this analysis highlights that

patients need support to manage both the temporary and the more permanent alterations in bowel function following sphincter saving surgery for rectal cancer.

Statements about unpredictable bowel symptoms also drew attention to the need for nurses to select strategies appropriate to the individual needs of participants. Nurses can give invaluable support by listening to participants concerns, by ascertaining how the bowel surgery has affected their lives and by finding out how they manage their symptoms. Rather than relying on a single solution, the range of self-care strategies that participants use to manage on-going bowel symptoms needs to be explored. This knowledge is vital to nurses in advising participants on the possible benefits of a range of self-care strategies. Participants should be given the opportunity to discuss their daily experiences of living with the reality of unpredictable bowel symptoms following sphincter saving surgery. This in turn, will help reduce the sense of alienation that some participants may be experiencing as a result of living with a number of problematic bowel symptoms postoperatively.

In addition, this research highlights the need to continue educating patients regarding the bowel symptoms associated with sphincter saving surgery beyond the initial postoperative period. Taylor and Morgan (2011) suggested that prior to bowel surgery any verbal advice given to patients should be supplemented with written information. Patients undergoing sphincter saving surgery need specific information on how this procedure will affect their bowel function postoperatively. Patients also need information on how long they should expect to experience these symptoms. The above information should also be supplemented with written literature on the type of bowel symptoms associated with sphincter saving surgery and the range of self-care

strategies that might be helpful to them in managing symptoms postoperatively. O'Neill (2001) highlighted that further education was required to help patients to differentiate between types of symptoms such as illness related symptoms compared with treatment related symptoms. It is possible that patients in the current study may have had difficulty differentiating between the bowel symptoms resulting from their surgery and those that might be associated with a return of their cancer.

Conclusion

A review of the literature highlighted a dearth of research on the symptom experiences and symptom management strategies of individual patients following sphincter saving surgery for rectal cancer. Data presented in this paper were drawn from the qualitative analysis of a broadly based semi-structured question which formed part of a larger quantitative multi-site study. The paper provides insight into patients' daily struggles in living with the effects of a number of bowel symptoms on their daily lives and the self-care strategies that work for them in the management of these symptoms.

This knowledge is important for clinicians as there may be a gap between the health care professionals' and the patients' perception of the nature, duration and consequences of bowel symptoms. Hence, clinical guidance on the management of the short term and long-term bowel symptoms associated with sphincter saving surgery was emphasised. In this regard, nurses have an important contribution to

make in facilitating patients to choose from a range of self-care strategies to help them manage their bowel symptoms. The study also highlighted that self-care strategies are frequently initiated by patients to manage their bowel symptoms. Thus, healthcare providers should assess for these strategies and help patients to evaluate their effectiveness. In conclusion, the findings of this research demonstrate that bowel symptoms are an ever present issue for some patients 24 months and beyond, following sphincter surgery that they must address and manage in all dimensions of their lives. There is a need for researchers to explore further the meanings behind the self-care strategies used in the management of their bowel symptoms. Future research should also compare the experiences of patients who undergo sphincter saving surgery and require a temporary stoma with patients who did not require a temporary stoma postoperatively.

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