Published in final edited form as:

Oncol Nurs Forum. 2011 September ; 38(5): 587–596. doi:10.1188/11.ONF.587-596.

GENDER DIFFERENCES IN QUALITY OF LIFE AMONG LONG-TERM COLORECTAL CANCER SURVIVORS WITH OSTOMIES

Marcia Grant, RN, DNSc, FAAN¹, Carmit K. McMullen, PhD⁶, Andrea Altschuler, PhD⁷, M. Jane Mohler, MPH, PhD^{2,3,4,5}, Mark C. Hornbrook, PhD⁶, Lisa J. Herrinton, PhD⁷, Christopher S. Wendel, MS², Carol M. Baldwin, PhD, RN, CHTP, AHN-BC⁸, and Robert S. Krouse, MD, FACS^{2,3}

¹City of Hope National Medical Center/Beckman Research Institute, Duarte, CA

²Southern Arizona Veterans Affairs Health Care System, Tucson, AZ

³University of Arizona College of Medicine, Tucson, AZ

⁴University of Arizona College of Public Health, Tucson, AZ

⁵University of Arizona College of Pharmacy, Tucson, AZ

⁶The Center for Health Research, Kaiser Permanente Northwest, Portland, OR

⁷Kaiser Permanente Medical Care Program, Oakland, CA

⁸Arizona State University, College of Nursing, Tempe, AZ

Abstract

Objective—To describe how gender shapes the concerns and adaptations of long-term (> 5 years) colorectal cancer (CRC) survivors with ostomies.

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

Setting—Member of Kaiser Permanente, residing in either Oregon, Southwest Washington State, or Northern California.

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

Methods—Eight focus groups, discussed 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/intimacy. Coping and adjustment difficulties were discussed by women with men only discussing these issues to a small extent. Difficulties with sleep were primarily identified by Low HRQOL women. Problems with body image and depression were discussed only by Low HRQOL women.

Address Correspondence and Reprint Requests to: Marcia Grant, RN, DNSc, FAAN Director and Professor City of Hope Division of Nursing Research and Education 1500 E. Duarte Road Duarte, CA 91010.

Conflict of Interest Statement The authors do not have any financial or personal relationships between themselves or others that might bias this work. Also, potential conflicts of the authors do not exist.

Conclusions—Common issues included diet management, physical activity, social support and sexuality. Women with low HRQOL discussed problems with depression, body image, and sleep.

Implications for Nursing—Application of these gender-based differences can inform educational interventions for CRC survivors with ostomies.

Keywords

Ostomy; Colorectal Cancer; Quality of Life; Gender; Focus Groups

INTRODUCTION

Colorectal cancer (CRC) accounts for over 9.3% of all new cancer cases, and it has the third most frequent incidence rate for cancer in the US (American Cancer Society, 2010). Survival rates at one year and five years are 83% and 65% respectively (American Cancer Society, 2010). Approximately 18% to 35% of the 1.1 million persons alive in the US with a history of CRC, (Mariotto, Yabroff, Feuer, De Angelis, & Brown, 2006) especially those with low-rectal cancers, have received temporary or permanent intestinal stomas (ostomies) (Gastinger, et al., 2005; Jess P, 2002; Schmidt, Bestmann, Kchler, Longo, & Kremer, 2005). Studies have found that CRC survivors, especially women and those with ostomies, have persistent deficits in their health-related quality of life (HRQOL)(R. S. Krouse, et al., 2009; Nugent, Daniels, Stewart, Patankar, & Johnson, 1999; Thomas, Madden, & Jehu, 1987; Tuinstra J, 2004). Understanding how living with an ostomy affects these survivors, and how to best help them in the management of their ostomy-related challenges is necessary to supporting their HRQOL. We undertook this assessment of HRQOL concerns to develop interventions specifically geared toward relief of physical, psychosocial, and spiritual distress and to determine differences in the concerns and adaptations raised by men and women with high vs. low HRQOL. While the time that health care professionals have to provide care, education and support to CRC patients with ostomies and their families is limited, interactions with the patient and family, especially 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, the surgical exteriorization of the small (ileostomy) or large (colostomy) bowel to the 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, a 2005 Cochrane review found that contrary to what might be expected, HRQOL may actually be worse in rectal cancer survivors who were reconstructed without a permanent ostomy when compared with those where ostomy was required (Pachler J, 2005). This was due to issues of uncontrollable fecal leakage in those without ostomies versus more control in those with an ostomy.

A wide evidence base addresses the physical and psychosocial consequences of having an ostomy (Altschuler, et al., 2009; Baldwin, et al., 2009; Fazio VW, 1980; Grunberg, 1987; Hojo, Vernava, Sugihara, & Katumata, 1991; Hurny & Holland, 1985; Keyes, Bisno,

Richardson, & Marston, 1987; Klopp, 1990; R. S. 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). This 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; R. Krouse, et al., 2007). Why some people adjust more easily than others is still 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 (R. S. Krouse, et al., 2009). Women with ostomies scored consistently lower than men with ostomies for overall QOL, as well as the four QOL 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 (R. S. Krouse, et al., 2009).

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

RESEARCH DESIGN AND METHODS

Sample and Methods

We began with a database of 282 patients who participated in a mailed survey to colorectal cancer patients 18 years or older. Participants were at least 5 years since diagnosis and were members of Kaiser Permanente, residing in either Oregon, Southwest Washington state, or Northern California. Details regarding this original study may be found elsewhere (R. S. 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 (R. S. Krouse, et al., 2009; Mohler, et al., 2008). We contacted subjects who successfully adapted (in the highest HRQOL quartile, High-QOL), as well as those who were extremely challenged with stomal issues (in the lowest HRQOL quartile, Low-QOL). Potential participants were invited to participate in a focus group to discuss challenges and adjustments to living with an ostomy. We divided the focus groups by gender, based on evidence that challenges and adjustment to an ostomy have demonstrated gender differences in previous studies (Baider, Perez, & Kaplan De-Nour, 1989; Baldwin, et al., 2009; Fernsler, Klemm, & Miller, 1999; Forsberg & Cedermarck, 1996; R. S. Krouse, et al., 2009; Salkeld, Solomon, Short, & Butow, 2004). Our goal was to recruit four to eight participants for each gender/QOL-based focus group to provide adequate "saturation" (the point at which the moderator is hearing the same issues repeated with no new ideas arising). A total of eight focus groups were formed based and high vs. low QOL and gender.

Focus groups were audio recorded for later transcription. A discussion guide, with a series of open-ended questions, was used to elicit a broad spectrum of issues. We began with a discussion of individual cancer treatments and surgeries and then preceded 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 (MG) for each session was experienced in this role. In addition, there was a silent recorder (RK), who observed and took notes throughout each focus group in order 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 approximately two hours, providing sufficient time for each group to cover the questions on the focus group guide. Elaboration on some topics varied across groups, but all groups consistently addressed all topics on the guide. Focus group recordings were transcribed verbatim for qualitative analysis, with the exception that names were replaced by a focus group ID number.

The focus group recordings were transcribed as rich text format, and we analyzed content using HyperRESEARCH (Copyright 1997–2007, ResearchWare, Inc., Randolph, MA, USA). Because the goal of this 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; R. Krouse, et al., 2007). These include physical, psychological, social, and spiritual well-being. We then positioned relevant comments within the themes (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 in order to further refine and come to consensus on coding.

RESULTS

Focus group participation ranged from a low of two participants in one group to a high of eight. For the group with only two participants, two confirmed participants called in at the last moment unable to attend (Table 1) 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 non-Hispanic white, although we did have one African American, one Hispanic, and one participant who reported a multi-ethnic background (Table 2). Other socio-demographic characteristics that were 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 we analyzed the data. We used summative content analysis to identify the number of times comments occurred within each theme (Hsieh & Shannon, 2005). This approach provided us with 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 (Table 3). In general, High QOL groups addressed fewer themes within each of the four quality of life dimensions than did Low QOL groups. Females had a greater number of comments across themes than males. In addition, the physical and the social well-being dimensions had the most themes and comments and the 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 QOL focus groups raised a broader range of topics than High QOL focus groups.

Quality of Life and Gender Similarities and Differences

Specific quotations provide additional information about the similarities and differences across the focus groups (Table 4). Comments revealed unmet needs and challenges as well as ways participants successfully adapted. Illustrative quotations for subdomains are labeled High-QOL Women, High-QOL Men, Low-QOL Women and Low-QOL Men.

Physical Well Being—Participants across all groups identified foods that caused gas and rapid evacuations. Gassy foods, fatty foods, and spicy foods were discussed frequently. In addition to specific foods, the focus group participants elaborated on their own behavior in relation to food and eating. Participants discussed how they discovered over time what foods to eat and what foods to avoid by the somewhat idiosyncratic reactions they had to specific foods. While specific foods to avoid had some variation from one individual to another, approaches to learning what foods to eat were identified across the 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 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 both female groups, less frequently in the LM group, and was not mentioned in the HM group. **Physical Activities**, was a code discussed primarily in the Low QOL groups. Participants identified various activities that they stopped doing as a result of their ostomy. Participants identified activities such as hiking, bowling, and gardening 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 used to overcome concerns about offending others, 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 lower quality of life group. These difficulties were related to pouch leaks and sleeping positions, and illustrate that deep uninterrupted sleep does not occur for some of these participants.

Psychological Well Being—Themes within the psychological well being domain were discussed more frequently by men and women in the Low QOL groups. **Coping and the ability to adjust** was a code discussed by many, and 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 in relation to developing **self-sufficiency** occurred in both women's groups and the LM group. Comments revolved around how participants learned to care for the ostomy. Comments in relation to the **self-acceptance** code were not frequent, but illustrated positive thoughts.

Within the psychological domain, **body image** and **depression** were only mentioned by women. **Unpredictability** comments illustrate the loss of control that the ostomy exerts. An additional code in the psychological well being domain was discussed only by one High QOL man, namely **resignation**. 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 both positive and negative concerns, with far more codes and comments expressed by both men and women in the Low QOL groups. These comments are from individuals who are years away from their ostomy surgery 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 either being pressed too tightly and irritated, or wearing loose clothing so that the ostomy pouch was not visible.

Sexuality was also 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 the High QOL group began a relationship several years after her surgery. She traveled 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 ever take her clothes off again in front of a man.

A topic discussed across all four groups was the **challenges of travel**. The most common approach to travel was to be prepared with extra supplies. In addition to being prepared, one woman in the Low QOL group indicated that she would stay in a hotel, rather than a friend's or relative's home when visiting. Another woman in the Low QOL 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 was also discussed under social well being. This included both 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-women's group only; however, **financial concerns** were mentioned in all groups and with different concerns.

Spiritual Well Being—While 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 the high quality of life group, and several women in the low quality of life group. Gratitude was expressed only in the women's groups. Both men and women in the low quality of life 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 this study, we conducted focus groups based on gender and quality of life questionnaire scores. This method resulted in discussions about quality of life that expanded and clarified issues and challenges identified in previous surveys (Grant, 1999; Grant, et al., 2004; R. Krouse, et al., 2007). Some focus group themes occurred across all groups, while others were focused primarily in either high or low QOL 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 QOL women's groups. This confirms findings of Tuinstra, et al, who reported increased vulnerability to distress by females. Both men and women identified specific challenges with sexuality and intimacy. Di Fabio and colleagues assessed colorectal cancer patients 14–74 months after surgery using the European Organization for Research and Treatment (EORTC) questionnaire including a six item component on sexual function. Results revealed that 61% of the colon cancer patients reported no sexual dysfunction, while only 24% of the rectal cancer patients reported no problems. Patients

with no sexual problems reported a higher QOL. These results provide the quantitative evidence for the discussion on sexual problems in all of our focus groups. Difficulties with sleep were identified by women, and primarily in the low QOL group. Coping and adjustment difficulties were expressed by women. Men appeared less bothered by these issues. These results are similar to that of Baider et al in a study of adjustment in couples with colon cancer using the Brief Symptom Inventory and the Psychosocial Adjustment to Illness (Baider, et al., 1989). In the Baider et al study, gender differences illustrated that adjustment by male patients was superior to that of female patients. This also parallels the results of the meta analysis of symptom differences in coping behavior by Tamres, Janickii and Helgeson (Tamres, Janicki, & Helgeson, 2002). In this review women were more likely to engage in coping strategies, to 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; R. Krouse, et al., 2007; R. S. Krouse, et al., 2009; Nugent, et al., 1999; Thomas, et al., 1987; Tuinstra J, 2004). Low QOL groups illustrated the range of concerns within each of the four quality of life 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 (R. S. 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. These 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 ostomy patients early in their post operative 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. While group settings may seem inappropriate for discussing matters of intimacy, stigma, and defecation, participants in our 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 due to 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, especially fecal incontinence, may lead to stigmatization in our culture, especially in social interactions (Garcia, Crocker, & Wyman, 2005; McMullen, et al., 2008). Therefore, patients deserve to be assisted in adjusting and coping with the ostomy and continuing other life activities. As health professionals, we need to address their challenges and plan and test interventions that provide the best possible quality of life for these patients.

Our 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, 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. Nevertheless, drawing our sample from the highest and lowest quartiles of the 282 survey respondents targeted a representative sample.

IMPLICATIONS FOR NURSING PRACTICE

Findings from this study may be valuable to clinicians planning group support and other interventions to assist adaptation in the population of CRC cancer 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 the use of humor. For women in particular, depression, sleep disruption, and body image problems should also be addressed. The concerns were expressed by men and women at least five years post surgery. Thus, clinicians can 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 quality of life groups as well as by gender made evident both similarities and differences across these groups. Our 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 colostomies.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

Research Support: Research sponsored by National Cancer Institute grant R01 CA106912, "HR-QOL in Colorectal Cancer Survivors with Stomas" the City of Hope Cancer Support Grant CA33572 and the Arizona Cancer Center Support Grant CA023074. Resources and facilities were provided at the Southern Arizona VA Health Care System, Tucson, Arizona.

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Figure 1.
Example of Qualitative Analysis Schemes

Table 1

Focus Group Participants

Focus Group <u>HRQOL</u>	KPNW	KPNC	Total
High * Males	4	8	12
High Females	5	5	10
Low * Males	3	2	5
Low Females	3	3	6
Totals	15	18	33

KPNW = Kaiser Permanente Northwest

KPNC = Kaiser Permanente Northern California

* "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 mCOH-QOL-Ostomy, respectively.

Table 2

Socio-demographic and clinical characteristics for focus group participants

Characteristic	High* Males N=12 %	High* Females N=10 %	Low* Males N=5 %	Low* Females N=6 %
Mean age (SD)	73 (8)	76 (9)	67 (8)	63 (14)
Race/Ethnicity				
White, non- Hispanic	84	90	80	100
Black, non-Hispanic	0	10	0	0
Hispanic/Latino	8	0	20	0
Mixed	8	0	0	0
Education				
High school graduate	33	20	20	17
College	67	80	80	83
Annual Household Income				
> \$30,000 to \$50,000	33	30	60	83
\$50,001 to > \$75,000	50	50	40	17
Unknown/no answer	17	20	0	0
Married/Partnered Prior to Surgery	92	60	60	83
Married/Partnered Currently	83	30	60	67
Employment (N)				
Full-time	17	10	20	17
Part-time	17	0	0	17
Retired	66	90	80	66
Years since surgery – Mean (SD)	12 (8)	19 (8)	8 (3)	13 (8)

* “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 mCOH-QOL-Ostomy, respectively.

Table 3

Focus Group Comments within each Domain and Code

DOMAIN	Theme	High * Males	High * Women	Low * Males	Low * Women	TOTAL
PHYSICAL		11	41	38	52	142
	Diet Issues	10	23	23	24	80
	Gas/Odor	0	7	4	7	18
	Activity- limitations and resumed	1	5	13	12	31
	Sleep	0	6	3	10	19
PSYCHOLOGICAL	Fertility Issues	0	0	0	1	1
		7	7	13	17	51
	Coping/Adjustment	3	2	3	8	16
	Humor	2	3	5	3	13
	Self Sufficient	0	1	3	1	5
	Self Acceptance	1	1	2	1	5
	Unpredictability	0	0	0	2	2
	Body Image	0	0	0	1	1
	Sadness/Depression	0	0	0	1	1
	Resignation	1	0	0	0	1
SOCIAL		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	0	0	0	7	7
SPIRITUAL	Privacy	0	1	2	2	5
	Employment	0	0	0	3	3
		2	4	4	10	20
	Resilience/Inner Strength	1	2	3	3	9
	Appreciate Life	1	0	0	4	5

DOMAIN	Theme	High * Males	High * Women	Low * Males	Low * Women	TOTAL
	Gratefulness	0	2	0	1	3
	Reason to live/survivors	0	0	1	2	3
	Faith Community	0	0	1	0	1

* "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 mCOH-QOL-Ostomy, respectively.

Table 4

Illustrative quotes from City of Hope Domains

Physical well-being	High QOL women	High QOL men	Low QOL women	Low QOL men
Diet	<i>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.</i>	<i>There are some spicy foods that seem to linger a long time and I try to avoid..</i>	<i>I try to chew my food slowly, and I don't drink until after I eat.</i>	<i>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.</i>
Gas & odor	<i>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.</i>		<i>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.</i>	<i>It smells quite a lot. it depends on what you're eating.</i>
Activities			<i>They told me not to lift more than ten pounds. In the beginning I thought "Well, that's kind of hard" So even cat litter. I can only buy fourteen pounds. I asked before I had it "Can I still swim?" and he (an 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.</i>	<i>I used to run ten, twelve 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.</i>
Sleep	<i>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.</i>		<i>One thing that's changed is I wake up more often at night. I constantly reach down to find out if it is full.</i>	<i>I'm moving around and restless (all night).</i>

Psychological well-being	High QOL women	High QOL men	Low QOL women	Low QOL men
Coping & adjustment		<i>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.</i>	<i>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."</i>	<i>– Like I say, it's just an inconvenience now.</i>
Humor	<i>Once I said something about fart and kids said "No, mother – it's Muffy. Muffy makes fluffies. Fart we don't talk about."</i>	<i>When I go in those CT scans with the contrast stuff, I always empty my bag when I get home and turn off the light to see if it glows.</i>	<i>At least I don't have to go camping anymore.</i>	<i>If I'm having a problem with my system, I go to Taco Bell.</i>
Self-sufficiency	<i>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>		<i>I think I called an ostomy nurse once for some advice. You know, you just figure it out.</i>	<i>They'll give you some advice. And vary from it a little bit, if you think you have</i>

Psychological well-being	High QOL women	High QOL men	Low QOL women	Low QOL men
				<i>to, you have to get it to work best for you.</i>
Self-acceptance	<i>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. 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 more sensitive and I think, yeah, mine is.</i>		<i>I was getting so bold, I'd go to buy some clothes, I'd just say "I have a colostomy, so I can't wear that."</i>	<i>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.</i>
Body Image			<i>You're this person walking around with a bag of something hanging off you.</i>	
Depression			<i>There is a certain amount of depression after.</i>	
			<i>It totally destroyed all of our plans and things we had hoped for (respondent near tears)</i>	
Unpredictability			<i>You've always got that (bag filling) on your mind.</i>	
			<i>It could be just fine one day and the next day it's just like, oh crap! Here I go. I'm flying to the bathroom.</i>	

Social well-being	High QOL women	High QOL men	Low QOL women	Low QOL men
Clothing	<i>I never wear blue jeans. They fit too tight.</i>	<i>It's more convenient to wear bikini underwear, instead of briefs</i>	<i>I try to wear things that go over. I don't wear anything tucked in.</i>	<i>Suspenders, yeah. Or big overalls...carpenter overalls.</i>
Sexuality	<i>I was all burnt up...the radiation. There's nothing down there since I got it.</i>	<i>I am a widower, and am dating. I don't think anything can be done about having a sexual relationship.</i>	<i>The surgery shrank me and the scar tissue built up and tilted me, so our sexual relations basically went to almost nothing. Before we were very, very active. Now, I could care less because it hurts and I bleed.</i>	<i>There's no sex life anymore. It's gone.</i>
Travel	<i>I went to Hawaii... hardly went to the beach because I thought I couldn't get away from the hotel.</i>	<i>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>	<i>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.</i>	<i>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.</i>
Social Support	<i>I don't have any family, but just some very good friends who stood by me.</i>	<i>My wife is the one that got me through the whole thing. I would have never ever have made it.</i>	<i>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</i>	<i>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.</i>
Embarrassment related to employment			<i>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.</i>	

Social well-being	High QOL women	High QOL men	Low QOL women	Low QOL men
Financial issues	<i>(out-of-pocket expenses) I didn't pay one cent.</i>	<i>All mine is paid for.</i>	<i>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.</i>	<i>Even with Medicare, Medicaid, and K-, it was costing me \$75 every three months for supplies.</i>

Spiritual well-being	High QOL women	High QOL men	Low QOL women	Low QOL men
Resilience/inner strength	<i>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</i>	<i>It didn't stop me from taking care of my garden and my orchard...I'm doing alright. I have no complaints.</i>	<i>I think that you just have to make up your mind that you're gonna live with it, and you do.</i>	<i>You got to want to do something, you know... I'm going to have some fun. I'm not just going to quit.</i>
Appreciation for life		<i>I've had a very good life up to the point of the operation. I still enjoy life.</i>		<i>I considered the expression "better a bag than a box."</i>
Gratitude	<i>I'm just happy that the doctor discovered my cancer... I didn't go to him for cancer.</i>		<i>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.</i>	