

Gender Differences in Quality of Life Among Long-Term Colorectal Cancer Survivors With Ostomies

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Colorectal cancer (CRC) accounts for more than 9% of all new cancer cases, and it has the third most frequent incidence rate for cancer in the United States (American Cancer Society [ACS], 2011). Survival rates at one year and five years are 83% and 65%, respectively (ACS, 2011). An estimated 18%–35% of the 1.1 million people alive in the United States with a history of CRC (Mariotto, Yabroff, Feuer, De Angelis, & Brown, 2006), particularly those with low-rectal cancers, have received temporary or permanent intestinal stomas (ostomies) (Gastinger et al., 2005; Jess, Christiansen, & Bech 2002; Schmidt, Bestmann, Küchler, Longo, & Kremer, 2005). Studies have found that CRC survivors, particularly women and those with ostomies, have persistent deficits in their health-related quality of life (HRQOL) (Krouse et al., 2009; Nugent, Daniels, Stewart, Patankar, & Johnson, 1999; Thomas, Madden, & Jehu, 1987; Tuinstra et al., 2004). Understanding how living with an ostomy affects those survivors and how to best help them in the management of ostomy-related challenges is necessary to supporting their HRQOL. The authors undertook this assessment of HRQOL concerns to develop interventions specifically geared toward relief of physical, psychological, social, and spiritual distress and to determine differences in the concerns and adaptations raised by men and women with high versus low HRQOL. Although the time that healthcare professionals have to provide care, education, and support to patients with CRC with ostomies and their families is limited, interactions with the patient and family, particularly during long-term follow-up, should address the most common concerns and challenges that affect HRQOL on a daily basis. This article describes quality-of-life concerns as identified by gender-specific focus groups of cancer survivors with ostomies.

Background

Fecal ostomies, or the surgical exteriorization of the small (ileostomy) or large (colostomy) bowel to the

Purpose/Objectives: To describe how gender shapes the concerns and adaptations of long-term (i.e., more than five years) colorectal cancer survivors with ostomies.

Design: Qualitative study using content analysis of focus group content.

Setting: Oregon, southwestern Washington, and northern California.

Sample: Four female and four male focus groups (N = 33) selected from 282 quantitative survey participants with health-related quality-of-life (HRQOL) scores in the highest or lowest quartile.

Methods: Eight focus groups discussed the challenges of living with an ostomy. Content was recorded, transcribed, and analyzed using directive and summative content analysis.

Main Research Variables: HRQOL domains of physical, psychological, social, and spiritual well-being.

Findings: All groups reported avoiding foods that cause gas or rapid transit and discussed how limiting the amount of food eaten controlled the output. All groups discussed physical activities, getting support from friends and family, and the importance of being resilient. Both genders identified challenges with sexuality and intimacy. Coping and adjustment difficulties mostly were discussed by women, with men only discussing these issues to a small extent. Difficulties with sleep primarily were identified by women with low HRQOL. Problems with body image and depression were discussed only by women with low HRQOL.

Conclusions: Common issues included diet management, physical activity, social support, and sexuality. Although both genders identified challenges, women described more specific psychological and social issues than men.

Implications for Nursing: Application of these gender-based differences can inform educational interventions for colorectal cancer survivors with ostomies.

anterior abdominal wall, allow intestinal waste to flow directly into an external pouch (appliance). Ostomies may be permanent, as with low-rectal cancers, or temporary, when required to divert fecal flow related to emergent procedures or in protecting bowel anastomoses. Ostomies may be necessary in the surgical treatment of CRC

because of obstruction, metastatic disease, or other medical concerns. The HRQOL implications of CRC treatment options are a major consideration for survivors, and not always well understood (Solomon et al., 2003). Anastomosis reconstruction, in which the bowel is rejoined to allow for defecation through the anus, may seem preferable to an ostomy. However, Pachler and Willie-Jørgensen (2005) found that HRQOL actually may be worse in rectal cancer survivors who were reconstructed without a permanent ostomy when compared with those where ostomy was required. That was because of uncontrollable fecal leakage in those without ostomies versus more control in those with an ostomy (Pachler & Willie-Jørgensen, 2005).

A wide evidence base addresses the physical and psychosocial consequences of having an ostomy (Altschuler et al., 2009; Baldwin et al., 2009; Fazio, Fletcher, & Montague, 1980; Grunberg, 1987; Hojo, Vernava, Sugihara, & Katumata, 1991; Hurny & Holland, 1985; Keyes, Bisno, Richardson, & Marston, 1987; Klopp, 1990; Krouse et al., 2009; Liu et al., 2010; Lundy et al., 2009; Nugent et al., 1999; Ramirez et al., 2009; Sprangers, Taal, Aaronson, & te Velde, 1995; Sutherland, Orbach, Dyk, & Bard, 1952; Thomas et al., 1987; Wirsching, Drüner, & Herrmann, 1975). The evidence makes it clear that regardless of the type of ostomy or the reason for its creation, this life-changing procedure frequently results in profound changes in a person's functioning and well-being (Grant, 1999; Grant et al., 2004; Krouse et al., 2007). Why some people adjust more easily than others still is not well understood. A cross-sectional study of long-term rectal cancer survivors with ostomies provided a comparison of quality of life between genders and revealed areas of significant differences (Krouse et al., 2009). Women with ostomies consistently scored lower than men with ostomies for overall quality of life, as well as the four HRQOL domains of physical, psychological, social, and spiritual well-being. Women also scored worse than men on depression and suicidal ideation. Women with ostomies scored lower on spiritual well-being and family distress than did men with ostomies (Krouse et al., 2009).

Comments from people with long-term experience with an ostomy can provide valuable information for long-term adjustment to a permanent ostomy. The current authors' approach involved using focus groups to identify specific challenges ostomates face, their adaptation processes, and the strategies they adopted for self care.

Methods

Sample and Design

The authors began with a database of 282 patients who participated in a survey mailed to patients with CRC who were 18 years or older. Participants were at

least five years postdiagnosis and were members of Kaiser Permanente, an integrated healthcare delivery system, who resided in Oregon, southwest Washington, or northern California. Details regarding the original study may be found elsewhere (Krouse et al., 2009). Results of the survey included an overall quality-of-life score on the City of Hope Quality of Life–Ostomy questionnaire (Krouse et al., 2009; Mohler et al., 2008). The authors contacted participants who successfully adapted (in the highest HRQOL quartile, or high HRQOL), as well as those who were extremely challenged with stomal issues (in the lowest HRQOL quartile, or low HRQOL). Potential participants were invited to take part in a focus group to discuss challenges and adjustments to living with an ostomy. The focus groups were divided by gender, based on evidence that challenges and adjustment to an ostomy have demonstrated gender differences (Baider, Perez, & De-Nour, 1989; Baldwin et al., 2009; Fernsler, Klemm, & Miller, 1999; Forsberg & Cedermark, 1996; Krouse et al., 2009; Salkeld, Solomon, Short, & Butow, 2004). The goal was to recruit four to eight participants for each gender- and HRQOL-based focus group to provide adequate saturation. A total of eight focus groups were formed, based on high versus low HRQOL and gender.

Focus groups were tape recorded for later transcription. A discussion guide with a series of open-ended questions was used to elicit a broad spectrum of issues. Discussion began with individual cancer treatments and surgeries and then proceeded to questions on care, adjustment, and various ostomy concerns. All study procedures and protocols were approved by the Kaiser Permanente Northwest and Northern California review boards.

Prompts in the discussion guide were used to focus the moderator on topics to be discussed under that question, and for the moderator to use if the topic did not arise spontaneously. The group facilitator for each session was experienced in this role. In addition, a silent recorder observed and took notes throughout each focus group to record participants' statements to help clarify transcriptions and document field observations regarding participant behavior (e.g., early or late arrival time, demeanor in responding to focus group topics) and unobtrusive measures (e.g., manner of dress for the focus groups). Each focus group lasted about two hours, providing sufficient time for each group to cover the questions in the guide. Elaboration on some topics varied across groups, but all groups consistently addressed all topics in the guide. Focus group recordings were transcribed verbatim for qualitative analysis, with the exception that names were replaced with focus group identification numbers.

The focus group recordings were transcribed as rich text format and analyzed using HyperRESEARCH™. Because the goal of the current analysis was to uncover HRQOL-related concerns across defined domains of

HRQOL, analysis followed a directed content analysis approach based on the City of Hope four-dimensional framework (Grant et al., 2004; Hsieh & Shannon, 2005). Two clinical investigators trained in qualitative analysis reviewed all focus-group transcripts to identify themes for categorizing ostomy-related HRQOL discussions into domains of the City of Hope model (Grant et al., 2004; Krouse et al., 2007), including physical, psychological, social, and spiritual well-being. The authors then positioned relevant comments within the themes (see Figure 1). Two investigators completed a final validation review to ensure consistency and clarity across all data. Selections that were discordantly coded (10%–15%) were discussed to better refine and come to consensus on coding.

Results

Focus group participation ranged from two participants in one group to eight in another (see Table 1). For the group with only two participants, two confirmed participants called at the last moment, unable to attend. Reasons contributing to low participation rates included living a great distance from the centers, comorbidities, and forgetting to attend the focus group. Participants were overwhelmingly Caucasian, although the sample did include one African American participant, one Hispanic participant, and one participant who reported a multiethnic background (see Table 2). Other sociodemographic characteristics that varied across groups included income, marital status before surgery and currently, and employment status. Education level was similar across groups.

Focus Group Analysis

Using directive content analysis, focus group data were placed in the four domains of the quality-of-life model (Hsieh & Shannon, 2005). Similarities and differences in comments across groups became apparent as the data were analyzed. Summative content analysis was used to identify the number of times comments occurred within

Table 1. Focus Group Participants by Location

| Focus Group HRQOL | KPNW | KPNC | Total |
|-------------------|------|------|-------|
| High: Men | 4 | 8 | 12 |
| High: Women | 5 | 5 | 10 |
| Low: Men | 3 | 2 | 5 |
| Low: Women | 3 | 3 | 6 |
| Total | 15 | 18 | 33 |

HRQOL—health-related quality of life; KPNC—Kaiser Permanente Northern California; KPNW—Kaiser Permanente Northwest

Note. “High” and “low” indicate that the participant was in the high (better) or low (worse) quartile in the distribution of overall quality-of-life scores on the City of Hope Quality of Life–Ostomy questionnaire, respectively.

each theme (Hsieh & Shannon, 2005). That approach offered a valuable view of the unique character of each focus group. The number of comments under a theme indicates how responsive the group was regarding a particular topic area, whereas the number of codes represents the richness of topics mentioned in the discussion (see Table 3). In general, high-HRQOL groups addressed fewer themes within each of the four dimensions than did low-HRQOL groups. Women had more comments across themes than men. In addition, the physical and social well-being dimensions had the most themes and comments, whereas spiritual well-being had the least. The summative content analysis of the focus group data illustrates that the female focus groups discussed more unique HRQOL topics compared with the male focus groups. Low-HRQOL focus groups raised a broader range of topics than high-HRQOL focus groups.

Quality-of-Life Similarities and Differences by Gender

Quotations provide additional information about the similarities and differences across the focus groups (see Table 4). Comments revealed unmet needs and challenges, as well as ways participants successfully adapted.

Physical well-being: Participants in all groups identified foods, particularly those that were gassy, fatty, or spicy, that caused gas and rapid evacuations. In addition to specific foods, focus group participants elaborated on their own behavior in relation to food and eating. Participants discussed how they discovered what foods they could eat and what foods they had to avoid by the somewhat idiosyncratic reactions they had to specific foods. Although specific foods to avoid varied from one individual to another, approaches to learning what foods to eat were identified across the focus groups. Participants avoided foods that caused gas and rapid transit through the gastrointestinal tract. They also discussed how limiting the amount of food consumed helped control the output. Participants were eager to share what they had learned as they

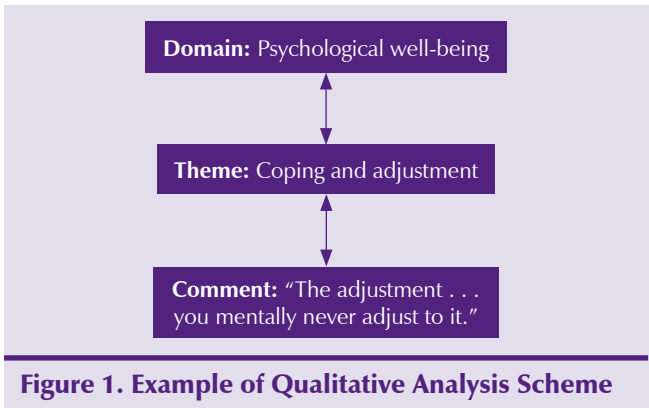


Figure 1. Example of Qualitative Analysis Scheme

adjusted to their ostomy and began to eat, try different foods, and connect what they ate with what ostomy output occurred. In relation to gas and odor, discussion occurred most frequently in all female groups, less frequently in a low-HRQOL men's group, and was not mentioned in a high-HRQOL men's group.

Physical activity was a code discussed primarily in the low-HRQOL groups. Participants identified a number of activities that they stopped doing as a result of their ostomy. Participants identified activities such as hiking, bowling, and gardening that they resumed after adjusting to the ostomy. Swimming was a popular topic, and many individuals figured out ways to resume swimming as well as other activities. Participants identified ways they overcame concerns about offending others with their condition, whether it was timing, clothing, or just not revealing anything about their ostomy.

Difficulties with sleep were expressed primarily by women and those in the low-HRQOL groups. These difficulties were related to pouch leaks and sleeping positions, and illustrate that deep uninterrupted sleep does not occur for some CRC survivors.

Psychological well-being: Themes within the psychological well-being domain were discussed more frequently by men and women in the low-HRQOL groups. Coping and adjustment was a code discussed by many that revealed differences in adjustment by gender. Both men's groups expressed little or no difficulties in adjustment. Using humor to cope was discussed by all the groups, and discussion related to developing self-sufficiency occurred in all women's groups and a low-HRQOL men's group. Comments revolved around how participants learned to care for the ostomy. Comments relating to the self-acceptance code were not frequent, but illustrated positive thoughts.

Within the psychological domain, body image and depression were mentioned only by women. Unpredictability comments illustrate the loss of control that the ostomy exerts.

An additional code in the psychological well-being domain, resignation, was discussed only by one high-HRQOL man. He said, "Here I am. I've got a pouch for the rest of my life."

Overall, codes within the psychological well-being domain illustrated positive and negative concerns, with far more codes and comments expressed by the men and women in the low-HRQOL groups. Those comments are from individuals who underwent ostomy surgery years ago and illustrate the enduring psychological challenges associated with an ostomy.

Social well-being: The large number of comments coded in the social well-being dimension illustrate the importance of the domain to all participants. Modifying clothing worn was a topic discussed in all the groups. Topics focused on protecting the ostomy from being pressed too tightly and irritated, or wearing loose clothing so that the ostomy pouch was not visible.

Sexuality also was discussed across all focus groups, with one or two comments that indicated sexual relations were not problematic and a number of comments in each group about sexuality and intimacy problems related to complications of surgery or radiation therapy. One single woman in a high-HRQOL group began a relationship several years after her surgery. She traveled

Table 2. Sociodemographic and Clinical Characteristics of Participants

| | High: Men (N = 12) | | High: Women (N = 10) | | Low: Men (N = 5) | | Low: Women (N = 6) | |
|------------------------------------------------|-----------------------|----|-------------------------|----|---------------------|----|-----------------------|----|
| Characteristic | \bar{X} | SD | \bar{X} | SD | \bar{X} | SD | \bar{X} | SD |
| Age (years) | 73 | 8 | 76 | 9 | 67 | 8 | 63 | 14 |
| Years since surgery | 12 | 8 | 19 | 8 | 8 | 3 | 13 | 8 |
| Characteristic | n | | n | | n | | n | |
| Race or ethnicity | | | | | | | | |
| Caucasian | 10 | | 9 | | 4 | | 6 | |
| Black, non-Hispanic | — | | 1 | | — | | — | |
| Hispanic or Latino | 1 | | — | | 1 | | — | |
| Mixed | 1 | | — | | — | | — | |
| Education | | | | | | | | |
| High school graduate | 4 | | 2 | | 1 | | 1 | |
| At least some college | 8 | | 8 | | 4 | | 5 | |
| Annual household income (\$) | | | | | | | | |
| 50,000 or less | 4 | | 3 | | 3 | | 5 | |
| 50,001 or more | 6 | | 5 | | 2 | | 1 | |
| Unknown or no response | 2 | | 2 | | — | | — | |
| Married or had partner prior to surgery | 11 | | 6 | | 3 | | 5 | |
| Married or has partner currently | 10 | | 3 | | 3 | | 4 | |
| Employment | | | | | | | | |
| Full-time | 2 | | 1 | | 1 | | 1 | |
| Part-time | 2 | | — | | — | | 1 | |
| Retired | 8 | | 9 | | 4 | | 4 | |

Note. "High" and "Low" indicate that the participant was in the high (better) or low (worse) quartile in the distribution of overall quality-of-life scores on the City of Hope Quality of Life–Ostomy questionnaire, respectively.

with her new friend out of town, expecting to be intimate for the first time since surgery. After taking off her clothes, however, her friend's reaction scared her. She promptly got dressed and went home, and was reluctant to take her clothes off in front of a man ever again.

A topic discussed in all eight groups was the challenge of travel. The most common approach to travel was to be prepared with extra supplies. In addition, one woman in a low-HRQOL group indicated that she would stay in a hotel, rather than a friend's or relative's home, when visiting. Another woman in a low-HRQOL group discussed her difficulties with traveling in a tour group, specifically having a stranger as a roommate, being on buses for long periods of time, and eating different foods.

Support also was discussed under social well-being. That included spousal support for those who were married and support from friends for those who may or may not have been married. Comments on support received were from each of the focus groups.

Embarrassment related to employment was a theme brought up in the low-HRQOL women's group only; however, financial concerns were mentioned in all groups and with different concerns.

Spiritual well-being: Although this domain generated the least amount of discussion, all four groups talked about resilience or inner strength and its importance in their life after having an ostomy. An appreciation for life was expressed by one man in a high-HRQOL group, and several women in the low-HRQOL groups. Gratitude was expressed only in the women's groups. Men and women in the low-HRQOL groups identified seeing their children and grandchildren as a reason to live. Only one participant commented on the value of her faith community.

Discussion

For the current study, the authors conducted focus groups based on gender and quality-of-life questionnaire scores. That method resulted in discussions about HRQOL that expanded and clarified issues and challenges identified in previous surveys (Grant, 1999; Grant et al., 2004; Krouse et al., 2007). Some focus group themes occurred across all groups, whereas others were focused primarily in either high- or low-

Table 3. Number of Focus Group Comments Within Each Domain and Code

| Theme | High: Men | High: Women | Low: Men | Low: Women | N |
|-------------------------------|-----------|-------------|-----------|------------|------------|
| Physical Domain | 11 | 41 | 38 | 52 | 142 |
| Diet issues | 10 | 23 | 23 | 24 | 80 |
| Physical activity | 1 | 5 | 13 | 12 | 31 |
| Sleep | — | 6 | 3 | 10 | 19 |
| Gas or odor | — | 7 | 4 | 7 | 18 |
| Fertility issues | — | — | — | 1 | 1 |
| Psychological Domain | 7 | 7 | 13 | 17 | 51 |
| Coping and adjustment | 3 | 2 | 3 | 8 | 16 |
| Humor | 2 | 3 | 5 | 3 | 13 |
| Self-sufficient | — | 1 | 3 | 1 | 5 |
| Self-acceptance | 1 | 1 | 2 | 1 | 5 |
| Unpredictability | — | — | — | 2 | 2 |
| Body image | — | — | — | 1 | 1 |
| Sadness and depression | — | — | — | 1 | 1 |
| Resignation | 1 | — | — | — | 1 |
| Social Domain | 20 | 17 | 21 | 34 | 92 |
| Clothing | 5 | 5 | 3 | 5 | 18 |
| Sexuality | 6 | 2 | 5 | 3 | 17 |
| Travel | 4 | 3 | 3 | 7 | 17 |
| Financial issues | 4 | 3 | 4 | 5 | 16 |
| Social support | 1 | 2 | 4 | 2 | 9 |
| Embarrassment | — | — | — | 7 | 7 |
| Privacy | — | 1 | 2 | 2 | 5 |
| Employment | — | — | — | 3 | 3 |
| Spiritual Domain | 2 | 4 | 4 | 10 | 20 |
| Resilience and inner strength | 1 | 2 | 3 | 3 | 9 |
| Appreciation for life | 1 | — | — | 4 | 5 |
| Gratefulness | — | 2 | — | 1 | 3 |
| Reason to live | — | — | 1 | 2 | 3 |
| Faith community | — | — | 1 | — | 1 |

Note. "High" and "low" indicate that the participant was in the high (better) or low (worse) quartile in the distribution of overall quality-of-life scores on the City of Hope Quality of Life–Ostomy questionnaire, respectively.

HRQOL groups, or in specific gender groups. When discussing dietary issues, all groups reported avoiding foods that cause gas or rapid transit, and discussed how limiting the amount of food eaten at any one time controlled the output. All focus groups also discussed physical activities, getting support from friends and family, and the importance of being resilient. Problems with body image and depression were discussed only in the low-HRQOL women's groups. That confirms the findings of Tuinstra et al. (2004), who reported increased vulnerability to distress by women. Men and women identified specific challenges with sexuality and intimacy. Di Fabio, Koller, Nascimbeni, Talarico, and Salerni (2008) assessed patients with CRC 14–74 months after surgery using the European Organisation for Research and Treatment of Cancer questionnaire,

Table 4. Illustrative Quotes From City of Hope Domains

| Variable | High-HRQOL Women | High-HRQOL Men | Low-HRQOL Women | Low-HRQOL Men |
|---------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Physical Well-Being | | | | |
| Activities | — | — | <p>They told me not to lift more than 10 pounds. In the beginning I thought, “Well, that’s kind of hard.” So even cat litter—I can only buy 14 pounds.</p> <p>I asked before I had it, “Can I still swim?” and [the ostomy teacher] said, “Yes.” I mentioned it to another teacher, who had a colostomy, and she said “Can you still swim?” And I said “Yeah, it doesn’t come off. Nothing comes out of it.” But they told me, don’t go tell the health club that you have one because people don’t understand. I make sure I don’t eat before I go, and I go early in the morning.</p> | <p>I used to run 10, 12 miles a day. Now I just walk. It doesn’t bother me with walking too much. Running seems to just agitate my system to the point where anything in there, it works it out.</p> |
| Diet | <p>You learn over the years, what you can and can’t do. And you can’t overeat. That’s why it is wise to graze. You just eat all the time, and that’s not a problem. But if you just sat down and ate a huge meal, like a farmhand, it would be a bad thing. You know, the pouch fills, and you get uncomfortable, things back up.</p> | <p>There are some spicy foods that seem to linger a long time [that] I try to avoid.</p> | <p>I try to chew my food slowly, and I don’t drink until after I eat.</p> | <p>It’s a matter of not so much when you eat, but what you eat. You kind of develop a sense for what’s gonna work in your system, what’s gonna stay in your system and stay in a solid form, and not rush through the system or pour out.</p> |
| Gas and odor | <p>Talk about blowing up, immediately. I don’t know what there is about it. It’s like “Hello, stomach. Boom.” So I don’t eat that.</p> | — | <p>I try everything at home for odor control and it’s just an odorous thing. There’s not a lot you can do about it.</p> | <p>It smells quite a lot. It depends on what you’re eating.</p> |
| Sleep | <p>I sleep on my back. That’s something new since the ostomy. But if I turn over, and the bag is kind of full, it will pop.</p> | | <p>One thing that’s changed is I wake up more often at night. I constantly reach down to find out if it is full.</p> | <p>I’m moving around and restless (all night).</p> |
| Psychological Well-Being | | | | |
| Body Image | — | — | <p>You’re this person walking around with a bag of something hanging off you.</p> | — |
| Coping and adjustment | — | <p>After the operation I lifted up the sheets and I look and I says, “Oh, so that’s what it is, huh?” And that was it. It never bothered me after that. I didn’t have any problems adjusting to it.</p> | <p>It’s been nine years and I will stand over the toilet some days going, “Why me?” And then I have to still think back and say “Well, I’m alive.”</p> | <p>Like I say, it’s just an inconvenience now.</p> |

(Continued on the next page)

CT—computed tomography; HRQOL—health-related quality of life

Table 4. Illustrative Quotes From City of Hope Domains (Continued)

| Variable | High-HRQOL Women | High-HRQOL Men | Low-HRQOL Women | Low-HRQOL Men |
|---------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------|
| Psychological Well-Being (continued) | | | | |
| Depression | — | — | There is a certain amount of depression after. It totally destroyed all of our plans and things we had hoped for [respondent near tears]. | — |
| Self-acceptance | It's just kind of fun to talk about it, but it's part of my life. That's it. That's the way it is. | — | I was getting so bold, I'd go to buy some clothes, [and] I'd just say "I have a colostomy, so I can't wear that." | Well, the biggest thing was learning to live with it. It's there and you never get used to it, you just learn to live with it. |
| Self-sufficiency | Actually, I kind of taught myself. The doctor kind of showed me . . . and then the bag had the instructions on it. I just really taught myself. | — | I think I called an ostomy nurse once for some advice. You know, you just figure it out. | They'll give you some advice. And vary from it a little bit, if you think you have to, you have to get it to work best for you. |
| Unpredictability | — | — | You've always got that [the bag filling] on your mind. It could be just fine one day and the next day it's just like, "Crap. Here I go." I'm flying to the bathroom. Even after nine years, I'm still trying to think what is it that's making me do this? You say it's [ostomy] more sensitive and I think, yeah, mine is. | — |
| Social Well-Being | | | | |
| Clothing | I never wear blue jeans. They fit too tight. | It's more convenient to wear bikini underwear instead of briefs. | I try to wear things that go over. I don't wear anything tucked in. | Suspenders, yeah. Or big overalls . . . carpenter overalls. |
| Embarrassment related to employment | — | — | I was having accidents. And I was also a teacher. . . . I was totally embarrassed. You probably don't really think hard about it very much except when you are having an accident at work—that is really hard. | — |
| Financial issues | I didn't pay one cent [of out-of-pocket expenses]. | All mine is paid for. | I learned that there are different avenues you can look into, but there was nobody really to help me with the cost . . . it was very spendy. | Even with Medicare, Medicaid, and K-, it was costing me \$75 every three months for supplies. |
| Sexuality | I was all burnt up . . . [from] the radiation. There's nothing down there since I got it. | I am a widower, and am dating. I don't think anything can be done about having a sexual relationship. | The surgery shrank me and the scar tissue built up and tilted me, so our sexual relations basically went to almost nothing. Before [the surgery], we were very, very active. Now, I could care less because it hurts and I bleed. | There's no sex life anymore. It's gone. |

(Continued on the next page)

CT—computed tomography; HRQOL—health-related quality of life

Table 4. Illustrative Quotes From City of Hope Domains (Continued)

| Variable | High-HRQOL Women | High-HRQOL Men | Low-HRQOL Women | Low-HRQOL Men |
|--------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Social Well-Being (continued) | | | | |
| Social support | I don't have any family, but just some very good friends who stood by me. | My wife is the one that got me through the whole thing. I would have never ever have made it. | To have somebody keep you there on the phone and talk to you and get you through crying, I was definitely glad that they were there. | After surgery I was still bowling. I had a couple of accidents. It was a really good bunch of guys I was bowling with. They just said, "Deal with it. Take off. Take care of it." |
| Travel | I went to Hawaii . . . [I] hardly went to the beach because I thought I couldn't get away from the hotel. | I'm going on an outing with a bunch of guys. To be on the safe side, I take extra of everything with me . . . extra pair of pants, two extra shirts. | I just have to remember to bring stuff with me. I have a bag in my purse and an extra plastic sack to wrap something in if I need to get rid of it. | You want to take your little bag and make sure you've got a week's worth of supplies with you . . . and don't put it in the luggage. You want it . . . right with you in your seat. |
| Spiritual Well-Being | | | | |
| Appreciation for life | — | I've had a very good life up to the point of the operation. I still enjoy life. | — | I considered the expression, "Better a bag than a box." |
| Gratitude | I'm just happy that the doctor discovered my cancer. . . . I didn't go to him for cancer. | — | I'm glad the [the doctor] made the decision, because I don't think I would have wanted to be in a diaper for the rest of my life. | — |
| Resilience and inner strength | You have to have a positive attitude. My sister said "I'm not like you. I can't live like that." She had surgery, was not going to accept it. . . . Three weeks later she was dead. | It didn't stop me from taking care of my garden and my orchard. . . . I'm doing alright. I have no complaints. | I think that you just have to make up your mind that you're gonna live with it, and you do. | You got to want to do something, you know. . . . I'm going to have some fun. I'm not just going to quit. |
| CT—computed tomography; HRQOL—health-related quality of life | | | | |

including a six-item component on sexual function. Results revealed that 61% of patients with colon cancer reported no sexual dysfunction, whereas only 24% of patients with rectal cancer reported no problems. Patients with no sexual problems reported a higher HRQOL. These results provide the quantitative evidence for the discussion on sexual problems in all of the focus groups. Difficulties with sleep were identified by women, and primarily in the low-HRQOL groups. Coping and adjustment difficulties were expressed by women, whereas men appeared less bothered by these issues. These results are similar to those of Baider et al.'s (1989) study of adjustment in couples with colon cancer using the Brief Symptom Inventory and the Psychosocial Adjustment to Illness. In that study, gender differences illustrated that adjustment by male patients was superior to that of female patients (Baider et al., 1989). That also parallels the results of a meta-analysis of symptom differences in coping behavior by Tamres, Janicki and Helgeson (2002). In that review, women

were more likely to engage in coping strategies, seek emotional support, ruminate about problems, and use positive self-talk.

Comments provided by focus group participants provided in-depth information on the concerns identified in a number of surveys, and confirmed the patterns of gender differences in previously published quantitative surveys (Grant et al., 2004; Krouse et al., 2007; Krouse et al., 2009; Nugent et al., 1999; Thomas et al., 1987; Tuinstra et al., 2004). Low-HRQOL groups illustrated the range of concerns within each of the four domains: physical, psychological, social, and spiritual. The extensive themes and comments under social well-being mirrored the HRQOL questionnaire scale results in which low social well-being was associated with the poorest quality of life (Krouse et al., 2009). Focus group results provided specific examples of problems and needs.

The focus group guide was administered in the same fashion across all focus groups. Summative content analysis positioned the number of comments in response

to each of the questions and provided information on the nature and content of the discussion in each focus group. Those comments illustrate the differences across the HRQOL groups by gender as well as quality of life.

The directive content analysis provided evidence that can be used to design educational and supportive interventions to help patients with ostomies early in their postoperative recovery period, as well as content useful to long-term survivors. Because of the HRQOL differences identified by men and women, gender-specific support groups or interventions are recommended for at least some of the content. Although group settings may seem inappropriate for discussing matters of intimacy, stigma, and defecation, participants in the current study's focus groups made positive statements about being able to share their experiences among peers; some commented that they had not expected the camaraderie that emerged during the focus group discussion. In each of the groups, participants commented that focus group participation gave them an valuable opportunity to talk with others who had ostomies. On the other hand, some survivors may have declined participation in the focus groups because of a reluctance to discuss such matters. Nonetheless, discussion of challenges and adaptations in a group setting provided a rich variety of comments; thus, group approaches to education and support should be offered.

Having a colostomy or ileostomy typically means enduring incontinence as a way of life. Incontinence, particularly fecal incontinence, may lead to stigmatization in social interactions (Garcia, Crocker, Wyman, & Krissovic, 2005; McMullen et al., 2008). Therefore, patients deserve to be assisted in adjusting and coping with the ostomy and continuing other life activities. Healthcare professionals need to address patients' challenges and plan and test interventions that provide them with the best possible quality of life.

The current study's results may be somewhat limited by a lack of sufficient diversity in each of the groups and the small number of participants in some groups. Nevertheless, the findings provided in-depth information that reinforced and expanded the findings of the questionnaire, particularly with respect to the unique challenges faced by female CRC survivors with ostomies. Replication by additional focus groups with a larger sample size is recommended. Drawing the current sample from the highest and lowest quartiles of the 282 survey respondents, however, targeted a representative sample.

Implications for Nursing Practice

Findings from the current study may be valuable to clinicians planning group support and other interventions to assist adaptation in the population of CRC survivors with ostomies. Content should include specific aspects, such as how to exercise and resume valued activities, how to find a diet that minimizes gas and problematic ostomy output, plans for sexual activity, how to promote intimacy comfortably, and how to use humor. For women in particular, depression, sleep disruption, and body image problems also should be addressed. The concerns were expressed by men and women at least five years postsurgery, so clinicians should review adaptation, equipment, and other individual challenges in all follow-up appointments and address enduring problems.

In summary, the focus group approach was successful and the division by high- and low-HRQOL groups as well as by gender made evident similarities and differences across these groups. The findings can be used to design and test psychoeducational interventions provided at initial education sessions as well as long-term follow-up appointments for CRC patients who have ostomies.

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Digital Object Identifier: 10.1188/11.ONF.587-596

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