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SPIRITUAL WELL-BEING IN LONG-TERM COLORECTAL CANCER SURVIVORS WITH OSTOMIES

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Abstract

Objective—Spiritual well-being (SpWB) is integral to health-related quality of life (HRQOL). The challenges of colorectal cancer (CRC) and subsequent bodily changes can affect SpWB. We analyzed the SpWB of CRC survivors with ostomies.

Methods—Two-hundred-eight-three long-term (5 years) CRC survivors with permanent ostomies completed the modified City of Hope Quality of Life-Ostomy (mCOH-QOL-O) questionnaire. An open-ended question elicited respondents' greatest challenge in living with an ostomy. We used content analysis to identify SpWB responses and develop themes. We analyzed responses on the 3-item SpWB sub-scale.

Results—Open-ended responses from 52% of participants contained SpWB content. Fifteen unique SpWB themes were identified. Sixty percent of individuals expressed positive themes such as “positive attitude”, “I am fortunate”, “appreciate life more”, and “strength through religious faith”. Negative themes, expressed by only 29% of respondents, included “struggling to cope”, “not feeling ‘normal’”, and “loss”. Fifty-five percent of respondents expressed ambivalent themes including “learning acceptance”, “an ostomy is the price for survival”, “reason to be around despite suffering”, and “continuing to cope despite challenges”. The majority (64%) had a high SpWB sub-scale score.

Conclusions—While CRC survivors with ostomies infrequently mentioned negative SpWB themes as a major challenge, ambivalent themes were common. SpWB themes often were

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mentioned as a source of resilience or part of the struggle to adapt to an altered body after cancer surgery. Interventions to improve the quality of life of cancer survivors should contain program elements designed to address SpWB that support personal meaning, inner peace, interconnectedness, and belonging.

Keywords

cancer; oncology; spiritual well-being; ostomy; stoma; survivorship; HRQOL

BACKGROUND AND SIGNIFICANCE

Individuals often view serious illness and suffering as a crisis of personal meaning, which health psychologists describe as deficits in spiritual well-being (SpWB). The SpWB construct includes both existential and religious components [1]. Existential SpWB includes key components such as hopefulness, inner peace, and a sense of a reason to be alive. Religious well-being, on the other hand, “involves a sense of comfort derived from connectedness to a higher power that is sacred and eternal”(p. 162) [1]. Spiritual Well-Being (SpWB) is distinct from psychological and social well-being, and there is a growing interest in this previously overlooked component of health-related quality of life (HRQOL) [2].

While research has linked religious well-being to positive and negative health outcomes, religious aspects of SpWB have shown a weak relation to HRQOL [1,3]. In contrast, existential aspects of SpWB have consistently demonstrated stronger, direct effects on HRQOL among patients with serious illness, including cancer survivors. Previous research suggests that existential measures of SpWB should be more widely incorporated in HRQOL research and complete the biopsychosocial-spiritual model for HRQOL [4]. Evidence on the relevant content of SpWB can inform assessments and interventions to improve and support SpWB among patients with serious illness [1,5,6]. Despite this promise, however, studies using SpWB measures have done little to link SpWB with an understanding of how patients experience coherence versus disruption in their sense of personal meaning, which is best collected through qualitative techniques [7,8].

SpWB may be particularly important to our understanding of the experience of cancer survivors living with permanent physical changes related to their cancer or cancer treatment. These changes are not only traumatic in the weeks and months immediately following the cancer diagnosis and treatment, but may have a long-term impact on SpWB when they affect physical functioning and appearance.

Colorectal cancer (CRC) survivors with ostomies experience permanent and dramatic changes in their appearance and physical functioning. As such, these patients present an ideal population for examining SpWB. CRC is the fourth most common cancer in the United States and the third leading cause of cancer deaths among adults [9]. Intestinal ostomies are created when all or a portion of the bowel is removed and the end of the bowel is attached to an opening in the abdominal wall. An ostomy bag collects bowel contents. Ostomies and complications of CRC surgery have been shown to significantly impact overall HRQOL [10,11]. Among long-term CRC survivors, for example, patients with permanent ostomies report substantially poorer HRQOL than matched counterparts who have undergone

surgeries that restore anatomic defecation through the anus [12,13]. Challenges with an ostomy appliance include skin patency around the ostomy, gas, leakage between the skin and the bag, spillage of bag contents, noise, and fecal odor. For people who have been continent up to the point of their cancer surgeries, an ostomy represents a major alteration of body form, appearance, and function [12] that may affect their SpWB [14].

Researchers use qualitative and/or quantitative measures to examine SpWB. For example, Trevino et al [8] conducted focus groups with male veterans who were cancer survivors to explore the impact of cancer on religiosity/spirituality qualitatively. Baldwin and colleagues [14] conducted focus groups and analyzed open-ended written responses of veterans (92% male) with ostomies and found that ostomates in the upper and lower quartile of HRQOL based on a survey measure also differed when discussing the constructs of inner peace, hopefulness, and reason to be alive.

There are several quantitative measures of SpWB that variously explore religious beliefs and practices (e.g., the Brief Multidimensional Measure of Religiousness/Spirituality for Use in Health Research [15]) and existential forms of SpWB such as peace, meaning, and faith (e.g. the Functional Assessment of Chronic Illness Therapy–Spiritual Well-being [FACIT-Sp] [5,6] and the modified City of Hope Health-Related Quality of Life–Ostomy [mCOH-HRQOL-O] [16,17]).

In the current study we employed both qualitative and quantitative measures. We analyzed qualitative responses using standard techniques and then compared those findings with the quantitative SpWB measure to assess the degree to which the measures correlated. The purpose of this analysis is to explore patients' perspectives of the impact their disease and treatment has on the meaning of their lives and to expand our understanding of SpWB as a dimension of HRQOL among this group of long-term CRC survivors with ostomies.

METHODS

This analysis combines qualitative and quantitative methods to study the HRQOL of long-term survivors of CRC. A detailed description of the overall study methodology is presented elsewhere [18]. Study sites included three Kaiser Permanente (KP) Regions: Northern California (KPNC), Northwest (KPNW), and Hawai'i (KPHI). The Southern Arizona VA Health Care System (SAVAHCS) in Tucson, Arizona coordinated this study. The City of Hope Quality of Life Model provided a framework for the study's design, measures, data collection, and data analysis [16,17]. The Institutional Review Boards at the University of Arizona, KPHI, KPNC, and KPNW reviewed and approved the study protocol and survey instruments.

Study Participants

We recruited all adult CRC survivors (at least five years post-diagnosis) with permanent ostomies who were enrolled at one of the three KP sites during 2000–2006 to complete a health survey through the mail or over the telephone. We identified participants through North American Association of Central Cancer Registries (NAACCR)-certified tumor registries or a search of the electronic medical records at their respective sites. We mailed

surveys to 529 survivors and garnered a 53% response rate (n=283). The average age of participants was 72 years and 41% were female. About 38% of participants had a high school education or less and nearly 75% were non-Hispanic white.

Measures

The modified City of Hope Quality of Life-Ostomy (mCOH-QOL-O) questionnaire was used for both qualitative and quantitative SpWB measures [16,17]. We used a single, open-ended question as the qualitative measure: “Many people have shared stories about their lives with an ostomy. Please share with us the greatest challenge you have encountered in having an ostomy.” Responses to this question were transcribed into a textual database.

The mCOH-QOL-O includes four domain scales assessing physical, psychological, social, and spiritual well-being. Three items were used to create the SpWB scale score: Do you sense a reason for being alive? Do you have a sense of inner peace? How hopeful do you feel? Item response options consist of an 11-point scale ranging from 0 (“Not at all”) to 10 (“A great deal” or “Extremely”). Cronbach’s alpha for the scale was .84.

Analysis

We analyzed all responses to the greatest challenge question using a three-step content analysis process. First, the content of each response was analyzed to determine if it contained any reference to SpWB. The SpWB content found was defined in a summary statement reflecting the COH HRQOL framework, as previously described. Two team members independently coded all the responses. The two original coders and a third team member then met to review and resolve all coding discrepancies. In the second step, a card-sort methodology was used to identify and develop themes [19]. All responses previously determined to contain some element of SpWB were printed on index cards and sorted on a large table. Individual statements that reflected similar meaning were grouped and themes emerged through this process. In the third step, all responses were coded using the themes developed during the card-sort.

We created the SpWB scale score by averaging item responses when a minimum of two scale items were completed. Three people did not complete enough scale items to receive a scale score.

RESULTS

Greatest Challenge

Of the 283 participants, 176 (62%) responded to the greatest challenge question. We began our analysis by comparing individuals who responded to the greatest challenge question with those who did not. Only one significant difference was identified— individuals with a higher level of education were significantly more likely to provide a response than those with less education (X^2 (df=2) = 8.50, p = .014). (See Table 1 for characteristics of the full population and subsamples.)

Next, we compared individuals whose greatest challenge response contained SpWB content (92 individuals, 52%) to those whose greatest challenge response did not contain any

reference to SpWB. One significant difference was found: participants whose GC response contained SpWB content had higher scores on the QOL-Psychological domain compared to those whose GC response did not have SpWB content. Qualitative analysis of SpWB themes was conducted using only the 92 individuals whose response to the greatest challenge question contained SpWB content.

We identified 15 unique themes of SpWB during the card sort analysis. After completing theme development and coding all the responses we organized the 15 themes into three general dimensions: positive, negative, and ambivalent. The richness of SpWB content varied considerably with individuals providing from one to five themes. When a respondent provided multiple themes, the themes could all be in the same dimension, or they could cross dimensions. The themes are discussed within their dimensional framework below and Table 2 contains exemplars of each theme.

Positive dimension—We found seven unique themes that reflected positive SpWB. Positive themes expressed adjustment, acceptance, and positive coping. Fifty-five (60%) respondents used at least one positive theme. While most individuals who used a positive theme only used one positive theme (82%), 18% used two or three positive themes.

Two positive themes were most commonly used: “Empowerment through positive attitude” and “I am fortunate”. Individuals coded as expressing “Empowerment through positive attitude” referred directly to their positive outlook in dealing with their ostomy. They described a focus on enjoying life; one individual described the ostomy as a source of a positive change in life. “I am fortunate” was coded when individuals stated they were fortunate or lucky or discussed his/her life in strongly positive terms.

When individuals emphasized that they led an active, full life, or when they gave some credit for their recovery from cancer to getting out into the world and being physically engaged, “Active, full life” was coded. Several individuals mentioned that their “faith in their healers”, physicians, nurses, etc., played an important part in their ability to deal with the cancer surgery and /or recovery. We only used this code when medical caregivers were mentioned in a clearly positive way. “Strength through religious faith” was coded when the individual referred to religious faith and noted the positive role it played in his/her recovery. Mentions coded in this category were expressly religious in nature and mention of God or a specific religious group was required to receive this code. Finally, a small number of respondents gave responses categorized in two other themes. “Appreciate life more/second chance” was coded when individuals referenced their cancer surgery as a factor in creating a new appreciation for their life or when they noted that they now had a second chance to live a life that could have been ended by their cancer. We used the code “helping others helps me” when an individual noted the importance in their own life of helping others, and the fact that they gained deep personal satisfaction from that activity.

Negative dimension—We identified four themes that conveyed negative SpWB. Twenty-seven respondents (29%) used at least one negative theme. The majority (17, 63%) of the respondents who used a negative SpWB theme used only one, although six respondents used two negative themes (22%) and four respondents used three (15%).

Negative themes generally suggested the individual was struggling with the long-term consequences of their cancer and ostomy surgery. “Loss” was the most common negative theme and was used by 20% of respondents. Loss was coded for individuals who wrote about what they could no longer do or the body they no longer had. Individuals also reported losing the ability to travel or attend social activities; respondents commonly mentioned the drastic and permanent change to their body and loss of physical intimacy and sexual function. Approximately 10% of respondents expressed they were still “struggling to cope”. We coded responses in this category when survivors discussed the myriad challenges they faced on a daily basis to care for themselves physically and psychologically. “Struggling to cope” was coded when the response emphasized that individuals felt overwhelmed by challenges. “Not feeling ‘normal’” was reported by 9% of respondents who wrote that they were no longer normal physically or felt they needed to expend effort pretending to be normal. The fourth negative theme was coded when the respondent mentioned becoming dispirited by problems with the health care they received, either from the health system or from individual doctors and nurses. This theme was relatively uncommon with 6.5% of individuals reporting this as a challenge.

Ambivalent dimension—We found four themes that expressed ambivalent SpWB. Themes in this dimension contained complex messages expressing coping and acceptance mixed with regret and loss. Fifty one individuals (55%) expressed ambivalent themes and they were the most common type of theme used. The majority of people (32, 63%) who expressed an ambivalent theme used only one such theme in their response, while 35% (18) used two ambivalent themes and one person (2%) used three ambivalent themes.

The most commonly used themes were “Coping despite challenges” (24% of individuals) “Learning acceptance” (23% of individuals), and “Payoff (An ostomy is the price of survival)” (22% of individuals).

“Coping despite challenges” was coded for individuals who emphasized the difficulty of living with and caring for their stoma, but also noted that they were handling and coping with these difficulties. “Coping despite challenges” is a similar code to “Struggling to Cope,” which was categorized on the negative dimension. The difference between the codes is the emphasis the person placed on meeting and coping with the difficulties vs. becoming overwhelmed by the difficulties.

Many individuals directly stated that learning to accept the ostomy was their greatest challenge. Mentions of the challenge of accepting the ostomy were often accompanied by statements that emphasized the traumatic and dramatic requirement of the task of acceptance (e.g., “Once the major shock of cancer and the body function differences are accepted...”), but also that acceptance can lead to positive things (e.g., “...there is a feeling of future hope.”).

Some individuals discussed their ostomy in comparative terms, stating that whether or not they liked their ostomy, having it was the price they had to pay to continue living. This was coded as “Payoff”, the idea that having an ostomy is the price of survival. Responses coded as payoff were ambivalent in that individuals noted both the cost (having an ostomy) and

payoff (living) of the ostomy, but there was variation in how positively the payoff was perceived. While some individuals wrote extensively of the things they had done or seen, and/or the family and friends they had the opportunity to spend time with, others seemed to feel that, although they were glad to be alive, life no longer had very much to offer.

The fourth ambivalent theme identified was “Recovery from Trauma,” which was reported by 8 individuals (9%). As with the other ambivalent themes, this theme was coded when the individual included both positive and negative elements in their response. Recovery from trauma was coded when the respondent discussed that they experienced the cancer diagnosis or the ostomy surgery to be traumatic, but at the same time, focused on the ways they dealt with and recovered from the event.

The richness of SpWB content in each response varied considerably. Most people (75%) used one or two SpWB themes in their response while 24% expressed three or four different themes, and one person used five themes. Of the 56 people who expressed more than one theme, 36 (64%) had themes that crossed dimensions (e.g., a positive theme and an ambivalent theme). The majority of individuals with multiple themes that crossed dimensions generated positive and ambivalent themes (58%). A relatively small number of individuals generated negative and ambivalent themes (14%), and 14% of individuals gave responses that contained both positive and negative themes. Five people (14%) used all three types of themes in their response.

We also noted that only a small number of respondents mentioned religion as a source of support (10%) in their response to the greatest challenge question. To explore this further, we coded the data a second time to find every mention of religion, religious faith, attending services at a religious institution, or a deity. An additional six individuals were coded with this expanded definition. These mentions were all neutral in nature. No one mentioned religion or a deity in negative terms.

Spiritual Well-Being Scale

Based on their spiritual well-being scale score on the COH-HRQOL-O, individuals were categorized as having low, moderate, or high SpWB, categorized as follows: 0–5 = low SpWB (n=13, 14%), >5–8 = moderate SpWB (n=20, 22%), and >8 = high SpWB (n=58, 64%). We analyzed the relation of scale score to the greatest challenge themes by conducting three chi-square analyses comparing the scale score categories to the use of positive, negative, and ambivalent dimensions (see Table 3). We found consistency across the SpWB scale score from the COH-HRQOL survey and the themes expressed in response to the greatest challenge question. A significant relation was found between scale score category and expression of positive themes whereby individuals with a high SpWB scale score were significantly more likely to express positive themes ($p<.001$). We did not find a relation between the scale score and the use of negative or ambivalent themes.

DISCUSSION

Our analysis demonstrated that long-term CRC survivors in this study appear to be doing well in terms of SpWB in spite of the fact that they live every day with challenges related to

their cancer surgery and ostomy. The majority of our participants had a high SpWB scale score (64%) and most individuals used a positive theme when responding to the greatest challenge question (60%), suggesting resilience and coping in response to challenges. Not all participants had a high SpWB score, however, and 29% of greatest challenge respondents expressed a negative SpWB theme. Like other studies of SpWB, our analysis indicates that SpWB should be understood primarily as an existential sense of coherence, inner peace, and personal meaning, rather than as an expression of faith, religiosity, or comfort derived from religious faith [1,5]. The open-ended question about the greatest challenge respondents faced in living with an ostomy was neutral with respect to SpWB, yet 52% of the responses addressed issues of meaning, faith, or spiritual expression. The relatively infrequent mentions of faith or religion in those answers, in contrast with the frequent mentions of existential aspects of SpWB, strengthens the case for the more predominant role of existential SpWB in shaping HRQOL among cancer patients.

There has been some debate about the relation between religious and existential aspects of SpWB with respect to HRQOL [1–3,5,6]. Several studies found that a sense of meaning and peace is more strongly associated with HRQOL than is religious faith and have called for further analyses of what meaning and peace entail for specific populations of cancer patients. The open-ended data from this analysis offers an opportunity to address this issue and provides patients' perspectives of the impact their disease and treatment had on the meaning of their lives. These data provide examples of what clinicians can listen for in addressing patients' spiritual issues and thus more fully evaluate patients' wellbeing.

While existing quantitative measures of SpWB distinguish important components of SpWB [3,5,16], the qualitative analysis presented in this paper explores these issues in greater depth. As well as identifying the variety of themes reported by participants, we also found that more than half (55%) of long-term CRC survivors with an ostomy continue to express ambivalence with regard to their ostomy >5 years after diagnosis. The identification of the ambivalent themes provides a valuable contribution as these themes illuminate the internal conflict that remains with the individual, even after living with an ostomy for many years. Ambivalence is an important concept that adds to our understanding of the experience of the way CRC survivors make meaning of their lives [20,21]. The ambivalent themes demonstrate that individuals hold and express conflicting thoughts and feelings, a concept that is much harder to capture using quantitative measures.

Finally, a number of researchers have called for increased attention to spirituality's role in affecting cancer patients' quality of life [4–6]. Doing this requires better quantitative assessment of SpWB as well as qualitative assessment of the specific spiritual challenges and supports experienced by patients with various cancers. Identifying these particular challenges and supports can help inform spiritual care interventions, as proposed by Puchalski and colleagues [4]. Our analysis demonstrated that SpWB as measured quantitatively through the mCOH-QOL-O is significantly associated with the positive expressions of SpWB in an open-ended question. Future research could explore the feasibility of using measures that contain both quantitative and qualitative assessments to screen for patients with low SpWB and elicit information about the particulars of their spiritual suffering. While dispirited survivors are likely at higher risk for mental illness [22],

social isolation, and physical health problems, their specific challenges could suggest different avenues for intervention. For example, survivors who say they no longer feel like a normal person because of the alterations in their body would probably benefit from different interventions than those who say they cannot maintain a positive outlook on life [7]. While more research is needed in this area, our results demonstrate how using qualitative and quantitative assessment, grounded in a holistic model of HRQOL, yields information that could lead to personalized, disease-specific interventions to support the HRQOL of people with serious illnesses and disabilities.

LIMITATIONS/FUTURE RESEARCH IMPLICATIONS

The context in which a survey such as ours is administered might have an impact in the type of responses it elicits. For example, Kaiser Permanente is not a religious organization. This may discourage survivors from reporting religious aspects of their cancer and ostomy experience. Replicating this research with patients treated in a religious health care setting (e.g., Catholic hospitals) may stimulate a relatively greater proportion of stories related to the use of prayer and support from clerics in coping with the challenge of living with an ostomy among CRC survivors.

The wording of the greatest challenge question may have decreased the number and types of SpWB-related themes in participants' responses. The question's focus on challenges might have led patients to exclude beneficial aspects of their healing or sources of support and comfort.

This study was conducted in an HMO on the west coast of the United States whose members primarily receive coverage through employment or Medicare, limiting generalization. The study should be replicated in different geographic areas and health settings in the US to capture potential differences. Populations should include different SES, cultures, races, religious affiliations, and other demographic characteristics.

CLINICAL IMPLICATIONS

Our findings provide valuable evidence of the importance of spiritual wellbeing as a component of quality of life and point to the need to include aspects of spiritual wellbeing in clinical assessments. Once the diagnosis of cancer occurs, a profound existential shift occurs for most patients. Our findings support the need for clinicians to acknowledge this important change and listen to patients as they struggle to redefine their lives following diagnosis and treatment for cancer.

CONCLUSIONS

Spiritual wellbeing themes were often mentioned as a source of resilience or part of the struggle to adapt to an altered body after cancer surgery in this group of long-term CRC survivors with ostomies. Survivors' open-ended responses reinforce the importance of SpWB in coping with the challenges of disability and cancer survivorship, and confirm that assessment of spiritual wellbeing is a key element of quality of life among of long-term CRC survivors with ostomies. Interventions to improve the HRQOL of cancer survivors

should contain program elements designed to improve SpWB that supports personal meaning, inner peace, inter-connectedness, and belonging.

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Table 1

Participant Characteristics

Characteristic	All participants (N = 283 [*])			
	Participants who responded to the GC question (N = 176 [*])			
			GC response did not contain SpWB content (N = 84 [*])	GC response contained SpWB content ⁺ (N = 92 [*])
	M (SD)	M (SD)	M (SD)	M (SD)
Age at time of survey	72.31 (10.37)	71.82 (10.37)	72.44 (9.75)	71.25 (10.94)
Body Mass Index	(N = 278)	(N = 172)	(N=82)	(N=90)
	27.09 (6.01)	27.08 (5.34)	27.29 (5.86)	26.90 (4.84)
Follow-up years (From the date of index CRC diagnosis to date of survey)	12.58 (6.94)	12.37 (7.17)	13.23 (7.84)	11.59 (6.45)
QOL: Physical	7.34 (1.80)	7.24 (1.81)	6.96 (1.96)	7.49 (1.63)
QOL: Psychological	7.21 (1.77)	7.25 (1.76)	6.94 (1.74)	7.53 (1.74)
QOL: Social	7.23 (2.15)	7.11 (2.07)	6.95 (2.09)	7.25 (2.06)
QOL: Spiritual	(N=280)	(N=175)	(N=84)	(N=91)
	7.52 (2.46)	7.65 (2.44)	7.29 (2.54)	7.99 (2.30)
	n (%)	n (%)	n (%)	n (%)
Female	116 (41%)	75 (42.6%)	35 (41.7%)	40 (43.5%)
Race/ethnicity				
Non-Hispanic White	210 (74.2%)	137 (77.8%)	66 (78.6%)	71 (77.2%)
Asian	27 (9.5%)	12 (6.8%)	6 (7.1%)	6 (6.5%)
Hispanic (all races)	21 (7.4%)	10 (5.7%)	5 (6.0%)	5 (5.4%)
Other / Unknown / Multiple	25 (8.8%)	17 (9.7%)	7 (8.3%)	10 (10.9%)
Level of schooling	(N=278)	(N=173)	(N=83)	(N=90)
High School/GED	108 (38.8%)	56 (32.4%)	28 (33.7%)	28 (31.1%)
Some College or Vocational School	77 (27%)	51 (29.5%)	21 (25.3%)	30 (33.3%)
College Graduate	93 (33.5%)	66 (38.2%)	34 (41.0%)	32 (35.6%)
Married or partnered at time of survey	(N=279)	(N=175)	(N=84)	(N=91)
	174 (62.4%)	114 (65.1%)	56 (66.7%)	58 (63.7%)
Charlson-Deyo Comorbidity Index				
0	98 (34.6%)	56 (31.8%)	20 (23.8%)	36 (39.1%)
1	41 (14.5%)	30 (17.0%)	14 (16.7%)	16 (17.4%)
2+	144 (50.9%)	90 (51.1%)	50 (59.5%)	40 (43.5%)
Rectal tumor	(N=279)	(N=174)	(N=83)	(N=91)
	246 (88.2%)	151 (86.8%)	71 (85.5%)	80 (87.9%)
Received chemotherapy for initial tumor	(N=262)	(N=163)	(N=76)	(N=87)
	100 (38.2%)	62 (38.0%)	24 (31.6%)	38 (43.7%)
Received radiation therapy for initial tumor	(N=266)	(N=167)	(N=79)	(N=88)

Characteristic	All participants (N = 283 [*])			
	Participants who responded to the GC question (N = 176 [*])			
			GC response did not contain SpWB content (N = 84 [*])	GC response contained SpWB content ⁺ (N = 92 [*])
	101 (38.0%)	64 (38.3%)	27 (34.2%)	37 (42.0%)
Had post-surgical complications (from date of surgery to date of interview)	159 (56.2%)	104 (59.1%)	49 (58.3%)	55 (59.8%)

* When data was not complete for a variable, the variable total N is included on the row above the data.

⁺ Final Analysis Sample

For continuous variables, mean and standard deviation (SD) are presented. Categorical variables are shown as counts and percentages.

Table 2

Spiritual Well-Being Themes

Theme	Number (%) of individuals using the theme	Exemplar
<i>Positive</i>		
Empowerment through positive attitude	15 (16.3%)	<p>"I have no problem adjusting to my ostomy. I had my mind made up before my surgery that was something that had to be done to keep on living."</p> <p>"I find it helpful not only to myself but to my family and friends to have a positive outlook and attitude."</p> <p>"Having a positive attitude has been a great help."</p>
I am fortunate	15 (16.3%)	<p>"I am lucky that I have had no challenges in my life having an ostomy. I live each day to the fullest. I enjoy life."</p> <p>"I'm just glad to be alive!"</p> <p>"After having colon cancer surgery, chemo and radiation, the ostomy is the best thing that could ever happen to me."</p>
Faith in healers	11 (12.0%)	<p>"A big factor in my positive attitude was due to confidence in my surgeon."</p> <p>"I had some good doctors and nurses that keep me going."</p>
Active, full life	10 (10.9%)	<p>"I am 87 years old. I split our firewood, Rototill, plant and harvest the bounties of our garden, prune, spray and harvest the fruits of our orchard, drive my pick-up and car, am active in several organizations that meet weekly or monthly."</p> <p>"I have never looked back at my life before and have resumed a full and complete life with regular visits to the gym where I do aerobics exercise for about 45 minutes. ... I bicycle and water ski as well as snow ski during the appropriate seasons."</p> <p>"Now years after [my ostomy surgery] I am amazed of what [I] do. I walk, I swim, do some boating, cut and carry wood, garden, I have an active life"</p>
Strength through religious faith	9 (9.8%)	<p>"I have found it easy to live with my ostomy. I was out of the hospital early... I had a strong belief in God and the Virgin Mary. They have always helped me when I was down."</p> <p>"I always thank God for my living. Always have faith, love, and hope."</p> <p>"I praise my Lord for providing good health – no smoking, no drinking EVER. He is my constant companion and friend."</p>
Appreciate life more. "2 nd chance"	4 (4.3%)	<p>"I feel like I had a second chance to live when I needed a colostomy surgery... I'm grateful that I'm a survivor of the colon cancer."</p> <p>"I find myself enjoying things more. I like me better now. I don't take too many things for granted."</p> <p>"I am grateful that I am alive 9.5 years after surgery, radiation and chemo and am able to enjoy a rich life. I appreciate these days even more than my earlier life."</p>
Helping others helps me	3 (3.3%)	<p>"I volunteered at a hospital for 14 years to go and talk to the new ostomy patients and met with others at a different hospital in a support group. I found this activity very helpful."</p> <p>"I hope this helps others with their ostomies. They need to learn to live life anyway."</p> <p>"Thank you for including me in your survey. It means a lot to me to be able to help others ostomy-wise."</p>
<i>Total N of Individuals using a Positive Theme</i>	55 (60%)	
<i>Negative</i>		
Loss	18 (19.6%)	<p>"I have extreme pain that started with the surgery for cancer. And miss working. I am an alcoholic and have severe depression and am being treated with medication, meditation, and yoga. After my surgery they thought I would die. I have survived and hope to return to work."</p> <p>"[A] devastating challenge is the almost non-existent intimacy with my husband."</p>
Struggling to cope	9 (9.8%)	<p>"...my outlook on life isn't too rosy. But I keep plodding along."</p> <p>"I have had two surgeries for hernias and now the stoma is on the right side. I have a hernia again that I need to have repaired. I try to be "upbeat" about all this, but at times it gets to me. Sometimes I turn down events (movies, plays, etc.) because I am afraid I won't be able to use the restroom or will have an odor problem or make a noise."</p>
Not feeling "normal"	8 (8.7%)	<p>"At first I'd look at others and think they have a colon and rectum and I don't! And I never would have again."</p> <p>"I feel like I am half of a man since my surgery."</p>

Theme	Number (%) of individuals using the theme	Exemplar
		<p>"Life has not been easy and seems to be getting worse. Yet, I look healthy and no one thinks I'm "sick"."</p> <p>"My greatest challenge was having to pretend like I was normal (without the hole in my stomach)."</p>
Feeling let down/betrayed by healers	6 (6.5%)	<p>"I have periodic bouts of severe, painful irritable bowel and or blockage symptoms. I have had many diagnostic tests to determine the cause with no defining results – therefore no helpful treatments or suggested life or diet changes from the medical community."</p> <p>"Agreed I am happy that the cancer is going, but still wonder why this happened. [The physicians] told me it would be ok, but it isn't."</p>
<i>Total N of Individuals using a Negative Theme</i>	27 (29%)	
Ambivalent		
Continuing to cope and function despite challenges	22 (23.9%)	<p>"After operation, chemo, radiation, etc. I am with the loss of left leg, nerves in right leg, little upper body strength, etc., etc., which make ostomy care hard, but have done so for five years and have never been depressed even while in complete wheelchair care. Have really had to make a lot of little adjustments to suit my ostomy care."</p> <p>"As of now, health wise, I'm doing as well as I can with all these ostomy supplies which keep me alive."</p>
Learning acceptance	21 (22.8%)	<p>"Do I like it – hell no – but this is the card I've been dealt, so I got to play it."</p> <p>"Another challenge was learning to accept the fact that I would have a colostomy the rest of my life. It's not something I ever thought about, so it was a complete surprise to me."</p>
Payoff (Ostomy is the price for survival)	20 (21.7%)	<p>"When I consider the alternative to having an ostomy I feel very fortunate to be alive. It is a minor inconvenience which I can live with."</p> <p>"Having an ostomy has not bothered my routine. I've accepted it. This is the way it has to be. Get on with life and enjoy! I would rather buy pouches than a wooden box."</p> <p>"In retrospect, the problems are minor; I could well be dead instead of having to deal with the bag."</p> <p>"All in all I feel very lucky and glad that I'm on the right side of the grass!"</p> <p>"In brief, I look at my ostomy as a necessity for living, a thing to help you."</p>
Recovery from shock and trauma	8 (8.7%)	<p>"... The cancer reappeared. It was traumatic. My blood washed out of my system. I was very depressed... Colostomy is not that bad, you learn how to get used to it.. [At] that time I thought my life was ending. Now years after I am amazed [at what I can do]."</p> <p>"I had an agonizing and difficult recovery. ... Recovery took sustained patience and faith."</p>
<i>Total N of Individuals using an Ambivalent Theme</i>	51 (55%)	
Total Number of Themes	179	

Note: Total number of individuals using a theme is not the sum of the theme counts as a single individual could use more than one theme.

Table 3

Relationship of SWB quantitative scores with qualitative themes

	Spiritual Well-being Scale Score			
	Low (N=13)	Moderate (N=20)	High (N=58)	p-value *
Greatest challenge dimension				
<i>Positive</i>				.000
Yes (N=54)	2 (3.7%)	9 (16.7%)	43 (79.6%)	
No (N=37)	11 (29.7%)	11 (29.7%)	15 (40.5%)	
<i>Negative</i>				.124
Yes (N=27)	6 (22.2%)	8 (29.6%)	13 (48.1%)	
No (N=64)	7 (10.9%)	12 (18.8%)	45 (70.3%)	
<i>Ambivalent</i>				.212
Yes (N=50)	8 (16%)	14 (28%)	28 (56%)	
No (N=41)	5 (12.2%)	6 (14.6%)	30 (73.2%)	

* Pearson Chi-Square test of significance