A Descriptive, Qualitative Study to Assess Patient Experiences Following Stoma Reversal After Rectal Cancer Surgery

Maria Reinwalds, MSc, RN; Andrea Blixter, MSc, RN; and Eva Carlsson, PhD, ET, RN

Abstract
Standard surgical treatment for patients operated for rectal cancer is abdominoperineal excision of the tumor resulting in a permanent colostomy or an anterior resection, often with construction of a temporary loop ileostomy. Both options impact bowel function. Living with a permanent colostomy has been studied in depth, but knowledge is limited about patients’ experiences living with a resected rectum after stoma reversal and how it affects daily life. A qualitative study was conducted to describe the first 4 to 6 weeks after reversal of a temporary loop ileostomy due to rectal cancer. Patients from 1 university hospital and 1 county hospital in Sweden were recruited by telephone and were eligible to participate in the study if they: 1) had been operated for rectal cancer with an anterior resection and a temporary loop ileostomy that had been reversed; 2) were >18 years of age, fully oriented, and understood the Swedish language; and 3) had a postoperative course without complications. Interviews were conducted between December 2013 and June 2015 either at the hospital or at the participants’ homes. Participants were asked to narrate their experiences since stoma reversal. Probing open-ended questions were used to stimulate narration and clarify and enhance understanding. The interviews were recorded, transcribed verbatim, and analyzed using thematic content analysis. The 16 participants included 9 women and 7 men (median age 67 years). Three (3) main themes emerged: Life being controlled by the altered bowel function, with the subthemes loss of control over bowel function, uncertainty regarding bowel function, and being limited in social life; Striving to regain control over the bowel, with the subthemes using ability and knowledge, social support, and being grateful and hopeful; and A desire to be normal, with subthemes getting rid of the stoma and restoration of body image. Patients experienced severe bowel function problems, including increased bowel movement frequency and inability to anticipate or trust bowel function after stoma reversal. Outwardly, patients experienced a significant improvement in body image but continued to struggle with suboptimal bowel function. Patients needed reassurance that their bowel symptoms were normal. Participants strove to regain control over bowel function using various strategies, including what they had learned about diet and medication before stoma reversal and by trying to defy the restrictions of their new normal. They felt they were fighting to regain bowel control without help from health care professionals. In order to cope with altered bowel function, they needed the support of family and friends. The results suggest that, following stoma reversal, patients need information about available treatments to address their symptoms and require regular follow-up visits to evaluate and address functional results.

Keywords: qualitative evaluation, ileostomy, revision surgery, rectal cancer, fecal incontinence, anterior resection syndrome

Index: Ostomy Wound Management 2017;63(12):29–37

Potential Conflicts of Interest: The study was conducted with grants from the Local Research and Development Board for Gothenburg and Södra Bohuslän, Sweden.

Ms. Reinwalds is a nurse practitioner, Department of Surgery, Institute of Clinical Sciences, Sahlgrenska University Hospital Östra, Gothenburg, Sweden. Ms. Blixter is a head nurse, Department of Surgery, Angered Hospital, Gothenburg Sweden; and during data collection worked as a registered nurse, Kungälv Hospital, Kungälv, Sweden. Dr. Carlsson is an enterostomal therapist, Department of Surgery, Institute of Clinical Sciences, Sahlgrenska University Hospital Östra; and a senior lecturer, Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Gothenburg, Sweden. Please address correspondence to: Maria Reinwalds, MSc, RN, Department of Surgery/Colorectal Unit, Sahlgrenska University Hospital Östra, SE-416 85 Gothenburg, Sweden; email: maria.reinwalds@vgregion.se.
In Europe, approximately 140,000 persons are diagnosed with rectal cancer (RC) each year; the annual number in Sweden is slightly more than 2000 persons. The treatment for RC is surgical removal of the tumor, sometimes complemented with radiotherapy and/or chemotherapy. RC surgery (rectum resection with a permanent or temporary fecal stoma) affects bowel function. A prospective study among 57 patients (median age 66 years) surveyed preoperatively and at 1, 3, and 6 months postoperatively reported patients’ main concerns were the cancer diagnosis and the uncertain nature of the disease, worries about becoming a burden to or being dependent on others, and what their new life would entail. Focus group interviews with 7 patients with a temporary stoma (2 women, participant age range 40–75 years) concluded that in cases involving a temporary stoma, the closure of the stoma was an important event. Most patients felt hopeful about a future without a stoma and few worried about not being able to resume life as it was before the cancer surgery. The perceptions of patients living with a permanent colostomy and patient experiences in the early period after ostomy creation have been studied in depth, but knowledge is limited regarding patients’ early experience of living with a resected rectum after stoma reversal and how it affects daily life.

Background

Since the early 20th century, the standard treatment for RC has been surgery with removal of the rectum and anal sphincter, abdominopereineal excision (APE), and construction of a permanent stoma. According to a Cochrane review, as surgical technique has evolved, patients are increasingly undergoing sphincter-preserving surgery. The primary surgical choice whenever feasible is anterior resection (AR), with removal of the major part of the rectum and construction of an anastomosis between the colon and the small remaining part of the rectum or the anal canal. Leaving the anal sphincter and lowest part of the rectum makes it possible to keep bowel continuity or to restore it later. A Swedish randomized multicenter trial (N = 234 patients, median age 68 years) assessed the rate of symptomatic anastomotic leakage in patients operated on with low AR for RC. Patients randomized to a diverting loop ileostomy or loop transverse colostomy (n = 116) had leakage in 10.3% of cases; the rate was 28% in persons without stoma (n = 118). Therefore, the recommendation for patients operated on with a low AR was to construct a diverting stoma to reduce the risk of anastomotic leakage. The stoma, usually a temporary loop ileostomy, is reversed later.

The main reason for sphincter-preserving surgery becoming the gold standard for RC treatment has been the assumption that quality of life (QoL) was poorer for people with a permanent stoma than for people who underwent sphincter-preserving surgery. According to a qualitative, descriptive study in which 9 patients (age range 44–67 years) were interviewed 6 to 12 weeks after stoma surgery and a literature review, including 11 studies (N = 248 patients), living with a stoma means losing control over bowel function and having to cope with a changed body image, altered self, and changes in daily life. The loss of bodily control can affect the patient’s ability to maintain a sense of adulthood (ie, they are dependent in ways contradictory to adulthood and adult relations). Knowing the stoma is only temporary can make patients feel their usual life is on hold and that it will resume once the stoma is reversed, negatively impacting how they adapt to life with a stoma. A British prospective, longitudinal interview study with 16 participants (age range 51–87 years) that aimed to illuminate the recovery process following curative surgery for colorectal cancer found bowel function was a particular concern after colorectal surgery. The loss of continence and fear of stoma leakage could cause patients to view the temporary stoma as a short-lived surgical complication separate from their self — that is, patients who exhibited concern regarding the possibility of the stoma bag leaking tended to view their temporary stomas as a surgical complication of the physical body, unrelated to self and thus less problematic to the psyche.

Studies have tried to compare QoL in patients with and without a stoma due to RC treatment using demographic and treatment characteristics. Questionnaires used in the studies included the European Organization of Research and Treatment of Cancer Quality of Life-C30, the Hospital Anxiety and Depression Scale, and the Illness Cognition Questionnaire, all of which have been validated. In particular, a Dutch questionnaire study found no significant differences in health-related QoL between people with (n = 62, mean age 68.6) and without a stoma (n = 60, mean age 67.9). A Cochrane review challenged the assumption that patients operated on with an APE and a permanent stoma had poorer QoL; however, the lack of validated tools to measure QoL in long-term ostomate patients made it impossible to come to a definite conclusion. The authors conclude these patients need more information and closer postoperative follow-up.
QoL than patients operated on with an AR. The review included 35 nonrandomized studies with a total of 5127 participants. The studies did not support the assumption that QoL in people after AR is superior to that of people after APE/Hartmann’s surgery. The authors concluded that larger, better designed and executed prospective studies are needed to answer this question.

A descriptive review including 21 studies (N = 875 patients) reported that up to 90% of all patients operated on with sphincter-preserving surgery will subsequently suffer from altered bowel function, termed anterior resection syndrome (ARS). This syndrome includes a wide range of symptoms from increased bowel frequency to fecal incontinence (FI), which has been reported to occur up to 15 years post AR. Results of a qualitative, in-depth interview study involving 7 patients (age range 60–78 years) by Desnoo and Faithfull found patients treated for RC with an AR and a temporary loop ileostomy frequently experienced a change of bowel habits 7 to 20 months after stoma reversal. A literature review (N = 9 articles) examining QoL outcomes following stoma reversal after RC treatment noted the possibility of permanent difficulties after stoma reversal that can significantly affect patient QoL if left untreated. The patients survived the initial cancer treatment and the stoma was gone, but they were left with side effects or long-term symptoms from the bowel — symptoms that in many cases they did not expect.

Patients with RC not only deal with issues of daily living, but they also have to face the fact that the body is changing. In her doctoral thesis, Lindwall described the inability to trust the body again was important in order for patients to recover after surgical treatment for colorectal cancer.

Length of hospital stay for a patient undergoing surgical closure of a temporary loop ileostomy is often <48 hours; at hospital discharge, the patient has not always caught up emotionally after surgery and he/she remains uncertain as to how the bowel works. Research is limited regarding how patients experience the early period after stoma reversal. The authors propose greater knowledge of patients’ experiences would be useful in helping health care professionals determine the need for counseling and education (both preoperatively and during the early recovery period) as well as to organize the best follow-up for these patients. Therefore, the purpose of this study was to describe the patient experience during the first 4 to 6 weeks after reversal of a temporary loop ileostomy due to RC.

**Methods**

**Design.** This research effort is part of a larger study (ANTILoop) on early (present study) and late experiences following stoma reversal after RC surgery. To describe the patients’ experiences, an explorative qualitative design based on narrative interviews was chosen and subject to qualitative content analysis.

**Participants.** Patients who had undergone reversal of a temporary loop ileostomy treated at 1 public county hospital and 1 public university hospital in Sweden were invited to participate in the study. Inclusion criteria stipulated participants had undergone surgery for RC with an AR and received a temporary loop ileostomy; were >18 years of age; fully oriented to time, person, and place and able to understand the Swedish language; and had a postoperative course without complications. Participants were recruited by telephone; their names were provided by the surgical coordinator of each surgical unit.

According to the routine care plan, patients operated on with an AR and a loop ileostomy have 1 follow-up consultation with a surgeon 4 to 6 weeks after stoma reversal and once a year for 3 years for RC surveillance. Patients with a temporary loop ileostomy are followed-up postoperatively by an enterostomal therapist (ET) on the ward and at the outpatient clinic according to the following schedule: 10 to 14 days post discharge, 6 weeks, 3 months, 6 months, and 1 year post surgery. After stoma reversal, no regular follow-up by an ET or specialist nurse is provided.

**Data collection.** Interviews were conducted by the first and second author between December 2013 and June 2015 at the hospital where they had been treated or at the participants’ homes according to their wishes. The participants were asked to narrate their experiences since stoma reversal. The opening question was: Please describe your experiences at home in the initial period following your stoma reversal. Probing open-ended questions were used to stimulate further narration and to clarify and enhance understanding; for example, What or how do you mean? Can you tell me a little bit more? and How did you cope with that? The interviews were recorded and transcribed verbatim and consisted of extensive and rich narratives.

**Ethical considerations.** At the time of the interviews, participants received written information and signed an informed consent form. The study was conducted according to the ethical principles outlined in the Declaration of Helsinki. The study was approved by the Regional Ethical Review Board (D. Nr: 688-14).

**Data analysis.** The transcribed interviews were subject to qualitative content analysis as described by Graneheim and Lundman. The interviews were read several times to gain a sense of the whole. The text then was divided into meaning units that were condensed to shorten the text without losing relevant content. The meaning units were given a code. The codes were compared according to similarities and differences and sorted into 8 subthemes. Subthemes then were grouped, resulting in 3 themes. The themes expressed the latent content of the codes and condensed meanings in the interview texts. The analysis was primarily conducted by the

www.o-wm.com

DECEMBER 2017 OSTMORY WOUND MANAGEMENT® 31
first and second author, and the third author had a validating role throughout the analysis process.

Rigor. The validity and trustworthiness of qualitative research can be described using 4 components: credibility, transferability, dependability, and confirmability. The present study aimed to achieve these attributes by presenting the opening-question, detailed description of the context of the study, the recruiting process, and the analytic process and by illustrating the participants’ experiences using quotations. The chosen method was congruent with the aim of the study, and the data analysis was characterized by a critical and open dialogue among the authors. The presented findings were considered the most trustworthy interpretation of the text by all authors.

Results

Participants. All 16 invited patients (9 women, 7 men, median age 67 [range 33–81] years), 12 from the university hospital and 4 from the county hospital, agreed to participate. Initially, the study involved 5 consecutive patients and after a slight break in the study 11 more participants also were consecutively included. They were contacted at the hospital before discharge or by telephone after hospital discharge. Nine (9) interviews were conducted by the first author, and 7 interviews were conducted by the second author. Time from stoma reversal to the interview ranged from 4 to 6 weeks. The participants’ demographics and clinical history are shown in Table 1.

Table 1. Study participants demographic data and history

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Gender</th>
<th>Age (years)</th>
<th>Type of surgery /tumor level measured at colonoscopy</th>
<th>Neoadjuvant¹/ Adjuvant² treatment</th>
<th>Months between loop ileostomy construction and stoma reversal</th>
<th>Weeks between stoma reversal and interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Male</td>
<td>79</td>
<td>Anterior resection/9 cm</td>
<td>Radiotherapy¹ Chemotherapy¹ Chemotherapy²</td>
<td>12</td>
<td>6</td>
</tr>
<tr>
<td>2</td>
<td>Male</td>
<td>67</td>
<td>Anterior resection/9 cm</td>
<td>Chemotherapy²</td>
<td>14</td>
<td>6</td>
</tr>
<tr>
<td>3</td>
<td>Male</td>
<td>42</td>
<td>Anterior resection + sigmoid resection/8–9 cm</td>
<td>Radiotherapy¹ Chemotherapy¹ Chemotherapy²</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>Female</td>
<td>33</td>
<td>Anterior resection/7–8 cm</td>
<td>No</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>Male</td>
<td>68</td>
<td>Anterior resection/12 cm</td>
<td>Chemotherapy²</td>
<td>11</td>
<td>6</td>
</tr>
<tr>
<td>6</td>
<td>Male</td>
<td>81</td>
<td>Anterior resection/10 cm</td>
<td>No</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>7</td>
<td>Male</td>
<td>68</td>
<td>Anterior resection/14 cm</td>
<td>Radiotherapy¹</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>8</td>
<td>Female</td>
<td>54</td>
<td>Anterior resection/8 cm</td>
<td>Radiotherapy¹ Chemotherapy²</td>
<td>14</td>
<td>4</td>
</tr>
<tr>
<td>9</td>
<td>Female</td>
<td>75</td>
<td>Anterior resection/7 cm</td>
<td>Chemotherapy¹</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10</td>
<td>Female</td>
<td>60</td>
<td>Anterior resection/9 cm</td>
<td>No</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>11</td>
<td>Female</td>
<td>47</td>
<td>Anterior resection/7 cm</td>
<td>No</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>12</td>
<td>Female</td>
<td>76</td>
<td>Anterior resection/14 cm</td>
<td>No</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>13</td>
<td>Female</td>
<td>67</td>
<td>Anterior resection/12 cm</td>
<td>Radiotherapy¹ Chemotherapy²</td>
<td>14</td>
<td>6</td>
</tr>
<tr>
<td>14</td>
<td>Female</td>
<td>64</td>
<td>Anterior resection/11 cm</td>
<td>Radiotherapy¹ Chemotherapy²</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>15</td>
<td>Female</td>
<td>70</td>
<td>Anterior resection/8 cm</td>
<td>No</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>16</td>
<td>Male</td>
<td>65</td>
<td>Anterior resection/11 cm</td>
<td>Chemotherapy²</td>
<td>6</td>
<td>5</td>
</tr>
</tbody>
</table>

Table 2. Themes and subthemes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life being controlled by the altered bowel function</td>
<td>Loss of control of bowel function</td>
</tr>
<tr>
<td></td>
<td>Uncertainty regarding bowel function</td>
</tr>
<tr>
<td></td>
<td>Being limited in social life</td>
</tr>
<tr>
<td>Striving to regain control over the bowel</td>
<td>Using ability and knowledge</td>
</tr>
<tr>
<td></td>
<td>Social support</td>
</tr>
<tr>
<td></td>
<td>Being grateful and hopeful</td>
</tr>
<tr>
<td>A desire to be normal</td>
<td>Getting rid of the stoma</td>
</tr>
<tr>
<td></td>
<td>Restoration of body image</td>
</tr>
</tbody>
</table>

DO NOT DUPLICATE
Interview analyses: Life being controlled by the altered bowel function. The analysis of the interviews resulted in 3 themes and 8 subthemes (see Table 2). All participants described major concerns regarding altered bowel function. Loss of control over bowel function and uncertainty regarding how the bowel worked limited their social lives, which led to their entire lives being controlled by the altered bowel function.

Loss of control of bowel function. All participants reported an increase in defecation frequency compared to before the primary cancer surgery. It was not unusual to have to go to the toilet 20 times a day. This led to sores and wounds in the perineal area and caused pain, which sometimes prevented the patient from sitting down. Several patients also suffered from painful defecation.

Before the stoma reversal, participants received information that their bowel function would alter, but none described being prepared for this reality. Reactions of shock and surprise were frequently expressed by most of the participants. Constant feelings of rectal urgency were common and were described by 1 patient as constantly having a knife in your back, forcing you to go to the toilet. Fractioned defecation was described by all participants, causing prolonged time on the toilet.

No, but it's a bit like, you can go to the loo and you think you're done, you wash your hands and leave and say no, I have to go to the loo! And you keep on like that! And it's really bothersome! I go to the loo several times, like five times in a row. — Participant 4

Several participants also suffered from frequent bowel movements at night, causing disturbed sleep and tiredness during the day. The participants reported an inability to hold bowel movements and feelings of incomplete bowel evacuation. Almost all participants experienced episodes of FI. The total loss of control over bowel function was compared to having bad stomach flu.

Before in the old days, when you could regulate your defecation a bit, wait for a bit, sit and wait, and so on. Can't do that now! It's uncontrollable, and I have to manage it in my daily life. — Participant 7

Uncertainty regarding bowel function. Participants were greatly troubled by their inability to predict how the bowel would behave. bowel function varied on a daily basis with no systematic pattern. The bowel behaved differently than it did before cancer surgery and could no longer be trusted (the participants word choice). Function varied from obstructed defecation to daily episodes of fecal leakage. Not knowing how the bowel worked, loss of control regarding bowel function, and prior episodes of FI created feelings of uncertainty and anxiety.

So it’s like you don’t really dare to trust the system… so it’s…yes it’s clear that…it isn’t any fun to poo your pants. That’s the worst thing about it, I feel. — Participant 3

Not feeling comfortable with oneself and one’s body also was experienced. This also caused uncertainty, and the patients put a lot of effort and energy into getting to know their new bodies and trying to find some logic to the unpredictable bowel.

Being limited in social life. Altered bowel function and the need for frequent toilet visits restricted social life. Frequent urgency and the inability to hold bowel movements made almost constant access to a toilet necessary. Participants also described the need to shower after each toilet visit in order to feel fresh and clean. This, along with feelings of embarrassment about having to use the toilet with abnormal frequency within a short period of time, caused many of the participants to stay home instead of participating in social activities. Some had not left home at all during their first weeks because they did not dare leave the toilet. This made managing daily chores difficult and made patients dependent on other people. Participants expressed how they were unable to use public transportation, go see a movie, go for walks in the woods, or go to the gym.

My social life has been severely affected! I say no to all social events. — Participant 5

Striving to regain control over the bowel. Participants used different strategies to cope with the difficulties that arose due to their altered bowel function and focused on finding a way back to themselves and regaining control over the body. The participants coped by using their ability and knowledge, support from family and friends, and by being grateful and hopeful.

Using ability and knowledge. Most of the participants coped by using previous experience and knowledge in life and, in particular, their time with the stoma. Many tried to control bowel function by making dietary changes. Diets that had proven effective during earlier illness or operations and dietary advice from the time with their stoma were resumed, with questionable results. Foods such as onion or coffee were avoided by some of the participants. A common strategy was to totally refrain from eating, if something special was planned.

If something special’s going on then it’s better not to eat. I don’t eat in that case because it feels safer to just completely refrain. — Participant 15

When participants tried to tell health care professionals about their problems, they were told to be patient. This response caused patients to assume the symptoms were untreatable and turn to other sources (e.g., the internet) for advice on coping with their situation. Great insecurity prevailed about whether other patients also commonly experienced bowel symptoms. A lack of information from health care professionals caused the participants to distrust any information they did receive until it was proven accurate. Although they tried to the best of their ability to cope with the situation, none of the participants knew how to manage their altered bowel function satisfactorily. They expressed the thought
that concrete tips and advice from health care professionals, mostly regarding dietary advice and bowel regulating drugs, would have been appreciated. Several participants used antidiarrheals that were prescribed while they had a stoma. One patient stated it was a turning point when he started to use antidiarrheals. The use of these drugs allowed him to leave the home.

Some tips on how to eat, or that I could have taken that loperamide could have helped me from the start when I had diarrhea at the hospital. So perhaps I wouldn’t have had those worst 2 weeks there anyway. That would have been [appreciated]! — Participant 3

Planning their lives around bowel function was common to all participants. They were forced to constantly keep track of public restrooms and only dared to visit places with access to a toilet. To reduce the risk of fecal leakage outside the home, toilet visits were made before they left the house in order to try to empty the bowel. Another way to cope with potential leakage was to use incontinence pads or carry a change of clothes.

You have to think about this all the time, about having access to a toilet. Because you don’t know like when and what time anything will happen. — Participant 2

In striving to regain control over the body, 1 strategy was to challenge oneself. This strategy was most commonly seen among the younger (33- to 42-year-old) patients. They chose not to accept limitations due to altered bowel function but instead tried to force the body into obedience. One way was to ignore feelings of urgency, hoping that they would pass instead of trying to force the body into obedience. One way was to defy the fear of potential leakage was to use incontinence pads or carry a change of clothes.

I don’t really accept this thing with sitting on the loo for 5 hours every day! It doesn’t work for me, I can’t have a life like that... I take more of an attitude that my body has to adjust to what I think is right...” — Participant 4

Social support. All the participants found it important to have support from family and friends in order to cope with their altered bowel function. This included practical support, such as help with grocery shopping and doing daily chores such as cleaning the house and mowing the lawn. It also included emotional support (eg, having someone to share the difficulties in life, making them easier to bear). Because talking about bowel habits in public was considered taboo, it was even more important to have someone close to talk to.

My wife, of course... We know each other inside out and then, when you live together with the problems that one or the other has, and we’re very close, so we live with this together... this is what I need... she helps and supports me all the way... — Participant 7

A lack of support from health care professionals made support from family and friends indispensable. One participant said she could not share her own worries and difficulties with her family because they were sick and fragile and talking about her problems made them even sicker. This made her situation harder to bear and she felt all alone and abandoned. I think you can get quite lonely after leaving the hospital... When I was released, I went out through a door and then I was completely alone. I was completely abandoned! I should have had much, much more support than I did... No one can manage by themselves! They can’t... — Participant 10

Being grateful and hopeful. Despite great difficulties with their bowel symptoms, the participants expressed how grateful they were to have gotten rid of the stoma. They endured their altered bowel function because they felt having a stoma was worse. Only 1 patient said she sometimes regretted having the stoma reversed, but she also expressed gratitude that the stoma was gone. Most patients considered altered bowel function a fair price to pay as they were now cured of cancer. Oh God, I’ve been through cancer surgery – what should I expect? I’ve been lucky! I think I’ve got a little handicap and I’ll have to live with that... I’ve been given a second chance in life. And I’m going to take good care of it! — Participant 11

The participants dealt with the rough with the smooth as aspects of life and were grateful to be alive.

Yes, I’m still thankful. That’s how I think in order to handle the situation... there’s so much else when you look and listen and see that is so much worse... like the opposite to life... — Participant 8

All the participants hoped their bowel function would improve. None thought their symptoms would last for more than 1 year. They chose to be patient and positive about the future.

A desire to be normal. Participants stated they had high expectations of getting rid of the stoma and being physically restored. However, the high expectations were as yet unfulfilled due to the symptoms of altered bowel function.

Yes, first I thought I would be ecstatic to get rid of the stoma, but I never was! But that was because this was so much trouble instead... — Participant 13

Getting rid of the stoma. The participants viewed the stoma as a barrier to being able to freely choose clothes and recreational activities. They felt it limited them; for example, while they had the stoma they refrained from swimming, exercise, and other activities that involved public changes of clothes. Many chose not to tell people they had a stoma because it was considered not normal. Living with a stoma meant not having control over bowel function, which forced many of the participants to be preoccupied with access to toilets. Life with a stoma was difficult for most of the participants, and they had been looking forward to the day when it would be reversed. Receiving the date for stoma reversal surgery felt like winning the lottery.

It was such a relief to get rid of that bag! ...It’s so nice now to be able to bend, yes, the difference is like night and day. — Participant 12
Instead of having to cope with the stoma, patients were forced to use incontinence products, ointments, and nursery bags that are used for infants. This was perceived as returning to infancy.

*I thought it would be completely different. That I’d be able to wear those small briefs again... that it would be like before, but it never is...* — Participant 10

**Restoration of body image.** The participants had a strong desire to regain bowel continuity and have a normal bodily appearance. Many saw the stoma as a constant reminder of their cancer and the reversal as the end of a period of illness and the start of something new.

*I feel healthier, more whole. The disease doesn’t constantly remind me of it. The bag reminded me about what I’d gone through. And I’m so damned happy not to have that because now I don’t often think about what I’ve gone through during the day anymore. That’s so nice. That means I’ve moved on a bit.* — Participant 3

At the time of the interviews (4 to 6 weeks post stoma reversal), all the participants expressed relief that the stoma was gone, including gratitude that their bodies looked normal again. Only 1 participant said that if the symptoms persisted, he would consider having the stoma back.

**Discussion**

The findings of the study show that 4 to 6 weeks after reversal of a temporary loop ileostomy due to RC treatment, patients were grateful the stoma was gone. After the stoma reversal, participants envisioned their bodies would be restored and they expected life to return to normal. However, all participants experienced severe symptoms due to altered bowel function ranging from rectal urgency and frequent bowel movements to episodes of fecal leakage. Life was controlled by altered bowel function, something few patients were prepared for. In striving to regain control over bowel function, participants coped by using their ability and knowledge, support from family and friends, and gratitude that they were alive and hopeful about the future.

Participants reported bowel symptoms that were so severe they controlled their entire life. A large part of both the day and night revolved around their bowel function. Losing control over bowel function had physical (pain and sores) and emotional (sleep disturbance and distress) effects. The symptoms experienced included everything from evacuatory dysfunction to rectal urgency and FI and were consistent with the description of ARS by Bryant et al.11

The bowel symptoms reported in the present study varied from day to day with no obvious pattern. This, along with the inability to control bowel function and episodes of fecal leakage, caused feelings of uncertainty and distress; uncertainty over bowel function and the inability to trust the bowel led to a restricted social life. This is consistent with the findings in a British qualitative study19 with a phenomenological approach. Data were collected using indepth semistructured interviews that explored the lived experiences of 8 patients (median age 64 years) suffering from ARS after RC treatment during the same time period as the current study. Similar findings also are described in 2 studies of patients who, for various reasons, experienced FI, where the loss of control over bowel function was characterized by insecurity and led to limitations in everyday life.20,21

The first study was conducted according to the grounded theory approach and aimed to elucidate the life situation and psychosocial processes of 9 women suffering from postnatal FI and how they coped with their situation.20 In the second study, indepth interviews conducted among 5 women living with FI identified and described the lived experiences of people living with FI and how it affected daily life.21

Before stoma reversal, all participants in the present study were told that after the reversal their bowel function would be different from how it was before their cancer surgery. Nevertheless, none were prepared for the actual result. Participants expressed feelings of shock and wanted to know if anyone else was experiencing the same symptoms. Not knowing if they were alone in the symptoms caused even more uncertainty. According to Mishel’s uncertainty in illness theory,22 an individual’s perception of uncertainty is influenced by many factors, including the nature of the symptom. If the symptoms do not follow any pattern or if they are unexpected, the uncertainty may increase. Using a prospective, nonexperimental correlation design, Galloway and Graydon23 interviewed 40 patients (age range 43–89 years) who had undergone colon cancer surgery. Using the Mishel Uncertainty in Illness Scale,24 the authors found a relationship among distress symptoms, uncertainty, and the need for information. Patients who indicated more uncertainty needed more information regarding their treatment, possible complications, and everyday life. In other qualitative research,25 patients who had undergone resection for RC found sharing experiences and sensible matters with others in the same situation was helpful.

All participants strove to handle the difficulties that had arisen from altered bowel function and tried to regain control by using different coping strategies. According to Benner and Wrubel’s nursing theory,25 the choice of coping strategies a person uses is influenced by the person’s background, understanding, knowledge, and situation in life. The participants in the present study coped mostly by using the experiences, ability, and knowledge they had developed while living with the stoma. This included making dietary changes or the use of medications. In their descriptive cross-sectional study, Santos et al26 conducted interviews to compare and evaluate the use of coping strategies and QoL in patients with temporary (n = 42) and permanent (n = 72) stomas. They reported differences in coping strategies for patients with a temporary stoma compared to patients with a permanent stoma. The most common coping strategies for patients living with a temporary stoma was the use of escape-
avoidance and denial. This proved to be ineffective, because the person did not respond to or manage his/her new situation. Patients with a permanent stoma mainly used coping strategies focused on problem-solving and acceptance of the situation, thus increasing QoL. According to Danielsen et al,4 patients with a temporary stoma felt like life was “taking a break” because they knew the situation was not permanent. Similar strategies were seen in the present study — many participants had chosen to refrain from different activities while the temporary stoma was in place, thinking they could resume these activities once the stoma was gone. After the stoma reversal, coping strategies more focused on problem-solving were employed.

A few participants who shared their bowel symptoms with health care professionals were told to be patient. Lack- ing support and help, these patients expressed frustration at having to cope with their bowel symptoms on their own. Similar findings also were reported by patients suffering from ARS who stated they could not cope with the unpredictable bowel themselves and needed help.19 Nevertheless, most of the participants in the present study chose not to seek help from health care professionals. Ohlsson-Nevo et al27 conducted semistructured interviews with persons treated for colorectal cancer (n = 13) and their partners (n = 13) aiming to describe their experiences the first year after surgery. The authors found patients did not always choose to share their physical problems with a health care provider or service for a number of reasons: patients expected the problems to pass of their own accord and they had their own theory about the cause and solution of the problem. Similar perceptions prevailed among the participants in the present study; they thought their bowel symptoms were transient and would not last more than a year, and they had different theories as to why the bowel behaved differently. Although they struggled with their symptoms, all participants also expressed gratitude that the stoma was gone. Perhaps the fear of having the stoma recreated gave them an incentive to endure their bowel symptoms. The participants expressed gratitude to be alive. The altered bowel function was perceived as a fair price to pay for life, so they chose to take the good days with the bad days. This view also has been expressed by other survivors of RC.12

One coping strategy to regain control over the body was to challenge oneself, a strategy found among the younger patients. They chose to try to force the body into obedience by putting themselves in situations without direct access to a toilet. Fear of failure was always present, but younger participants sometimes had the nerve to fail while older participants refrained from the challenge. The younger participants stated that even though they were grateful to be alive, they would not want to live with their bowel symptoms for the rest of their lives. Although the study sample is small, this practice indicates that people from different generations have different attitudes. Clinicians should consider this in the light of higher demands made on younger people, such as societal demands to return to work and family responsibilities.

All participants expressed high expectations of getting rid of the stoma. For the most part, this was due to the perception that, without the stoma, the body would behave normally again. Patients with stomas experience a change in body image.28 After the stoma reversal, current study participants experienced altered bowel function. Although the stoma was gone, the body did not behave as it did before the cancer surgery. A fight to regain normality persisted. Desnoo and Faithfull12 described how, after reversal of a temporary stoma due to RC treatment, patients suffered from a change of body image and body ideal due to their altered bowel function. According to his theory, Price29 found loss of bodily control, as with FI, is highly associated with old age or infancy, subsequently strongly affecting body image among these patients. In the present study, several participants associated the loss of control over bowel function and the need to wear incontinence pads with returning to infancy. Feeling their loss of adulthood also has been described by patients living with a stoma.8 Following surgical treatment for colorectal cancer, patients were required to listen to their bodies to understand and discover its responses to surgery if they wanted to restore a sense of control.7 This involved finding patterns to make sense and establish meaning of a particular symptom; it was also important to be able to rely on family and friends for practical and emotional support.9 In the present study, participants had not yet found any pattern to their bowel symptoms. Outwardly, their bodies had been restored to presurgical appearance, but inwardly, their bowel function had not. In order to cope with the altered bowel function, it was important for patients to receive both practical and emotional support from family and friends.

Many participants chose not to tell the health care professionals about their bothersome symptoms, making it important for clinicians to follow-up the patients in terms of functional results. A validated instrument, the Low Anterior Resection Syndrome score (LARS score), has been developed for classification of low ARS aimed at the symptoms of bowel dysfunction.29 This could be used in the follow-up of these patients at an out-patient clinic led by specialist nurses.

Limitations

Limitations of this study include the exclusion of patients who did not speak Swedish and that the majority of the participants were recruited from the university hospitals because the county hospital performed fewer surgeries. However, a strength of the present study is that all of the participants were eager to tell their stories and that inclusion criteria allowed all patients who had undergone AR and stoma reversal regardless of symptoms to participate. This is in contrast to a study by Taylor and Bradshaw19 that only included patients reporting changes in bowel function after surgery.

Conclusion

The results of this qualitative study showed that severe bowel function symptoms were experienced in the early period (4 to
6 weeks) after stoma reversal. Many questions arose after discharge from the hospital, and patients needed reassurance that the bowel symptoms they were experiencing were normal. All participants strove to regain control over bowel function using various strategies. They were resourceful and demonstrated potential and viability despite having to prevail without help or support from health care professionals. These study findings reveal the need for patients to be followed-up regularly after stoma reversal. It is a human right, guided by ethical principles, to alleviate suffering and restore health, and to receive information and knowledge about exciting remedies and treatments. This information and knowledge should be provided verbally before discharge and written information needs to be developed.

Acknowledgments

The authors express sincere thanks to the patients who took part in the study.

References