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GOING WITH THE FLOW: QUALITY OF LIFE OUTCOMES OF CANCER SURVIVORS WITH URINARY DIVERSION

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Abstract

Purpose—The purpose of this descriptive study is to describe health related quality of life (HRQOL) concerns among cancer patients with continent and incontinent urinary diversions (UD).

Subjects and Settings—Study participants were accrued from members of the California United Ostomy Association and two cancer centers in Southern California.

Instruments—The City of Hope HRQOL-Ostomy Questionnaire (COHHRQOL-O) is a modified HRQOL measurement tool based on the original work done over a number of years by Grant and colleagues.

Methods—The COHHRQOL-O was mailed to 2890 individuals. Of the 1600 returns there were 307 responses from patients with UD indicating they had a UD and a diagnosis that clearly indicated cancer.

Results—The majority of respondents were diagnosed with bladder cancer and the average time since surgery was 9.5 years. While most patients reported being sexually active prior to UD less than 27% resumed sexual activity after surgery. Over 75% of patients also reported difficulty in adjusting to their UD with the majority reporting difficulty with urine leakage. Those who were incontinent reported a range of bothersome issues, such as skin problems around the UD, difficulties in managing UD care, fear of recurrence, financial worries, family distress, and uncertainty about the future.

Conclusions—The results of this study add to our understanding of how patients adjust to a UD and what problems and issues can occur, even years after the initial surgery. Mastering UD care is best done under guidance of a WOC nurse and access to WOC nurse is essential when problems occur.

Introduction

Urinary diversion (UD) is required when the bladder must be removed due to a variety of conditions including bladder cancer, invasive prostate cancer, severe cases of interstitial cystitis, neurogenic bladder, and refractory radiation cystitis. Bladder cancer is the most common cancer requiring urinary diversion. In the United States it is the fourth most

common cancer in men and the eighth most common among women, with approximately 68,900 estimated new cases in 2008¹. Radical or simple cystectomy requires creation of a urinary diversion or construction of an orthotopic neobladder using a segment of bowel. Both continent and incontinent cutaneous UD require physical, functional, psychological, and social adjustments that can negatively impact health related quality of life (HRQOL), regardless of the primary diagnosis.

Understanding the HRQOL issues that patients with UD face can provide valuable information for nurses when supporting patient treatment decisions, long-term adjustment and coordinating rehabilitation. Additionally, HRQOL concerns throughout the cancer experience provide the nurse with meaningful data upon which nursing interventions and patient education can be applied.

This study builds on work previously completed by Grant and colleagues^{2,3}. The purpose of this descriptive study is to describe HRQOL concerns among cancer patients with continent and incontinent UD. Quantitative data were gathered from three sites within California from cancer patients with UD. Findings presented will describe HRQOL issues using the City of Hope (COH), a multidimensional HRQOL construct that includes physical, psychological, social, spiritual domains of life experience (Figure 1).

Literature Review

HRQOL is an important outcome measure for cancer management, especially as more and more cancer patients are surviving their disease. It is a multidimensional construct that includes both positive and negative responses across physical, psychological, social, and spiritual domains of life, as well as discomfort and symptoms produced by the disease and treatment. Evaluation of HRQOL following surgery can supplement morbidity and survival data and provide clinicians insights into long term adjustment issues. One area of concern regarding HRQOL studies centers on the validity/reliability of available instruments. Porter and Penson⁴ cite the lack of valid and reliable tools as a reason for their inability to conclusively recommend one form of UD over another.

The following study expands City of Hope cancer patient HRQOL research spanning the last three decades from tool development, validation and reliability studies to adapting the tool for disease specific use, such as for survivors of bone marrow transplant (BMT). The current study used a psychometric-tested, multidimensional self-report disease specific COH-HRQOL – Ostomy Questionnaire. Findings report this tool to be a comprehensive valid and reliable measure of ostomy patient HRQOL³.

Small sample size has also been identified as a limiting factor when generalizing results from HRQOL studies. The current study has overcome this issue by surveying a large population of patients with UD from three settings within the state of California. Study participants were asked to answer HRQOL questions in relation to their current condition. Another limiting factor cited in quality of life literature is the lack of longitudinal data. While this is a cross-sectional study, we were able to survey patients over varying times following surgical creation of the UD (average 9.5 years).

Numerous HRQOL issues arise as a consequence of having radical cystectomy with a UD. Problems and concerns of patients with UD include urine leakage, bowel symptoms, impaired body image⁵, sexual dysfunction, curtailing social activities⁵, anxiety, and depression⁶. Over the last several decades advances in the creation of continent UD has prompted many researchers to compare HRQOL outcomes in patients with continent UD to those with incontinent UD⁷⁻¹². In contrast only a few early studies specifically addressed HRQOL concerns among cancer patients with incontinent UD^{13, 14}. Several studies have

focused their efforts on understanding how the patient with a UD adjusts psychologically and socially^{5, 11, 15}. Symptom management and late complications following UD have also been studied^{6, 16–19}. One study specifically explored the benefit of offering a psychosocial intervention to patients 4–9 weeks following radical cystectomy.²⁰

While most studies of cancer patients with UD include both male and female participants^{12, 20, 21}, few studies describe HRQOL gender differences²². Examination of gender differences is important to understanding the issues each gender faces in the adjustment to diversion surgery especially as it relates to body image and sexual functioning.

Assisting patients with managing their new UD is a vital component of WOC nursing practice. No studies were found that provided insight into how long it takes for the patient to integrate care of a UD into their daily routine. Gaining a better understanding of adjustment time and issues from the patient perspective will enable the WOC nurse to assess patient progress against comparable norms. Helping patients to master daily care of the UD could improve psychological and social well-being.

Materials and Methods

Three settings within the state of California were used for this multi-site study. Study participants were accrued from members of the California United Ostomy Association and two cancer centers in Southern California (COH and USC). The City of Hope HRQOL-Ostomy Questionnaire (COHHRQOL-O) and addressed-stamped envelopes were sent to a mailing list totaling 2890 individuals. Returns totaled 1600 for a response rate of 59%. The response rate was calculated omitting surveys returned because of incorrect addresses or surveys from respondents with an unknown type of ostomy, incomplete or an unknown diagnosis. Those members who responded had a variety of different types of intestinal stomas and UD. Of the 1600 there were 307 responses from patients with UD. This report focuses on those with a UD. Respondents were chosen who indicated that they had a UD and identified a diagnosis that clearly indicated cancer. Respondents with ambiguous descriptions like 'tumor' were not included in the analysis. The current study protocol was reviewed and approved by the Institutional Review Board with an understanding that return of the mailed survey was accepted as informed consent. The results of this study are part of a larger study investigating the quality of life outcomes of cancer and non-cancer patients with an ostomy^{2, 3}. This analysis specifically focuses on the experience of patients with a UD

Instrument

We used a four dimensional HRQOL model to measure HRQOL concerns of cancer patients with UD^{323–26}. The four dimensions, physical, psychological, social and spiritual well-being, are defined in Table 1. This model has been used to measure HRQOL concerns for a variety of cancer populations^{24, 27, 28}. The current modified HRQOL measurement tool is based on the original work done over a number of years by Grant and colleagues.^{2,3}

Following in-depth interviews of cancer patients with an ostomy, data were analyzed by a multidisciplinary team and revisions were made to the original questionnaire. This team consisted of a WOC nurse, two general surgeons, one urologist, and four nurse researchers. After initial composition of the questionnaire, it was forwarded to a panel of three additional WOC nurses and one additional nurse researcher. Psychometric analysis was performed on results of the questionnaires received following the mailing to a large population of cancer and non-cancer patients with UD. Details of the analysis are reported elsewhere³. The resulting ostomy-specific HRQOL model reflects the themes identified and validated

(Figure 1). The COHHRQOL-O was used to measure HRQOL in addition to other demographic and personal factors. The questionnaire can be downloaded in its entirety from a City of Hope Website (<http://prc.coh.org> under Research Instruments, HRQOL Instruments, Ostomy). The questionnaire is arranged in two sections. The first section has 46 forced-choice questions used to identify demographic, disease, treatment, ostomy specific, and other personal characteristics including diet, work, and activity. This is followed by the second section comprised of 43 items, divided into the four dimensions, physical, psychological, social, and spiritual. Each item within each dimension is scaled from 0 to 10, with 0 being the worst HRQOL, and 10 being the best HRQOL. Total scores for each dimension are calculated by adding scores on all dimension items and dividing by the total number of dimension items. An overall HRQOL score is calculated by adding scores for all items and dividing by 43. Confirmation of the revised four dimension conceptual model was performed by psychometric analysis providing evidence for acceptable reliability and validity with Cronbach alphas of the subscales ranging from 0.77 to 0.90 and Cronbach alpha of the total questionnaire at $r = 0.95$ ³. Comparative analysis is described below.

Statistical analyses were conducted using the JMP Statistical Discovery Software, version 4.0.0 final candidate 11, created by SAS Institute (SAS Institute Inc., Cary, NC). All P values were two-sided, and values ≤ 0.05 were deemed statistically significant. Univariate logistic regression methods were performed using the Pearson's Chi-square statistic. Multivariate logistic regression methods were performed using the Wald's test statistic. Missing data were excluded from the analyses.

Results

The 307, who indicated that they had a UD, were diagnosed with bladder (82.4%), prostate (5.5%) or some other cancer (Table 2). An incontinent UD was reported by 73.6%. The mean age was 74 years; 68.4% were male, and 92% were Caucasian. The average time since surgery was 9.5 years. Prior to surgery, the large majority of subjects were married (80%), compared to 70.4% at the time of study enrollment (Table 2). Most were retired (85.5%), and had health insurance (96.4%). Almost half of patients reported that their insurance covered all or partial costs for urostomy supplies.

In terms of sexual activity, most patients (70.4%) reported being sexually active prior to their UD, but only 26.7% resumed sexual activity after surgery. Twenty three percent indicated they were satisfied with sexual activities, and 44% of male subjects reported erectile problems. Approximately 44% reported feeling depressed after surgery, men and women were equally likely to report feelings of depression. More than half of patients reported belonging to an ostomy-specific support group, and 60% had contact with other persons with ostomies. Most patients did not find the location of their UD troublesome, and most did not find the need to change their style of clothing after placement.

The average length of time for patients to complete daily UD care was 36 minutes while some took up to two hours. The majority of patients reported it taking months to feel comfortable with daily care and diet. Over 75% reported difficulty adjusting to their UD, and most indicated some degree of difficulty with urine leakage. A little less than half reported embarrassment associated with their UD. Most respondents did not avoid specific foods such as carbonated beverages, dairy products, fruits, snacks, and vegetables because of their UD.

Quantitative analysis of the HRHRQOL scores involved calculating a mean overall HRHRQOL score using all 0 – 10 scaled items and then subscale means scores that averaged all items within the subscale. The average overall score was 7.7, with subscale

scores ranging from 7.8 for psychological well being to 8.2 for physical well being (Table 3). Further examination provided information on the lowest and highest item mean scores for each subscale. The smallest range of item mean scores was in the physical well being dimension and the largest range of item mean scores was in the social well being dimension (Table 3). The lowest item mean score was “interference with the ability to be intimate”, and the highest item mean score was “having enough privacy at home.”

Next we examined differences in demographic and personal characteristics and HRHRQOL scores across genders. This analysis revealed a difference between males and females for psychological well being, with females having a significantly lower mean score (Table 4). Women were significantly younger than men (Table 5). While men were significantly more sexually active before UD than women, both men and women reported decreased sexual activity after UD. Significantly more men reported decreasing sexually activity than women. Sexual activity was more satisfying to women after UD. Significantly more men talked with other persons with an ostomy, while more women changed their clothing style.

Men scored higher in feelings of control and had less fear of recurrence. Women reported significantly more interference with personal relationships, greater perceptions that the UD interfered with intimacy, and were significantly less satisfied with their appearance than men (Table 6).

Next we examined differences that occurred when we divided the group by continent versus incontinent UD. Continent versus incontinence UD was defined in the database based on reports of wearing a bag or pouch. Results revealed that 226 subjects wore a pouch and were defined as incontinent; while 70 were defined as continent (11 did not answer this question). Respondents with a continent UD were significantly younger than those with an incontinent UD (71.5 versus 75.6, $p < 0.001$). No other differences in demographic characteristics were revealed (Table 7). Significant differences were found in some personal characteristics. While there was no difference in sexual activity prior to UD, those who were incontinent had significantly less activity after UD, were more likely to belong to an ostomy or other support group, had more problems with the location of the UD, and were more likely to change their clothing and their diet. In relation to HRHRQOL, those who were incontinent reported a range of significant items, such as skin problems around the UD, difficulties in managing UD care, fear or recurrence, financial worries, family distress, and uncertainty about the future (Table 8).

Discussion

Information regarding HRQOL provided by patients following cancer treatment can provide clinicians with a broader understanding of their status beyond morbidity and survival data. Additionally, this information can be used to augment existing data in comparing various treatment modalities. Previous studies exploring HRQOL of patients who have a UD have focused on comparing outcomes between continent and incontinent diversion. Comparison of these two forms of diversion is driven primarily by the assumption that a patient will have higher quality of life with a continent diversion. Though studied extensively, conflicting results regarding quality of life remain ^{21, 29}.

Methodological flaws have been cited for the inability to conclusively determine HRQOL benefits of various surgical approaches following radical cystectomy ^{4, 29}. Shortcomings include lack of baseline assessment, longitudinal data and a valid instrument. This current study describes HRQOL following radical cystectomy in 307 survivors with a malignancy focusing on how the patient is adjusting physically, psychologically, socially, and spiritually to their UD. Each survivor completed the COHHRQOL-O which has demonstrated validity

and reliability³. Study participants were mostly male, diagnosed with bladder or prostate cancer, over the age of 70 and reported having an incontinent UD. These findings are consistent with previous studies. Our sample had a median time since surgery or 9.5 (range of 3–31 years). While most studies have included participants up to four years postoperatively, few studies have included survivors who underwent UD more than 10 years ago^{6, 12, 14, 16, 17, 20, 30}. Our analysis reveals a broad range of issues that long-term survivors face when adjusting to life with a UD.

Participants in our study report reduced sexual activity post operatively accompanied by dissatisfaction with their sex life and erectile dysfunction in men. Poor sexual performance following surgery is consistent with the findings of previous studies^{7, 10, 11, 22}. While poor sexual performance following UD surgery is commonplace, few studies provide comparison data indicating those patients with incontinent diversion have less sexual activity following surgery and more difficulties^{7, 10}. Our findings concur with these results.

One study examined male and female sexual function following a UD and found 41% of men were not able to achieve an erection²². Our results indicate men experienced erectile dysfunction regardless of surgical approach. Due to the complexity of sexual dysfunction following surgical treatment it is important for WOC nurses to assess sexual concerns pre- and post-operatively, taking into consideration tumor stage, previous treatment, proposed surgical intervention (e.g. continent or incontinent UD), psychological disposition, body image issues, and the patient's general state of health and age.

Adjustment following surgery is viewed to be successful when the patient is comfortable and secure in managing urine elimination regardless of diversion type. For many of the patients in our study, adjustment to managing their UD required months and was deemed difficult. This is the first study we found that reported how long it took for patients to adjust to managing their UD. The ability to master daily care is an important part of learning to live with a UD. Feelings of self efficacy play an important role in optimal adjustment. The inability to manage complications related to daily care and to obtain needed supplies can hinder adjustment. Preoperative education by the WOC nurse can contribute to improved adjustment³⁰. Successful transition to self care management is likely to occur with instruction in self care and psychological support in adjusting to a new body image³¹.

Only a third of respondents described having an excellent HRQOL. The ability to manage physical aspects of self care following surgery can influence the patient's overall perception of HRQOL as well as psychological, social, and spiritual adjustment. Physical adjustment challenges described in the current study included peristomal skin irritation, bowel changes, and urine leakage which are consistent with the findings of others^{8, 9, 11}.

Many of our participants, and especially women, struggled with depression immediately following surgery. In addition, fear or anxiety associated with potential urine leakage of urine, fear of disease recurrence and embarrassment were recurring themes. In one study researchers evaluated how symptoms following surgery influence the development of anxiety and depression. Findings revealed that well-being and the risk of anxiety and depression decrease 10 years after surgery⁶. These results parallel ours in the length of time needed for adjustment and acceptance.

Many of our participants described feeling embarrassed and having issues with their appearance. The negative impact of urine leakage on social activities has been described in several reports. Nordstrom and associates⁵ noted that urine leakage is a source of psychological distress in UD patients. Thirty eight percent of females reported having a negative body image as compared to 15% of males. Negative views of body image can

impact both current and future relationships. Our study also found a relationship between the UD and psychosocial issues.

Limitations

Several limitations are present in the current study. The sample was drawn from patient lists using a retrospective approach and did not allow for a comparison group. However, this did provide us with some valuable long term data on patient adjustment. The design was cross sectional, and we were unable to sample equal portions from continent versus incontinent UD patients. Because the sample size was large, we were still able to make comparisons across genders and types of UD. The sample was predominantly Caucasian, with only a few minorities represented.

Implications for WOC Nursing Practice and Research

The results of this study underline the importance of WOC nursing intervention before and following creation of a UD. Mastering UD care is best done under guidance of a WOC nurse and access to WOC nurse is essential when problems occur. Because adjustment takes a long time, and problems may continue for years after surgery, ongoing access to a WOC nurse is important in maintaining HRQOL and preventing further deterioration.

Patient teaching content should include a wide variety of information. Physical aspects of care are important, especially early in the recovery period. Support for psychological adjustments can be provided in a variety of ways. Ostomy specific support groups are reported by patients as being valuable. Respondents in the current study even used general support groups. The problems of anxiety, depression, and adjustment are frequent and can be addressed in individual and group venues.

Problems with sexuality are especially predominant in this population and they affect both women and men. Gender differences present in this study highlight the importance of assessing sexual performance, intimacy, relationship and appearance issues of the UD patient. Alteration of any of these has the potential to decrease UD patient QOL. The WOC nurse plays a pivotal role in patient education and the monitoring and management of sexuality related issues post operatively in these patients. Sexual counseling is an important aspect to be included in post operative education. Because gender differences occur across a number of problem areas future studies should include educational approaches that make allowances for these differences and test separate sessions for men and women. In addition, further testing of the value of separate groups may provide evidence for future educational methods.

Conclusions

The results of this study add to our understanding of how patients adjust to a UD and what problems and issues can occur, even years after the initial surgery. These problems and issues fall clearly in the realm of the WOC nursing role, and can be addressed during education sessions provided for this population. Testing of such educational interventions would be an important next step in building the scientific foundation of care for this special population.

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Key Points

- Long term follow up of UD survivors reveals a broad range of issues that survivors face in adjusting to life with a UD
- Since adjustment following surgery takes a long time, and problems may continue for years after surgery, access to a WOC nurse is important in improving and maintaining HRQOL.
- Problems with sexuality are especially predominant in the UD population and occur in both males and females.
- The WOC Nurse plays a pivotal role in pre and post operative patient education and management.

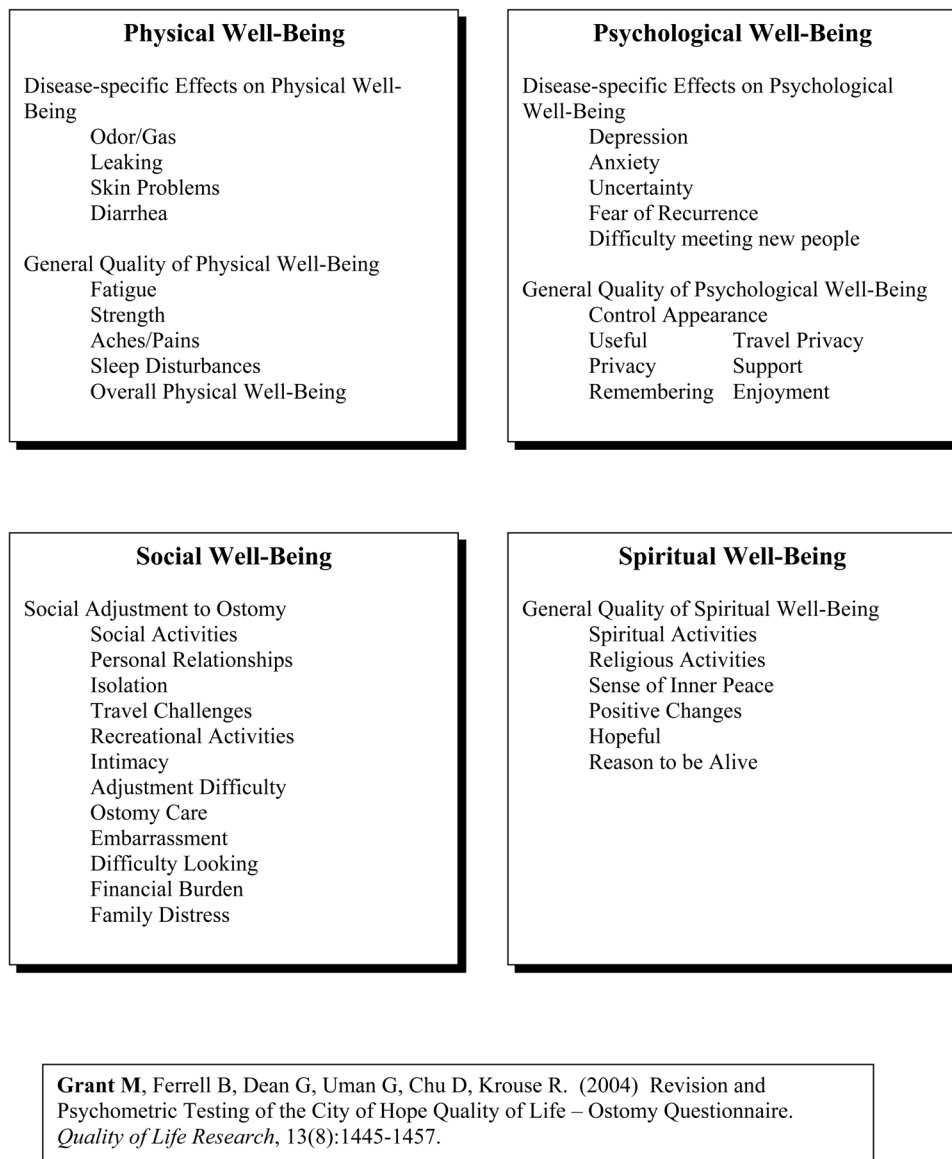


Figure 1.
Quality of Life Model for Ostomy Patients

Table 1

Quality of Life Dimension Definitions *

Dimension	Definition
Physical well-being	Physical symptoms and functional ability
Psychological well-being	Emotional components of the illness including positive as well as negative aspects
Social well-being	Role of the patient with the family and society including occupation, sexual, and personal relationships
Spiritual well-being	Religious aspects and existential concerns

* Created with data from Grant³

Table 2**Patient Characteristics** (mean \pm standard deviation, number (%) of patients)

Characteristics	N = 307	
Cancer Diagnosis		
Bladder	253	82.4
Prostate	17	5.5
Bladder Plus Other Organs*	21	6.7
Cervical/Vaginal/Other Gyn	5	1.6
Missing	11	3.6
* Other organs include prostate, colon and ureter		
Type of urostomy		
Continent	70	22.8
Incontinent	226	73.6
Missing	11	3.6
Age (years)	74 \pm 8.7 (range 38–95)	
Time since surgery (years)		
Mean	9.5	
SD	6.3	
Median	9.4	
Range	3–31	
Length of time for daily urostomy care (minutes)		
Mean	36	
SD	31	
Median	30	
Range	0–180	
Gender, n (%)		
Male	210	68.4
Female	97	31.6
Marital Status prior to surgery, (%)		
Married	246	80.1
Single	14	4.6
Divorced	9	2.9
Widowed	37	12.1
Separated	1	0.3
Marital Status now, (%)		
Married	216	70.4
Single	17	5.5
Divorced	11	3.5

Characteristics	N = 307	
Widowed	60	19.5
Missing	3	1.0

Table 3

Quality of Life Overall and Dimension Scores

Scale	Mean	SD	Range of Mean Item Scores
Physical Well being Dimension	8.2	1.8	7.8 – 8.7
Psychological Well Being Dimension	7.3	1.9	6.5 – 8.9
Social Well Being Dimension	8.0	1.7	4.5 – 9.2
Spiritual Well Being Dimension	7.4	2.3	5.4 – 7.8
Overall Quality of Life	7.7	1.5	4.5 – 9.2

Table 4**HRQOL Subscale Scores by Gender** (means \pm standard deviation)

Subscales by Gender	Scores*
Physical Well-Being	
Female	8.1 \pm 1.9
Male	8.3 \pm 1.8
Psychological Well-Being**	
Female	6.8 \pm 2.0
Male	7.5 \pm 1.9
Social Well-Being	
Female	8.1 \pm 1.8
Male	7.9 \pm 1.6
Spiritual Well-Being	
Female	7.4 \pm 2.2
Male	7.3 \pm 2.3
Total HRQOL	
Female	7.7 \pm 1.5
Male	7.8 \pm 1.5

* Scored 0–10 with 10= Best HRQOL

**
p= 0.006

Table 5

Analysis of Personal Characteristics by Gender [yes N(%)]

Variables	<i>Male</i>	<i>Female</i>	<i>p-value</i>
Age, $\bar{X}(SD)$	75.2 (7.9)	73.0 (10.3)	0.04
Sexual activity before urinary diversion	163 (80)	53 (55)	<0.001
Sexual activity after urinary diversion	52 (28)	30 (39)	<0.001
Sexual Activity Satisfying	47 (29)	22 (34)	0.05
Talked to other ostomates	136 (66)	49 (52)	0.01
Changed clothing style	68 (33)	48 (51)	0.004

Table 6

Comparison of Selected HRQOL Items by Gender (M [SD])

Variables	Male N = 210	Female N = 97	p-value
Feelings of control	7.8	6.7	0.004
Fear of recurrence	7.9	7.0	0.02
Urinary diversion interfered with personal relationships	7.7	8.7	0.01
Urinary diversion interfered with intimacy	4.3	6.7	<0.001
Satisfaction with appearance	7.3	5.8	<0.001

Scale 0–10 with 10=Best HRQOL

Table 7

Analysis of Forced-Choice Items by Continence (% yes) *

Variables	Incontinent (n=226)	Continent (n=70)	p-value
Age, $\bar{X}(SD)$	75.6 (8.2)	71.5 (9.2)	<0.001
Sexual activity before urinary diversion	163 (72)	50 (71)	NS
Sexual activity after urinary diversion	124 (55)	45 (64)	0.04
Belong to an ostomy support group	160 (71)	10 (14)	<0.001
Belong to other support groups	40 (18)	5 (7)	0.05
Problem with location of urinary diversion	65 (29)	10 (14)	0.01
Changed clothing style	102 (45)	17 (24)	0.002
Adjusted diet after urinary diversion	49 (22)	6 (8)	0.01

NS = not significant

* N=296, 11 did not respond

Table 8

Comparison of Selected HRQOL Items by Continence (means)

Variables	<i>Incontinent</i>	<i>Continent</i>	<i>p-value</i>
Problems with skin around urinary diversion	7.6	8.5	0.009
Difficulty caring for urinary diversion	8.3	9.0	0.01
Fear of recurrence	7.8	7.0	0.04
Financial burden from urinary diversion	8.1	7.2	0.007
Family distress	7.2	6.4	0.04
Uncertainty about future	7.4	6.5	0.02

Scale 0–10 with 10=Best HRQOL