

HEALTH-RELATED QUALITY OF LIFE ASSESSMENT FOLLOWING RADICAL CYSTECTOMY IN POPULATION OF A SOUTH ASIAN COUNTRY

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Abstract

Purpose: Radical cystectomy is carried out for muscle invasive bladder (BL) cancer, which greatly affects the quality of life. The objective of our study was to assess the health-related quality of life (HRQoL) in patients following radical cystectomy.

Methods: A retrospective review was done in patients that underwent radical cystectomy between July 2009 and November 2014 at Shaukat Khanum Memorial Cancer Hospital and Research Centre, Lahore, Pakistan. HRQoL assessments of 34 patients done during clinical psychology review were included in this study. HRQoL was assessed using functional assessment of cancer therapy-BL questionnaire.

Results: Low scores were observed in physical well-being and emotional well-being domains with mean scores of 7.32 and 7.97, respectively. Patients scored high on social and family well-being, functional well-being and additional concerns, with mean scores of 24.9, 17.24 and 21.73, respectively.

Conclusions: Psychological evaluation and rehabilitation should be an integral part of surveillance after radical cystectomy.

Key words: Bladder cancer, functional assessment of cancer therapy-bladder, health-related quality of life, radical cystectomy, South Asian

Introduction

Radical cystectomy is the standard of care for muscle invasive bladder (BL) cancer. After cystectomy, various methods are used for urinary diversion. Commonly ileal conduit, continent cutaneous diversion and orthotrophic neo-BL reconstruction are performed. Although cancer control is similar with various modes of diversion, each one of these carries their own risks and benefits.

BL conservative approaches have been used in selected cases with possibly better-preserved quality of life,^[1] but there have been no comparative prospective clinical trials regarding oncological outcome.^[2]

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Health-related quality of life (HRQoL) refers to the physical, psychological and social domains of health that are influenced by a person's experiences, beliefs, expectations and perceptions.^[3] HRQoL has become an important consideration following radical cystectomy. In addition to the morbidity of major surgery, urinary diversion has a great impact on the HRQoL. There is no convincing evidence from existing literature that any particular method of urinary diversion offers superior HRQoL outcomes. Rather, there is growing evidence that good HRQoL can be achieved with patient education and consideration of each patient's clinical and psychosocial situation.^[4] HRQoL studies have been reported by leading urooncological centres across the globe.^[5] Patients with BL cancer who undergo radical cystectomy have significant declines in multiple components of physical and mental HRQoL.^[6]

Limitations to existing literature are the lack of an available BL cancer-specific, validated instrument to measure HRQoL. In addition, HRQoL differs significantly between countries, cultures and races as the sociocultural milieu in which the patient lives can influence their perception of health and illness. Studies have also begun to explore the role of cultural differences in HRQoL. Some BL cancer-specific HRQoL instruments have been validated including BL cancer index, functional assessment of cancer therapy (FACT)-Vanderbilt cystectomy index and FACT-BL.^[4]

There is a lack of studies in literature observing HRQoL in South Asian population following radical cystectomy. We used FACT-BL for this particular study to observe HRQoL in Pakistani BL cancer population that underwent radical cystectomy in a cancer hospital setting. To the best of our knowledge, this is the first ever HRQoL assessment study performed in South Asian population following radical cystectomy.

Methods

This was an observational study which used descriptive statistics. The study was based on retrospective review of existing clinical data from patient that underwent radical cystectomy between July 2009 and November 2014 at the Shaukat Khanum Cancer Hospital and Research Centre, Lahore, Pakistan. This is a rare patient group and all 34 patients that underwent radical cystectomy were included in the study. They were assessed by clinical psychologist in their routine follow-up following surgery. We did not do a sample calculation, as this was an observational study design.

HRQoL was measured using FACT-BL questionnaire. FACT-BL questionnaire was translated into Urdu for the local population understanding. There is no validated Urdu version of FACT-BL available. The translated version was presented to the Scientific Review Committee and Institutional Review Board at SKMCH and RC and was approved.

The FACT-BL is a 39-item quality of life assessment questionnaire, where patients score their responses on a scale from 0 to 4, with 0 being a point of no concern and 4 being of highest concern. The questionnaire comprises

physical well-being (max. score 28), social and family well-being (max. score 28), emotional well-being (max. score 24) and functional well-being (max. score 28) domains along with area of additional concerns (max. score 48).

Higher scores indicate poorer quality of life. Patients were asked to fill out this questionnaire at their post-operative hospital visit. The demographics and clinical data were recorded using the electronic hospital information system.

The data and HRQoL scores were recorded and analysed using the SPSS software, version 19.

Results

A total of 34 patients with BL cancer who underwent radical cystectomy and urinary diversion were evaluated. Of these, 31 were male and three were female patients. The mean age of the patients was 56.3 years (range 34–74 years). The mean time of HRQoL assessment from the time of surgery was 5.9 months (range 1–20 months). 73.5% ($n = 25$) of patients underwent radical cystectomy and ileal conduit (RC and IC), whereas 26.5% ($n = 9$) of patients underwent radical cystectomy and neo-BL formation (RC and NB).

QoL assessment scores on the basis of physical, social, emotional and functional well-being and additional concerns were also noted [Table 1].

Additional concerns were mostly related to the alteration in body shape in patients undergone ileal conduit urinary diversion and lower urinary tract symptoms in patients with neo-BL. The best scores were noted in physical domain with a mean score of 7.32 with lack of energy and pain being the main symptoms [Figure 1]. Patients scored rather poor as far as social and family well-being was concerned, family support, acceptance and deterioration of sex life being the main concerns [Figure 2]. Sadness was the main concern in emotional evaluation [Figure 3]. Enjoyment and recreational activities were effected in most people when functional well being was analyzed [Figure 4].

Discussion

In BL cancer patients, radical cystectomy is known to be one of the most traumatic cancer operations in terms of psychological stress and alteration in lifestyle.^[7] Biggest

Table 1: QoL assessment scores

	Physical well-being	Social/family well-being	Emotional well-being	Functional well-being	Additional concerns
Mean±SD	7.32±4.41	24.91±33.15	7.97±4.38	17.24±6.27	21.73±5.90
Range	0–19	8–21	0–18	0–28	11–35

SD: Standard deviation

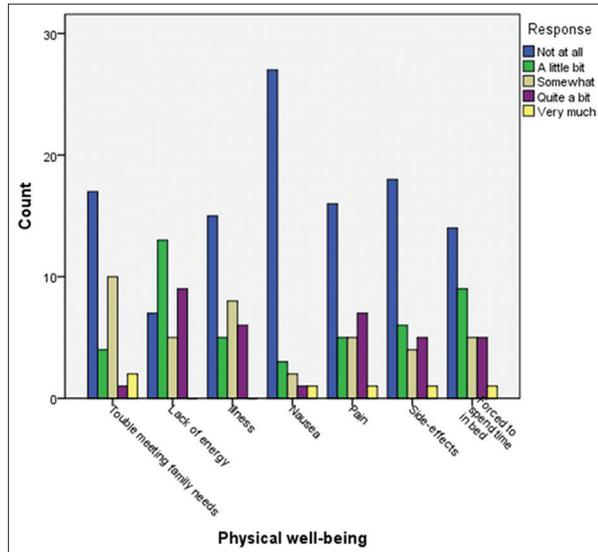


Figure 1: Physical well-being

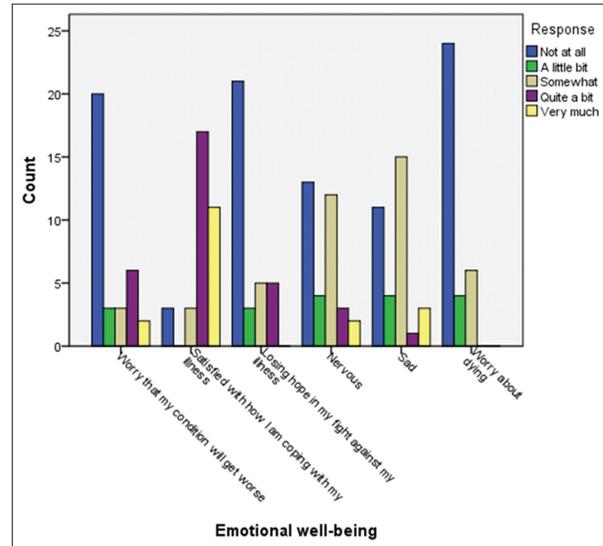


Figure 3: Emotional evaluation

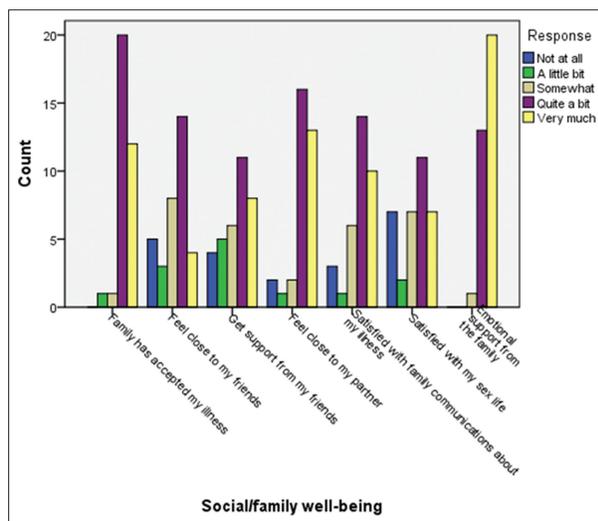


Figure 2: Social and family well-being

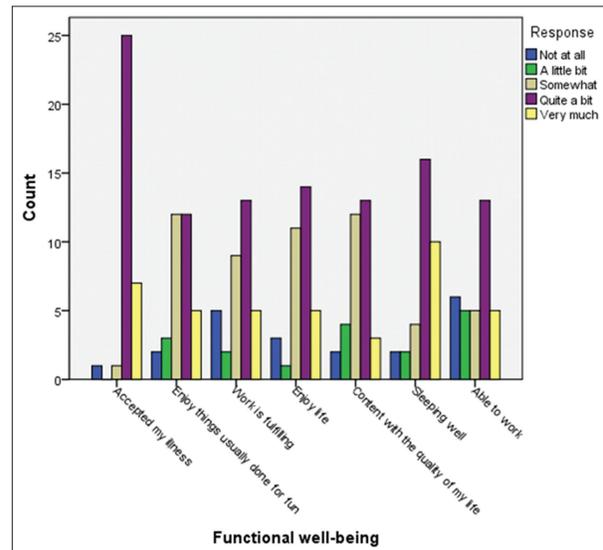


Figure 4: Functional well being

determinants of quality of life for an individual are family relationship, general health and finances. Body image and general health certainly play a major role in this.

Furthermore, erectile dysfunction, bodily disfigurement, actual or risk of urinary leakage and odour and common

sequelae of cystectomy and conduit diversion may even lead to marital breakdown.^[7] Many factors, for example, an individual's social support system, general and psychological condition of health, disease control and value system play a role in defining the HRQoL of a patient. In another study, FACT-BL domains most negatively affected by surgery were the physical well-being and family well-being.^[8] These findings in the previous studies are consistent with our results, which demonstrated poor scores in social and family well-being where main concerns were not getting emotional support and acceptance from family. Our patients also reported deterioration in their sex life and concerns secondary to alteration in body image.

Mansson's also reported in their study that fatigue and depression were common among these patients. Many patients reported restlessness, a sense of meaninglessness, a reluctance to ask for help, heightened irritability, gloom and increased sensitivity and nervousness.^[7] This was also consistent with our study findings where our patients scored high on feeling sad and nervous. Various studies conducted on HRQoL showed that levels of psychological distress decreased significantly 1 month after surgery compared to pre-operative levels. Palapattu has shown that 45% of patients demonstrated psychological distress before cystectomy, which decreased to 34% 1 month after surgery with significant improvements in general distress, depression and anxiety.^[9] While recovery may affect QoL and vary from patient to patient, it was demonstrated that psychological and HRQoL stabilise at about 12 months following radical cystectomy.^[10] Hence, it is safe to assume that with time distress associated with emotional well-being reduced significantly. Meantime of HRQoL assessment in our study was around 6 months after surgery and the scores were generally low in the emotional well-being domains (except sadness and nervousness) with a mean score of 7.97, which could be because the assessments were carried out several months after the surgery.

HRQoL may also be affected by the type of diversion whether that is incontinent ileal conduit or continent diversion in the form of neo-BL/BL reservoir. In general, majority of the patients get satisfied with their diversion and adapt well socially, physically and psychologically, and the type of urinary diversion does not appear to be associated with differential quality of life.^[11] Neo-BL

patients were more able to adapt to their new life and had a better QoL with regard to self-confidence, rehabilitation and restoration of leisure, professional, travelling and social activities.^[12,13] However, other studies indicated that the HRQoL differences between neo-BL and ileal conduit are non-existent or marginal at best, highlighting that the younger age and improved health in general of neo-BL patients may account for the small differences in HRQoL.^[14,15] Furthermore, Kikuchi *et al.* reported in their prospective study that the type of urinary diversion did not appear to be associated with a different HRQoL by general cancer-related assessment.^[16] We had patients who had both ileal conduit and neo-BL surgeries performed; however, we did not specifically look into differences in scores on HRQoL between the two groups given the depth of research done on this already as demonstrated above. Furthermore, a prospective study designed to look into this would have been a more appropriate study method.

A major obstacle in assessing the quality is lack of disease-specific HRQoL instrument, which could universally compare patients after urinary diversion. Given the limitations of HRQoL research for urinary diversion, a number of research studies fail to demonstrate superiority of any diversion type with regard to psychological or HRQoL. In addition, over a period, better, surgical techniques and various types of urinary diversions have developed to attain better oncological outcome; however, HRQoL remains major concern in such patients.

We do recognize that the study done in one institute may not represent the whole South Asian population, but our study is the first of its kind in this population and further studies are required involving other institutions for the results to be generalised. Limitation of the study was that it was a retrospective review. A prospective study with follow-up reviews of HRQoL would be a better design to focus on different types of surgeries and their impact on specific domains of well-being and their relation with time.

Conclusions

Psychological evaluation focusing on HRQoL should be done after a major surgical procedure such as radical cystectomy. It is more important when such a procedure affects the body image. Psychological evaluation and rehabilitation should be an integral part of surveillance

after radical cystectomy. Based on this family and social support should be established for better long-term care of patients with radical cystectomy. Furthermore, there is a need for carrying out prospective research on HRQoL assessment in patients undergoing radical cystectomy in South Asian population to look into the relation of different types of the urinary diversions and their impact of the specific domains of well-being to better address post-operative follow-up care and support.

Conflict of Interest

The authors declare that they have no conflict of interest.

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