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## Surviving Colorectal Cancer: Long-Term, Persistent Ostomy-Specific Concerns and Adaptations

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### Abstract

**Purpose**—The purpose of this paper is to describe persistent ostomy-specific concerns and adaptations in long-term (> 5 years) colorectal cancer survivors with ostomies.

**Subjects and Settings**—Thirty three colorectal cancer survivors who participated in eight gender- and health related Quality of life (HRQOL) stratified focus groups and 130 colorectal cancer survivors who provided written comments to two open-ended questions on ostomy location and pouch problems participated in the study. Data were collected on health maintenance organization members in Oregon, southwestern Washington and northern California.

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**Methods**—Qualitative data were analyzed for the 8 focus groups and written comments from 2 open-ended survey questions. Discussions from the focus groups were recorded, transcribed and analyzed using content analysis. Written content from the open-ended questions was derived from a mailed questionnaire on health related quality of life in survivors with ostomies and analyzed using content analysis.

**Results**—Discussions related to persistent ostomy-related issues more than 5 years after formation were common. Persistent ostomy-related issues were focused on clothing restrictions and adaptations, dietary concerns, issues related to ostomy equipment and self-care, and the constant need to find solutions to adjust and re-adjust to living with an ostomy.

**Conclusions**—Ostomy-specific concerns persist 5 years and more for long-term colorectal cancer survivors after initial ostomy formation. Adaptations tend to be individualized and based on trial and error. Findings underscore the need to develop long-term support mechanisms that survivors can access to promote better coping and adjustment to living with an ostomy.

## Introduction

Colorectal cancer (CRC) is one of the most commonly diagnosed cancers worldwide, and has the third highest incidence rate among all cancer types in the United States.<sup>1, 2</sup> Colorectal cancer-related mortality rates have gradually but steadily declined over the years, and the relative survival rate at 5 years is currently 64.3%.<sup>2</sup> Approximately 1 million people alive today have a history of CRC, making this cancer survivor population one of the largest in the United States.<sup>3</sup> An estimated 18%–35% of CRC survivors have received temporary or permanent intestinal ostomies as part of their cancer treatment.<sup>4, 5</sup> These statistics suggest that more CRC survivors with ostomies would be expected to live longer with the associated consequences.<sup>6</sup> Our group has shown that persistent concerns are common in long-term CRC survivors with ostomies, and these concerns may be detrimental to survivors' health-related quality of life (HRQOL).<sup>7–14</sup> Understanding persistent ostomy-related concerns and survivors' adaptations to them are necessary to assist health care professionals in developing evidence-based supportive care strategies to enhance long-term adjustment for CRC survivors with ostomies. This article describes persistent ostomy-specific concerns and adaptations of long-term (> 5 years) CRC survivors who participated in a population-based survey study and focus groups.

## Background

Ostomy formation is an intrusive surgical operation that results in the loss of an important body function. It may result in long-term consequences such as disturbed sleep and peristomal skin irritations, and enormous challenges for personal care.<sup>6, 15–20</sup> Ostomy formation has psychological and social consequences that can be complex and persistent. Predictors of adjustment to ostomy include success of ostomy self-care, satisfaction with body image, amount of social support, and time since surgery.<sup>6, 21</sup> Survivor competence related to ostomy care has been described as the most important predictor of positive adjustment to ostomies.<sup>21, 22</sup> Survivors who perceived a lesser change in body image more readily adjusted to life with an ostomy when compared to those who experienced a more altered body image.<sup>21, 23, 24</sup> Psychological issues related to ostomy include low satisfaction with body image, and perceived low social support.<sup>4, 21, 25, 26</sup> Depression, suicidal ideations, and low self-esteem are prevalent in CRC survivors with ostomies when compared to non-ostomy survivors.<sup>9, 27–30</sup>

Ostomy formation generally has negative consequences on an individual's HRQOL and may affect survivors' lifestyle in several ways.<sup>21</sup> Ostomies can result in negative changes to a person's diet, clothing, travel, sports, sexuality, isolation, social activities, and

employment.<sup>21, 26, 31–35</sup> Evidence suggests that the negative consequences of permanent ostomy formation occur regardless of the type of ostomy or the reason for ostomy creation.<sup>13, 36</sup> Functional limitations are also common, and may be related to ostomy location and self-care strategies.<sup>13, 36</sup> Practical difficulties and concerns of CRC survivors that affect ostomy daily self-care include allergic reactions to adhesives, leakage, odor, and pouch ballooning related to intestinal gas.<sup>7, 17, 37</sup> As a result, survivors report changing jobs because of their ostomy, and serious impairment of long-distance traveling.<sup>6, 38</sup> Stomal and peristomal complications secondary to ostomy formation are prevalent.<sup>8, 39–44</sup> Evidence suggests that the risk of complications from ostomy formation can be life-long, but the incidence is highest in the first 5 years following ostomy creation. Overall incidence rates of complications vary from 21%–60%.<sup>44</sup> For example, parastomal hernias are usually asymptomatic; however, as their size increases they may cause inconvenience and discomfort to survivors who may also experience difficulties in fitting the stoma appliance.<sup>42, 44</sup> In addition, an inability to conceal the hernia may be a source of social embarrassment.<sup>12</sup> Stomal stenosis often results in a noisy stoma when flatus is passed, which can be distressing and embarrassing for the survivor.<sup>44</sup>

Research from our group and others has shown that one of the greatest challenges faced by CRC survivors with ostomies is caring for their ostomy and appliances.<sup>6, 16, 17, 21, 22, 45, 46</sup> Adaptations related to ostomy care and appliances are common, and frequently are related to situations such as traveling, use of public restrooms, or development of new relationships.<sup>45</sup> In many cases, survivors adapt to ostomy and appliance care needs based on trial and error, where effective and ineffective solutions are tried in order to find the best strategies to manage the practical aspects of ostomy care.<sup>7</sup>

Overall, the current literature provides evidence that lowered HRQOL, functional limitations, and lifestyle challenges are common for CRC survivors living with ostomies. Despite the evidence, persistent ostomy-specific challenges and adaptations are not well-defined in the current body of evidence. Understanding long-term and persistent ostomy-specific concerns and adaptations in CRC survivors can provide information for developing comprehensive supportive care strategies for this understudied cancer population.

## Methods

Detailed design and methods for the parent study of this qualitative analysis have been published elsewhere and are summarized below.<sup>9</sup> In the parent study, 282 long-term CRC survivors with an intestinal ostomy participated in a survey study that aimed to describe their HRQOL. Survivors were 18 years or older, at least five years post-diagnosis and were members of the Northwest (Oregon and southwest Washington), Northern California or Hawaii Kaiser Permanente, an integrated healthcare delivery system. The modified City of Hope Quality of Life Ostomy-specific (mCOH-QOL-Ostomy) questionnaire was used to assess HRQOL.<sup>9, 10</sup> Two open-ended questions within the survey asked survivors to share problems related to ostomy location and pouch. Based on HRQOL scores, survivors who had successfully adapted to their ostomy (defined as those in the highest HRQOL quartile, or high HRQOL) and survivors who were not adapting successfully (defined as those in the lowest HRQOL quartile, or low HRQOL) were invited to participate in focus groups to share their challenges and adjustments to living with an ostomy. Study procedures and protocols were reviewed and approved by the University of Arizona and Kaiser Permanente Northwest, Northern California, and Hawaii Institutional Review Boards.

Based on high versus low HRQOL and gender, 8 focus groups were formed. A discussion guide with open-ended questions was used by skilled group facilitators to focus on topics to be discussed as well as topics that did not arise spontaneously. A research team member

served as a silent recorder and attended each focus group to document field observations related to survivor behavior and statements to aid in transcription clarifications. In addition, all focus groups were audio-recorded for transcription purposes. Each focus group lasted for approximately 2 hours to provide sufficient time for discussions on all topics in the guide.

Qualitative data derived from the open-ended questions and focus groups were transcribed into text format and analyzed using HyperRESEARCH™ (ResearchWare, Randolph MA). Investigators experienced in qualitative analysis reviewed the transcripts and identified themes-related to ostomy-specific problems. Separate investigators conducted a final validation review of the themes to ensure consistency and clarity across all qualitative data. Data discordantly coded were discussed for refinement and consensus purposes.

## Results

Thirty three survivors who participated in the parent survey study took part in eight focus groups (16 women, 17 men). Sociodemographic and clinical characteristics of the survivors that participated in the eight focus groups have been published elsewhere, and are summarized below.<sup>47</sup> The mean ages for the focus groups ranged from 63 to 76 years. On average, survivors were 8 to 19 years post cancer diagnosis. They were primarily Caucasian, had either a high school or college degree, and were retired.

One hundred thirty survivors out of the 282 who completed the parent study also participated; the responded to 2 open-ended questions related to ostomy location and pouch problems (Table 1). Their mean age was 70 years (range 43–92 years) and 56% were men. The majority of participants had either a high school (27.1%) or college degree (24.8%). Most survivors were retired and reported an annual household income that was between \$15,000 and \$30,000. The mean time since diagnosis was 12.8 years (range 5 to 33 years). The mean time since surgery was 11 years; most survivors had a colostomy.

### Ostomy-Specific Concerns

Survivors in the 8 focus groups provided valuable insight into persistent ostomy-specific concerns. Thirteen prominent themes emerged following content analysis; representative quotes related to ostomy-specific concerns are shown in Table 2. Survivors identified several bathroom issues that resulted in challenges to daily ostomy management. These included public bathroom design (toilets being too low), cleanliness, and availability of toilet paper in public facilities. Clothing restrictions and adaptations were common in all focus groups, with men reporting changing the type of underwear and the use of suspenders instead of a belt. Overall, both male and female survivors reported the need to wear larger size shirts and pants to accommodate their ostomy. Many shared the challenges experienced in abandoning their entire wardrobe and difficulties in finding clothing to fit their needs. Challenges with seatbelts were also common; ostomy location often interfered with wearing a seatbelt, because the seatbelt rubbed right across the ostomy. This became a specific and lingering problem when survivors were traveling long-distances. Survivors also shared solutions that they created to cope with wearing a seatbelt, such as sticking one hand over the ostomy to protect it from rubbing.

Dietary adjustment and its impact on ostomy-specific concerns was also a common theme across all focus groups. Survivors described alterations in the type of foods they ate (e.g. avoiding foods such as salads and corn), as well as the timing of their meals. Several survivors described the need to eat frequent, small meals throughout the day in an attempt to manage ostomy output, and the need to chew foods thoroughly. Respondents also described limiting food consumption or not eating at all before planned public outings or long distance travel. Overall, dietary adjustments were highly individualized, and were often derived via

“trial and error.” Comments related to gas and odor were, in many cases, related to the type of food eaten. Several survivors perceived that nothing could really be done to eliminate gas and odor issues completely, even when several strategies were employed (e.g. lighting matches). Gas and odor issues were particularly challenging for survivors when in a public setting, such as a restaurant or bathroom. Furthermore, the design of public restroom stalls resulted in challenges for survivors seeking to wash out their ostomy bags.

Survivors also shared experiences related to family knowledge and acceptance of their ostomies. Several respondents were able to show their pouch and stoma to family members, particularly young children. Many described the dilemma that they experienced in deciding to show their ostomy to grandchildren, but in retrospect they stated they were glad that they did. However, not all stories that were related to family knowledge and acceptance were positive. Survivors described the challenge of having spouses and family members who did not understand the experience of living with an ostomy.

Several themes focused primarily on ostomy complications, equipment, daily self-care and solutions. Ostomy complications were a common theme across all the focus groups, with the majority of complications being hernias and stoma prolapse. Multiple hernias were common for survivors, and multiple surgical repairs were needed to correct them. Some survivors described their reluctance to undergo surgery for hernia repair, and in an effort to delay repair, they determined to live with the hernias for as long as possible. Ostomy equipment failure was another common theme across all focus groups, and these discussions were focused around wafer and pouch problems. Numerous survivors described having “accidents” throughout the years, primarily related to loose wafers and leaking pouches. Too often, these accidents happened in public, causing embarrassment and anxiety for survivors.

Ostomy daily self-care was a theme that was discussed commonly in the focus groups. Irrigation was discussed by a few survivors, and those who practiced irrigation stated they found it easier than wearing pouches. They also stated that irrigation helped with common ostomy concerns such as odors. Many survivors described washing their bags on a daily basis, sometimes multiple times per day. The daily cleansing routines were also related to ostomy bag duration, and for many survivors the daily cleaning/rinsing meant that the same pouch could be used for many days.

Survivors in the focus groups also shared many ostomy-related solutions and tips that they had learned throughout the years of living with an ostomy. Some noted that ostomy supplies have improved over the years, and they were grateful for the advancements. Others noted that some of their favored ostomy supplies were discontinued, which resulted in a frantic search for new supplies that were comparable to the discontinued designs used previously. Solutions shared were, in general, focused on how to prevent or diminish potentially-embarrassing situations with ostomy-specific problems when in public. For example, it was imperative for survivors to pack as many extra supplies and extra clothing as possible for all events, including long-distance traveling.

### **Problems with Ostomy Location and Pouch**

Themes, the number of comments, and selected comments from the open-ended questions related to ostomy location and pouch problems are presented in Table 3. Clothing adaptation was the most common problem related to ostomy location. Similar to comments from the 8 focus groups, clothing adaptations included wearing larger sizes of clothing and using suspenders rather than belts. Comments related to problems with equipment were also common, and many were related to leakage when the ostomy was located in the area of a belt. Comments about ostomy complications centered around hernias that resulted in having to move the ostomy to a different location. Activity limitations included difficulty bending



over and having to give up physical activities such as golf because the ostomy location impaired completion of a golf swing. Finally, coping and adjustment comments focused on the constant and exhausting need to monitor the ostomy in an effort to prevent embarrassing accidents.

When asked about problems related to their ostomy pouch, survivors reported leakage problems that were related to strenuous physical activity, blockage, leaks from the bottom of drainable pouches, and uncertainty surrounding the potential for future leakage. Pouch seal and adhesive were also common issues that were exacerbated by hot weather, which caused the faceplate of the pouch to “melt a little” and unseal. Skin problems were, in general, attributed to allergic reactions to the plastic pouch or adhesive. Odor control was a constant battle for many survivors; the pouch had to be emptied and cleaned several times a day in order to eliminate unpleasant odors. Pouch size problems were often resolved by cutting the opening to make it fit the ostomy. Finally, survivors described problems with enclosure clips that come loose and snag on clothing and furniture.

## Discussion

In this study, we explored long-term, persistent concerns and adaptations in CRC survivors living with an ostomy. Comments from the eight focus groups and open-ended questions from the parent survey study provided valuable insight into the ostomy-specific challenges experienced by survivors even five years after their ostomy formation. In general, survivors continue to face challenges related to bowel function, clothing restrictions, and dietary adjustments. This finding has been described in a previous analysis by our group, where survivors described avoiding foods that caused gas and limiting the amount of food eaten in order to control output.<sup>47-50</sup> Comments related to family knowledge and acceptance of ostomy suggests that survivors valued opportunities to share their experience of living with an ostomy with family members, particularly young grandchildren. However, family acceptance and their willingness to understand this experience were often challenging, and survivors perceived that getting someone to understand their feelings and experiences was often difficult and frustrating. The current literature suggests that social well-being and perceived social support are predictors of overall HRQOL in CRC, and can foster better coping and adjustment for CRC survivors.<sup>6, 26, 41, 51-57</sup> Further research is needed to explore factors related to family knowledge and acceptance of ostomies and how social support can affect coping and adjustment in long-term CRC survivors with ostomies.

Evidence from studies conducted in chronic illness settings suggests that adaptation to disease management and self-care is a long-term process and re-adjustments may be needed when an individual's context changes.<sup>6, 55-57</sup> In the focus groups, CRC survivors were able to openly discuss solutions and strategies for ostomy care that they have used throughout the years. Ostomy solutions were primarily focused on strategies to prevent and/or decrease potential embarrassing situations when in public, such as leaking or gas. These comments revealed there is a constant need to adjust and readjust to living with an ostomy, even years after its formation. As a survivor's context changes, for example weight gain or changes in family and living arrangements, new strategies and solutions must be developed in order to adapt to the new context. In many situations, the new context and its challenges can result in embarrassing situations and anxiety that, in turn, can negatively affect the entire adjustment process for survivors. This observation suggests that health care professionals, including ostomy nurses, must understand that re-adjustments to living with an ostomy may be required.<sup>6, 55-57</sup> Furthermore, as persons with ostomies age, a certain proportion will experience functional or cognitive deficits. Their effect of these changes on ostomy management must be taken into account. This underscores the need to design supportive

care strategies that can foster positive, long-term adjustments for CRC survivors, including age-related issues.

Written comments provided by CRC survivors in the open-ended questions related to ostomy location and pouch problems were focused around common themes, including clothing, complications, activity limitations, leaking, odor, pouch adhesive issues, skin problems and pouch size problems. Over the years, notable improvements have been made in ostomy appliances, and new products are introduced frequently to fit the needs of ostomates. Some of these improvements include stoma plugs, two-piece pouches or plugs, and even flushable pouches that can aid in easy disposal of fecal contents.<sup>46</sup> In theory, these appliance improvements should help survivors regain their confidence in pursuing social and physical activities. However, the continuing high proportion of survivors who adjust poorly to their ostomies<sup>58</sup> suggests that technology and appliance improvements alone have a limited impact on adjustment. Although development of new and improved ostomy appliances is important, it is equally important to develop strategies to support self-efficacy in utilizing new technologies and appliances.<sup>59</sup>

## Limitations

Limitations of the present study included the lack of wide racial/ethnic or cultural diversity within the study population and the small numbers of survivors who participated in the focus groups; thus findings may not be wholly generalizable. Nevertheless, this qualitative analysis provided preliminary evidence for persistent ostomy-specific challenges and adaptations experienced by CRC survivors years after ostomy formation, representing longitudinal adjustment experience. Further research is needed to replicate the findings in a more diverse population of CRC survivors.

## Conclusions

Findings from the current analysis provide valuable information for WOC nurses and other clinicians who routinely care for CRC survivors with ostomies. The valuable services provided by WOC nurses should accommodate the persistent needs of long-term CRC survivors as well. Types of services may include periodic check-ups and follow-up contacts during periods in which the survivor's context changes.<sup>60</sup> The valuable comments provided by survivors can aid in the planning of group or individual support methods for long-term adjustment to CRC survivorship. For researchers, the findings can be used to design evidence-based interventions to promote better coping and adjustment for CRC survivors living with an ostomy. Intervention content should include specific information related to dietary adjustments, physical activity strategies, and general information to aid in self-efficacy related to ostomy management. Support should also be provided to family members of CRC survivors.

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### Key Points

- Ostomy formation has long-term consequences that impact HRQOL for CRC survivors.
- Ostomy location and pouch problems included activity limitations, leaking, odor, pouch adhesive problems, skin irritations, and pouch size problems.
- Years after ostomy formation, persistent ostomy-specific concerns and adaptations continue to affect overall coping and adjustment of CRC survivors. Long-term supportive care strategies are needed for CRC survivors to promote better adjustment to living with an ostomy.

**Table 1**

Sociodemographic and clinical characteristics of survivors that answered the open ended questions (n=130)

Characteristic	No.	%
Age (years)		
Mean (SD)	70.37 (10.96)	
Range	43.00–92.84	
Gender		
Male	73	56.15
Female	57	43.85
Race/Ethnicity		
White, non-Hispanic	104	80.00
Others/Unknown/Mixed	26	20.00
Education		
No high school	18	13.95
High school/GED	35	27.13
Vocat/Sectrl/Busin	5	3.88
Some college	32	24.81
Graduate college	17	13.18
Some graduate college	11	8.53
Graduate degree	11	8.53
Annual Household Income		
<15,000	14	11.57
15–30,000	35	28.93
30–50,000	29	23.97
50–75,000	20	16.53
75–100,000	15	12.40
>100,000	8	6.61
Missing	9	-----
Employment		
Full time	20	15.38
Part time	11	8.46
Retired	92	70.77
Unemployed/unknown	7	5.38
Years since cancer diagnosis		
Mean (SD)	12.87 (6.57)	
Range	5.27–33.04	
Years since surgery		
Mean (SD)	11.97 (7.34)	
Range	0.51–35.33	
Type of stoma		

Characteristic	No.	%
Colostomy	111	88.80
Ileostomy	14	11.20
Missing	5	----

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Table 2

## Selected Quotes Related to Ostomy-Specific Concerns

Theme	High-HRQOL Women	High-HRQOL Men	Low-HRQOL Women	Low-HRQOL-Men
<b>Bathroom Issues</b>	-	-	I'd like a higher toilet so it's a little easier to eliminate. I would just like, when you're inside the bathroom, and everything's nice and neat and clean. And the toilet paper is there. I always have to look to see if there's toilet paper before I go in one of the stalls. Just a lot of things that other people don't have to worry about that we do.	-
<b>Clothing restrictions and adaptations</b>	I've gone to the over blouses for swimming. No more bikinis. I wear two panties and a pair of shorts when I go to bed. I buy those waterproof pads to cover the mattress. Had to get rid of the first mattress.	Since my ostomy, it's more convenient to wear bikini underwear, rather than briefs. I use suspenders most of the time.	I try to wear things that go over. I don't wear anything tucked in, anymore. I've even tried to remember to put my purse on my right shoulder. I'm used to having it on my left, and I find it'll hit it [ostomy]. I had to literally get rid of a whole wardrobe that I used to wear that I can't wear anymore. Loose or long. It's hard to find clothes that fit when on one side you're flat and the other side you've got this big bulge.	I have to wear boxers now. When I was wearing a bag I had to use two sizes larger pants and suspenders.
<b>Dietary adjustments</b>	And you learn, over the years, what you can and can't do. And you can't overeat. That's why it's good to graze. You just eat all the time. But if you just sat down and ate a huge meal, it would be a bad thing. You know, the pouch fills, and you get uncomfortable, things back up.	I don't eat popcorn and I don't eat corn.	I used to not eat if I knew I was going somewhere. And most things you can eat, if you don't eat too many at one time. And I try to chew my food slowly. And I don't drink until after I eat. I don't eat as many salads. Now I'll eat a little bit, but some things I couldn't eat because they went right through. But you have to eat a healthy diet, too.	I watch my diet, especially if I'm going to go out into public or do some traveling. And 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 your system and pour out.
<b>Irrigation</b>	It's old-fashioned, but gets rid of odors and other things that bothers. I did irrigate for five years. I retired, and I haven't irrigated a day since. It's twice as nice. I think of all those years I sat on that toilet and it's ridiculous.	I have never irrigated. I think I'm so irregular it probably wouldn't work anyway.	I irrigated for a while and I loved it. I went in there [bathroom] and told everyone to leave me alone.	I don't know anything about it. What would be the advantages or disadvantages.
<b>Gas and odor</b>	I just go to the bathroom and open up the pouch. I kind of watch what I eat. Wake up at night because of the smell.	-	The odor is bad, no matter what you do. I've come out of the bathroom stalls a couple of times, and somebody will start to go in there, and it's kind of like, "oh." I light matches. I try everything at home for	Sometimes the smells quite a bit, and it depends on what you're eating.

Theme	High-HRQOL Women	High-HRQOL Men	Low-HRQOL Women	Low-HRQOL-Men
			odor control, and it's just an odorous thing. There's not a lot you can do about it.	
<b>Nickname for ostomy</b>	It's Sweet Pea. You have to be friends with it, so if you can give it a name that would be fine.	-	-	-
<b>Ostomy bag duration</b>	I just change my pouch. Just change the whole thing.	Sometimes I go 12 or 13 days before it needs it. I think cleaning it all the time helps.	-	-
<b>Ostomy complications</b>	Went back to work too soon, got hernia by lifting patients. Needed to do another surgery and change stoma to other side. Kept putting it off. You know, I guess, you know, let it be.	-	Hernias have been a problem. I've had them repaired. And in fact, I've got another one now, but I just decided I want to live with it as long as I can.	My prolapse, the reason it's so bad it filled up part of the bag. I've gone back twice and I don't know how common that is. You know, really, they didn't give me a very good manual on how to deal with this.
<b>Ostomy family knowledge and acceptance</b>	That night she [granddaughter] started asking questions, about eight. And she said to me, "Can I see it?" So I showed her the pouch, and she wanted to see the actual stoma. So I opened it and showed her. And then she says to me, "Can I touch it?" And that's the only time I said, "I'd rather not." And that I kind of regretted. I haven't told the grands. Some of the grands know, but the little ones wouldn't understand.	-	To try to explain to a little tiny one why you're wearing a bag on yourself. It's usually my husband who's like, can't you just do this. The biggest challenge is just getting someone to understand what I am dealing with. My sister would always say, TMI – too much information. She doesn't want to hear the detail; she doesn't even want to hear the basics.	I have a four year old [grandson]. He comes into the house, "Your bag." And the other one asked me, "Are you okay, grandpa?" So, I've never told them about it, but they can see it, you know. They were curious, at first, and asked some questions, but not anymore. When they see it first, they said, "You okay, grandpa?" So I guess that and going to church every Sunday probably keeps me alive.
<b>Ostomy solutions</b>	I play golf and I walk. I have these little mini bags that I'll snap on if I am wearing a bathing suit that don't take up so much room.	One thing I do a little bit different than maybe the other folks is our toilet seat is such a small hole and we have a small stool in the bathroom that's the same height as the toilet, so I sit facing the toilet and it give me a lot of working room there to take care of it. I have noticed I over-pack when we're going someplace just to be on the safe side. Where before I never did. I'd take one extra pair of pants and two shirts and that was it. Now I take a little more than that.	My friends know that if we go to the movies, I like to sit on the aisle – and, at least, if there's an odor problem, it will go out that way. Or I can get up and leave. You've got to have things for every event. And whenever you get a stomach cramp, don't wait. Go right to the bathroom. It had to have been a month because that's when I started going to the ostomy association meetings. Prior to that, I wouldn't even leave the house for about three weeks. I was just going to stay at home and not have to worry about anything. But I went to that meeting and then, after that, I started going out more. But it probably took about three weeks – so you	I found two pairs of curved scissors to make the pouch fit. You just put a pencil mark on there how big you want it and just follow it right around in a circle. What I do with the pouch now, I get a piece of tissue and I put in there. But I push the tissue all the way, it absorbs some of the liquid, and then it's easier when you go to the bathroom to get rid of. It absorbs some of the liquid and it's easier to flush it out. I always carry a bottle with me, and I fill that with water before I go in and use the public restrooms. What I've found is that instead of

Theme	High-HRQOL Women	High-HRQOL Men	Low-HRQOL Women	Low-HRQOL-Men
			would know kind of when you were going to go to the bathroom.	having to get on your knees and do it that way, I just sit on the toilet backwards. Before it leaks, you'll get a smell first. Then you know you've got a problem. So I don't like to take anything for that, because if you smell something you know it's time to go look for a place to fix it.
<b>Seatbelts</b>	I wear it, but I often think that if I were in a wreck I wonder what would happen because it goes right across it.	-	It [seatbelt] keeps pulling tight and I'm constantly pulling it back out because it rubs right across here. So I adjust it and then I'll stick like one hand here for a little while. If we're driving long distance, it's worse. But if I'm driving in traffic, I have a stick shift so one hand's here and one hand's on the wheel.	-
<b>Ostomy daily self-care</b>	-	The one thing that I do that probably the rest of them don't, I wash mine. When I take the clip off and empty it, I have a bottle for dish soap. I put about that much dish soap in the bottle and then fill it with water. Then I hold it up and I put in a bunch of water, rinse it and empty it. I've been doing that for a long time and I just feel good about it.	-	You just have to wash it every day with soap and water, and clean it, and use alcohol with a swab to clean it – before you switch from the night bag to the day bag.
<b>Ostomy equipment failure</b>	-	The wafer came off once, and thank goodness it didn't come off until I got home and we were getting ready for bed. That would have been awful embarrassing to be at the people's house and have that wafer come off, and I didn't take a spare one.	I wouldn't want to go in a place and have the bag open up. That's my big fear.	In the summertime, if it's real hot, you're active and you start sweating, then it has come loose before.

**Table 3**

## Written Comments Related to Ostomy Location and Pouch Problems

Does the location of your ostomy cause you other problems?		
Theme	Number of Comments	Selected Comments
Clothing adaptations	24	<ul style="list-style-type: none"> <li>The stoma is directly under my belt line. I must wear very loose pants with suspenders to stay above the stoma so it will drain.</li> <li>Only can wear bigger underwear.</li> <li>I need shirts with elastic on the bottom so it don't show.</li> <li>Looser fitting clothing over waist and hipline.</li> </ul>
Complications	11	<ul style="list-style-type: none"> <li>Have developed a hernia right above the colostomy, which causes pain. If I have surgery, probably cause more problems. Hope it doesn't rupture.</li> <li>Original stoma left lower side became herniated. Repaired and stoma moved to right side.</li> <li>I have a serious prolapse which protrudes and becomes irritated. This condition also keeps me from swimming or using public showers.</li> </ul>
Equipment issues	8	<ul style="list-style-type: none"> <li>Drops off body because of sweating.</li> <li>Retaining clip rubs/pokes pelvis, flips and grabs clothing.</li> <li>Has a tendency to leak in area of belt when driving or sitting because of pressure. Does not fit well or seal – makes mess – requires constant attention!</li> <li>Only since being in a care facility and the caregivers fasten a brief over the colostomy pouch and when it fills with gas and or feces it is not easy to let the gas out.</li> </ul>
Coping and adjustment	5	<ul style="list-style-type: none"> <li>You never get used to colostomies, you just live with it. Thank God and my doctor that I am alive.</li> <li>Very exhausting. Having a colostomy is not easy. You can't feel it going, so have to constantly try to monitor whether bag is full of gas or poo.</li> </ul>
Activity limitations and adaptations	4	<ul style="list-style-type: none"> <li>Difficult to bend over.</li> <li>Underside of ostomy is always chafed because I bend over at my computer.</li> <li>Gave up golf. Kept hitting the stoma.</li> </ul>
Seatbelt issues	2	<ul style="list-style-type: none"> <li>Seatbelts can often cause discomfort. On long distance driving I often put a small pillow/pad under the belt on stoma area.</li> </ul>
Stoma site and size	1	<ul style="list-style-type: none"> <li>The original stoma was much too low on left side, and stoma was too small. The ostomy was moved to slightly higher area on the left side. Prior to second surgery ostomy nurse marked location where new stoma should be located.</li> </ul>
If you wear a pouch and have encountered any problems with it, please explain below what those problems are/were.		
Theme	Number of Comments	Selected Comments
Leakage	23	<ul style="list-style-type: none"> <li>Sometimes leaking, because waste gets blocked in opening.</li> <li>Appliance leaks at edges during or after strenuous physical activity.</li> <li>Leakage from clip at the bottom of the drainable pouch.</li> </ul>

Does the location of your ostomy cause you other problems?		
Theme	Number of Comments	Selected Comments
		<ul style="list-style-type: none"> <li>I've no warning when my pouch will fill. Too often it chooses my sleep time – over fills, pulls away, disgusting mess on me, my bed, bed linens.</li> </ul>
Seal and adhesive issues	22	<ul style="list-style-type: none"> <li>My main problem is adhesive on bag is not good enough to last all day to support my active lifestyle.</li> <li>The tape around the pouches comes unstuck after one day only.</li> <li>During very hot weather the wax on the pouch tends to melt a little and slip. Therefore during this time more pouches are needed.</li> <li>In the summer heat sweat loosens the adhesive and releases the pouch.</li> <li>Pouch does not stay on well. Frequent breakages due to small hernia. Repaired hernia, but continue to have accidents.</li> </ul>
Skin issues	15	<ul style="list-style-type: none"> <li>Allergic to adhesive for pouch. Gives me rash under the tape.</li> <li>Plastic pouch causes skin rash and irritation.</li> </ul>
Odor issues	11	<ul style="list-style-type: none"> <li>Bag is supposed to hold odor, but after a day bag has odor.</li> <li>Odor control a constant battle. Must be emptied/cleaned several times a day.</li> </ul>
Pouch size issues	8	<ul style="list-style-type: none"> <li>Cut to fit it perfectly.</li> <li>For over a year I had to cut out the size of opening for my stoma. Had to travel with scissors which were confiscated at the airport.</li> </ul>
Enclosure clip issues	7	<ul style="list-style-type: none"> <li>Clip snagging on furniture or equipment.</li> <li>Clip does not stay clipped comes loose and fall off.</li> <li>In the beginning not being made aware of how the clamp works and its limits.</li> </ul>