Concerns and Quality of Life Before Surgery and During the Recovery Period in Patients With Rectal Cancer and an Ostomy

Eva Carlsson n Ina Berndtsson n Anne-Marie Hallén n Elisabet Lindholm n Eva Persson

PURPOSE: Rectal cancer is the most common reason for a person to undergo ostomy surgery. The aim of this study was to assess concerns and health-related quality of life (HRQOL) before surgery and during the first 6 months following ostomy surgery in the presence of rectal cancer.

SUBJECTS AND SETTINGS: The sample comprised 57 patients at a university hospital in Gothenburg, Sweden. Their median age was 66 years (range, 30-87); 35 men and 22 women participated in the study.

METHODS: Participants prospectively answered questionnaires preoperatively, and at 1, 3, and 6 months postoperatively. Concerns were assessed using the rating form of the Inflammatory Bowel Disease Patient Concerns, and HRQOL was evaluated using the 36-Item Short Form Health Survey. Results were compared with population norms.

RESULTS: Participants expressed concerns associated with developing cancer, being a burden on others, and related to the uncertain nature of disease. Health-related quality of life scores dropped significantly in 6 of 8 domains when preoperative scores were compared to those obtained 1 month postoperatively, but scores improved at 6 months. There were significant differences between preoperative study group scores and population norms on physical and emotional role function, social function, and for mental health domains. Significant differences persisted when population norms were compared to study group scores 6 months following surgery on all these domains except mental health. Participants identified good relations with significant others, social and leisure activities, psychological issues, and health as important for maintaining QOL. Obstacles to maintaining QOL included fatigue, pain, illness-induced limitations in life, and worries over what their new life would entail.

CONCLUSION: Surgical management of rectal cancer raises concerns and profoundly impairs QOL during the first several postoperative months.
considered a key outcome measure.3 Validated generic and disease-specific health-related quality of life (HRQOL) questionnaires are used to measure these important outcomes. Traditionally, the formation of a colostomy after APR was thought to lower the HRQOL in patients with RC,4,5 although contradictory results exist.6,8 However, pooled data from Cochrane review of 20 nonrandomized studies enrolling 1412 patients with APR and a colostomy found that they did not have poorer HRQOL than patients undergoing AR.2 Only one study found that an ostomy slightly affected HRQOL as compared to 4 studies that found that patients with APR had significantly poorer HRQOL. Addressing HRQOL assists nurses to identify important aspects in this patient population and refine or revise care based on these insights.9

Even though the evidence does not support that patients undergoing APR have worse HRQOL when compared to those undergoing AR, studies have shown that patients with an ostomy face clinically relevant challenges.10-14 For example, persons with an ostomy must adjust to an altered self-concept and body image, sexual concerns, changes in daily routines, and changes in work and leisure activities. How persons with an ostomy and their partners adapt to these changes profoundly influences psychosocial and sexual functioning.15

A diagnosis of cancer tends to provoke fear of death and associated anxiety. Regardless of the prognosis, a diagnosis of cancer profoundly influences daily life for both the patient and the family.12,16 The concerns of patients with RC both prior to and following ostomy surgery are not well known. Greater knowledge of these concerns can be useful in assisting WOC nurses and other health care professionals to determine issues for which counseling and education is required both preoperatively and during the initial recovery period. The overall aim of this study was to assess concerns and HRQOL before and during the first 6 months following ostomy surgery for RC.4,5 although contradictory results exist.6-8 However, pooling data from Cochrane review of 20 nonrandomized studies enrolling 1412 patients with APR and a colostomy found that patients with APR had significantly poorer HRQOL. Addressing HRQOL assists nurses to identify important aspects in this patient population and refine or revise care based on these insights.9

Specific research questions included the following: (1) What concerns do patients have preoperatively and during the recovery period? (2) How is HRQOL affected preoperatively and during the recovery period compared to a population norm? (3) How do patients define good QOL and obstacles to QOL preoperatively and during the recovery period?

Methods

Patients undergoing elective surgery for RC that included either a temporary loop ileostomy or a permanent colostomy between April 2003 and March 2005 were eligible for the study. The study setting was the colorectal unit, Sahlgrenska University Hospital in Gothenburg, Sweden. Patients were approached preoperatively by a WOC/Enterostomal Therapy nurse concerning participation in the study. Patients who underwent emergency surgery for RC, those whose cognitive ability prevented completion of study instruments, and those who did not understand written Swedish were excluded from participation.

Ethical approval for study procedures was obtained from the research ethics committee of Sahlgrenska Academy, University of Gothenburg, Sweden (Approval No. Ö176-03). Participants received oral and written information about the study preoperatively by the WOC nurse at the hospital, and written consent was obtained. Questionnaires were given to the patient 1 to 2 weeks before surgery and were returned by mail to an assistant not involved in patient care. Participants received questionnaires by mail at 1, 3, and 6 months postoperatively. One reminder letter was sent to participants who had not returned the first questionnaires.

Instruments

The Rating Form of Inflammatory Bowel Disease Patient Concerns (RFIPC) is a disease-specific questionnaire that rates worries and concerns in patients with inflammatory bowel disease (IBD).17,18 It was originally developed for nonsurgical IBD patients and Drossman (personal written communication, 2002), who developed the instrument, suggested that it could be used in other patient populations, provided an opportunity to express additional worries and concerns was included. We concurred that the RFIPC appeared appropriate for patients with RC undergoing ostomy surgery and included the open question in the original questionnaire in order to ensure that we identified worries and concerns specific to this patient group.17,18 The RFIPC consists of 21 items; responses are scored on a 100-mm visual analogue scale. Extremes were 0 mm, indicating “not at all” and 100 mm, indicating “a great deal.” The stem of each item included the following phrase, “Because of your condition, how concerned are you with…having cancer, or…having an ostomy pouch.” The RFIPC questionnaire has been validated in the United States17,18 and Sweden,19 but it has not been used in patients with RC and ostomies. The dimension “worries and concerns” deals with both the current state of the disease and the patient’s expectations regarding living with their disease.20

Health-related quality of life was evaluated with the Swedish version of 36-Item short form SF-36 version 2.0.21,22 The 36-item questionnaire measures 8 different health domains: physical function; role limitations due to physical problems, bodily pain, general health, vitality, social function; role limitations due to emotional problems; and mental health. Subscales are computed according to standardized procedures and range from 0 to 100; higher scores indicate a better HRQOL.22 A reference sample (N = 57), age and gender, matched to our sample was randomly drawn from the Swedish SF-36 v2.0 national normative database (N = 2185)22 to compare with the patient group.

Participants also answered questions about QOL. Initially, participants were asked about a good QOL. Specifically, they were asked to “Describe what you think contributes
to a good quality of life and what you think is an obstacle to good quality of life.” They were also asked how they perceived their QOL and their health. Responses were scored on a visual analogue scale from 0 to 100 mm, where 0 indicated the worst possible score and 100 indicated the best possible score.

Data Analysis
Descriptive data are reported as median and range. Rating form of inflammatory bowel disease patient concern results were reported as median and interquartile range (IQR).19 When analyzing the rank order of the median values, the item with the highest IQR was assigned the lowest rank value. Median and IQR were reported when QOL and general health were evaluated using the visual analogue scale scale described earlier. We calculated the Mann-Whitney U test for gender differences for RFIPC and perceived QOL and health. The Mann-Whitney U test was also used to compare HRQOL scores (SF-36) preoperatively and at 1, 3, and 6 months postoperatively. One-sample t test was used to compare the SF-36 subscale total scores preoperatively for the study group and 6 months postoperatively with a population norm. All P values < .05 were considered statistically significant. All analyses were completed using SPSS 14.0 for Windows package (Chicago, Illinois).

Qualitative data were analyzed via content analysis.23 Each questionnaire was read several times in order to get an overall picture of the content. The transcripts were searched for words and phrases that were relevant to what the person associated with good QOL and for obstacles to QOL. The words and phrases were then divided into domains for good QOL. The transcripts of obstacles to QOL were deemed richer in content and therefore divided into meaning units that were condensed and abstracted.

Results
Eighty-one patients who underwent surgical management for RC and creation of an ostomy were eligible for study participation. However, 7 patients declined to participate, and 10 were not included because of administrative failure. Preoperatively 7 patients did not answer the questionnaires, and they were also excluded. As a result, 57 patients, including 35 men and 22 women, comprised the study sample. Their median age was 66 years (range, 30-87 years). Forty-four had a colostomy and 13 had a loop ileostomy (Table 1). A WOC nurse followed these patients, based on existing hospital routines at our outpatient os-

<table>
<thead>
<tr>
<th>TABLE 1. Patient Characteristics</th>
<th>Patients (N = 57)</th>
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<tbody>
<tr>
<td>Male/female</td>
<td>35/22</td>
</tr>
<tr>
<td>Age median (range)</td>
<td>66 (30-87)</td>
</tr>
<tr>
<td>Age median male/female</td>
<td>68/64</td>
</tr>
<tr>
<td>Partner/no partner</td>
<td>46/11</td>
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<tr>
<td>Colostomy/loop-ileostomy</td>
<td>44/13</td>
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<tr>
<td>Radiation therapy (preoperatively) short/long</td>
<td>33/10</td>
</tr>
<tr>
<td>Chemotherapy (pre/post)</td>
<td>2/22</td>
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Concerns
The concerns were most predominant during the immediate preoperative period and they gradually declined during the following 6 months. The most intense concerns preoperatively were in the following rank order: (1) developing cancer; (2) being a burden or dependent on others; (3) dying early; (4) uncertain nature of disease; and (5) loss of bowel control. The concern for developing cancer and being a burden on others remained the highest-ranked concerns across the 6-month period (Table 2). Concern for energy level was ranked 11th preoperatively, but 1 month after surgery, it was one of the highest concerns (3rd). At 3 and 6 months, concern for energy level was ranked 4th. Concern for having an ostomy pouch ranked 12th preoperatively out of the 25 concerns addressed in the instrument.

Women generally scored higher (worse) on the concerns than men. When measured postoperatively, women expressed significantly higher concerns regarding “producing unpleasant odors” (P < .003), “feeling dirty or smelly” (P < .01), “pain or suffering” (P < .037), “having an ostomy pouch” (P < .038), and “feeling alone” (P < .006). Women’s median score related to concerns associated with having an ostomy was 73 (IQR 26-95), whereas
the men’s median score was 24 (IQR 18-68). There were no significant differences when concerns were compared based on gender at 1, 3, and 6 months postoperatively. One month postoperatively, women ranked concerns for feeling dirty or smelly as 5th whereas men ranked it 15th. Concerns related to sexual performance gradually increased in men from 17th preoperatively to 4th at 6 months postoperatively; among women it was ranked as 14th at 6 months.

Nine (15.7%) out of 57 participants responded to the open question regarding concerns before surgery. Further concerns not included in the RFIPC questionnaire were (1) recurrence of cancer; (2) not being given all the available information to make one’s own decision; and (3) later problems in life because of the operation.

One month after surgery, 12 (30.7%) out of 39 participants expressed additional concerns not addressed in the RFIPC. They were as follows: (1) ostomy pouches not adhering properly, (2) leakage from the ostomy, (3) uncertainty in time when the ostomy will be reanastomosed, (4) no sensation in the genital area, (5) lower urinary tract symptoms, (6) healing of the perineal wound, (7) pain and malodorous discharge from the perineal wound, (8) later problems in life because of the operation, (9) recurrence of cancer, (10) chemotherapy, (11) waiting for histopathologic tissue analysis, and (12) lack of information. Three months after surgery, 6 (13.6%) out of 44 patients identified additional concerns, which were as follows: (1) cancer recurrence; (2) disease is incurable; (3) working capacity; (4) lack of energy; (5) too long between follow-ups to the doctor; and (6) lack of information. Six months after surgery, 5 (14.2%) out of 35 patients identified the following concerns not addressed in the RFIPC: (1) pain in the perianal area, (2) the perineal wound, (3) restrictions in the choice of clothes, (4) adverse side effects of chemotherapy, and (5) strain on the family.

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**TABLE 2.**

<table>
<thead>
<tr>
<th>TABLE 2. Disease-Related Concerns for Patients Being Operated for Rectal Cancer and an Ostomy*</th>
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</thead>
<tbody>
<tr>
<td><strong>RFIPC Item</strong></td>
</tr>
<tr>
<td><strong>(N = 57)</strong></td>
</tr>
<tr>
<td>Developing cancer</td>
</tr>
<tr>
<td>Being a burden (or dependent) on others</td>
</tr>
<tr>
<td>Dying early</td>
</tr>
<tr>
<td>Uncertain nature of disease</td>
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<tr>
<td>Loss of bowel control</td>
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<tr>
<td>Producing unpleasant odors</td>
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<tr>
<td>Having surgery</td>
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<tr>
<td>Achieve full potential</td>
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<tr>
<td>Feeling dirty or smelly</td>
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<tr>
<td>Pain or suffering</td>
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<tr>
<td>Energy level</td>
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<tr>
<td>Having an ostomy poucha</td>
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<tr>
<td>Feelings about my body</td>
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<tr>
<td>Access to quality medical care</td>
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<tr>
<td>Effects of medication</td>
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<tr>
<td>Feeling out of control</td>
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<tr>
<td>Loss of sexual drive</td>
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<tr>
<td>Feeling alone</td>
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<tr>
<td>Attractiveness</td>
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<tr>
<td>Intimacy</td>
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<tr>
<td>Sexual performance</td>
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<td>Being treated as different</td>
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<tr>
<td>Financial difficulties</td>
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<tr>
<td>Passing the disease to others</td>
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<tr>
<td>Ability to have a child</td>
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</tbody>
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Abbreviations: IQR, interquartile range; RFIPC, Rating Form of Inflammatory Bowel Disease Patient Concerns.

Values range from 0 to 100, with 0 = not at all concerned and 100 = a great deal.

Having an ostomy pouch was only asked preoperatively.
Health-Related Quality of Life
The SF-36 scores declined significantly when preoperative results were compared to scores at 1 month following surgery. Significant declines included physical function (P < .0011), physical role function (P < .001), bodily pain (P < .002), vitality (P < .003), social function (P < .005), and emotional role function (P < .003) domains. In contrast, all domain scores showed significant improvement when preoperative scores were compared to scores obtained 6 months following surgery (Figure 1). No gender differences were found when SF-36 scores were compared.

When preoperative scores were compared to the population-based reference sample described earlier, we found significant differences for physical role function (P < .0071), social function (P < .0009), emotional role function (P < .0172), and mental health (P < .0002) (Figure 1). Significant differences persisted in physical role function (P < .0013), emotional role function (P < .0026), and social function (P < .0044) when results were compared at 6 months following surgery.

QOL measured on the visual analogue scale showed a median of 73 preoperatively; this decreased 1 month postoperatively but rose to preoperative values at 6 months. Perceived health gradually improved from the preoperative assessment, median 53 to 70 6 months postoperatively (Table 3). Analysis revealed no significant differences between men and women.

Content Analysis
Content analysis revealed that the most frequently mentioned descriptions of good QOL both pre- and postoperatively were good relations with significant others, friends, and relatives; social and leisure activities; psychological issues; and health (Table 4). Individual respondents described characteristics of a good QOL as “Being healthy, associating with family and friends,” “Being able to do what you want and like without having to burden someone else,” “Having a positive attitude towards life,” “Having control over life,” and “Giving and receiving love.” Obstacles to QOL described preoperatively were of a general nature, and only a few were specific to RC. Disease-specific obstacles included inability to visit friends because of toileting frequency, pain, and fatigue.

When interviewed at 1 month postoperatively, participants were able to identify more obstacles specific to RC and having an ostomy. Respondents reported anxiety related to what their new life situation would entail. At this point during the recovery period, there was an uncertainty of what limitations and restrictions the new life would imply. For example, one participant reported experiencing “a paralyzing fatigue and waiting for further treatments and an uncertainty of what will happen ... [that] makes me totally exhausted.” Another reported “not being able to look ahead, feeling alone and abandoned.”

When interviewed at postoperative month 6, some participants continued to report pain, fatigue, and worries for the future. One respondent stated, “The ostomy contributes to the fact that I can’t relax and feel comfortable.” Worries were also expressed for the future such as “not being able to do the activities I want to do and that I was able to do before surgery.” Pain and fatigue remained predominant, but some reported nausea associated with chemotherapy treatments. At postoperative month 6, some participants continued to report pain, fatigue, and worries for the future. One respondent described “a body that all the time demands a maintenance of artificial accessories (ostomy appliance).” Others continued to feel restrictions related to their RC and ostomy. One described “being sick, not feeling well and not being able to do what one desires.”

Discussion
We evaluated concerns and HRQOL before surgery and the first months during the recovery period in patients being
operated for RC with an ostomy. Health-related quality of life declined significantly in 6 of 8 domains of the SF-36 when preoperative scores were compared to those measured at 1 month following surgery, but scores improved at 6 months. There were significant differences between the study group and the norm population preoperatively for physical and emotional role function, for social function, and for mental health. At 6 months, there were still significant differences in the same domains except for mental health. Obstacles to maintaining a good HRQOL were fatigue, pain, illness and limitations in life, fear of what the new life would entail, and worries for the future.

The RFIPC questionnaire gave new insight into concerns of patients with RC and an ostomy. An unexpected finding was the high concern for being a burden or dependent on others; this remained the second highest concern throughout the 6-month period. Fear of being a burden has also been observed in patients with short-bowel syndrome and persons with IBD receiving psychiatric counseling. Our findings suggest that the individual with RC not only experiences a struggle against a life-threatening disease but he or she must also cope with a complicated operation, an ostomy, and other factors imposing limitations in daily life. Our findings also suggest that these stressors exert a negative influence on family life. In the literature, the issue of caregiver burden has received considerable attention. Less focus has been directed at the care recipients’ perception of being a burden to others, referred to as “self-perceived burden.” As many as 77% of patients with higher-stage cancers in palliative care experienced being a source of burden to their family caregivers. Comparisons of participants with high or low levels of self-perceived burden showed the importance of this factor in overall HRQOL. A qualitative study of persons receiving palliative care for advanced-stage malignancies revealed that patients divide perceptions of burden into 3 categories. Concerns for others included the physical, social, and emotional hardships that participants believed they were creating for others, as well as concerns about the future and likely effect of their death and those around them. The second category, implications for self, was characterized by feelings of responsibility associated with causing hardships to others, resulting in distress, and a diminished sense of self. The third category, minimizing burden, was defined as coping strategies used by participants to alleviate the burden and reduce the negative impact on others. The results of our study suggest that concern for being a burden also exists in patients with RC who require creation of an ostomy. Participants also reported concerns related to the uncertain nature of their disease, fear of cancer recurrence, anxiety over what their new life will entail, and worries about the future. According to Mishel, uncertainty is the inability to determine the meaning of illness-related events and occurs when insufficient cues prevent the person from adequately structuring or categorizing an event, thus inhibiting the person’s ability to predict outcome adequately. Uncertainty disrupts the development of personal meaning regarding an illness, thus creating a more threatening and stressful situation for patient and family. The loss of control and accompanying uncertainty lead to psychological distress. Galloway and Graydon studied the relationship between uncertainty, distress symptoms, and information needs in patients undergoing surgical management of colon cancer and found a direct proportional relationship between uncertainty and a greater need for information. Wilson and colleagues identified uncertainty as a determinant of HRQOL in patients recovering from surgery for colorectal cancer. Shahe and colleagues reviewed the literature on uncertainty in patients with breast, prostate, or colorectal cancer and identified 3 main themes: (1) uncertainty because of limited or lack of information; (2) uncertainty related to treatment course and treatment options; and (3) uncertainty related to everyday life and coping with the disease.
Respondents in our study expressed concern for energy levels throughout the postoperative period, and fatigue was identified as an obstacle to QOL. Fatigue was reported as a common symptom among cancer patients in several studies.32,33 Fatigue associated with cancer and related treatments differs from ordinary tiredness that patients often associated with deteriorating health. It is therefore important to discuss fatigue when managing patients with RC and an ostomy, including counseling that physical activity has been shown to have a positive influence on the perception of fatigue and on recovery.35

Women reported significantly greater levels of concern about having an ostomy bag, producing unpleasant odors, and feeling dirty than men. Teaching patients colostomy irrigation postoperatively can be one way to address these issues and alleviate concerns, and here the WOC nurse has an important role.36

Concerns related to sexual performance gradually increased in men during the 6-month observation period. In a study, following patients over a 2-year period, men reported difficulties with sexual enjoyment, and over time sexual problems created high levels of strain.37 For both men and women, the sense as a sexual human being may be threatened not only by the illness that led to surgery but also by the lived experience of having an ostomy.38

The SF-36 scores dropped significantly below baseline except for general health and mental health 1 month postoperatively. However, HRQOL gradually improved over the 6-month period of data collection. Schmidt and associates37 reported similar results comparing patients with RC over a 2-year period. Our participants stated that pain had a substantial influence on HRQOL at 1 month. Pain was also identified as an obstacle to QOL, and it ranked as the fifth highest concern 1 month postoperatively. Persson and associates16 found that spouses of patients with RC also reported that their partners experienced pain after discharge from hospital. However, we were not able to identify research on postoperative pain in this particular context in the literature.

We found significant differences between the study group and the general population in physical and emotional role function, social function, and mental health assessed by the SF-36. Although scores improved by the 6th postoperative month, significant differences between study and population-based groups persisted on all of these domains except mental health. Participants’ descriptions of good QOL focused on social relations, social and leisure activities, psychological issues, and health. Similar findings were found in a national survey by Bowling.29 Obstacles to QOL were fatigue, pain and limitations in life, and these could be some of the reasons why participants tended to report impaired social life. Vironen and coinvestigators,38 who questioned patients 1 year after surgery for RC, also reported poorer social functioning than population controls. They also reported that lower urinary tract and erectile dysfunction were associated with impaired social functioning.

Respondents in our study also identified lower urinary tract symptoms as impairing QOL following surgery.

**Limitations**
Several limitations were associated with the study. The response rate at the various data collection intervals varied and was lower than desired. However, an operation for RC is physically and psychologically demanding and we hypothesize that these factors influenced response rates. The RFIPC questionnaire has not been validated in patients with RC. We selected the instrument because we believed that items of concerns were also appropriate for patients with RC and an ostomy. An open question allows respondents to express additional concerns, but relatively few were identified. We believe that this finding strengthens the case for using the RFIPC in this population.

**Conclusions**

The results of this study enable deeper insight into patient-centered concerns and HRQOL in patients with RC and an ostomy. The presence of an ostomy was not seen as the major problem; instead, stressors were associated with the cancer diagnosis and its surgical management, which affected patients both physically and emotionally. HRQOL scores were especially impaired the first month following surgery, but they tended to improve by the sixth postoperative month. Talking openly about worries and concern regarding the new life situation may alleviate suffering and reduce uncertainty. WOC nurses and other health care professionals play an important role in the care of patients with RC and an ostomy and greater insights into the worries and concerns affecting this population are anticipated to improve postoperative counseling and education.

**KEY POINTS**

- Surgical management for RC influences HRQOL during the immediate postoperative period; HRQOL domains tend to improve gradually over the next 6 months.
- Patients expressed concern for being a burden on others preoperatively and during the first 6 months postoperatively.
- Patients reported concern related to the uncertain nature of RC and fear of what their new life would entail.
- The presence of an ostomy was not perceived as the major problem during the recovery period; instead, concerns were associated with cancer diagnosis and surgery for RC.
- Patients with RC who undergo ostomy surgery require ongoing support and frequent follow-up by a WOC nurse and other health care personnel.
ACKNOWLEDGMENTS

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