

# Health-related quality of life in bladder cancer patients undergoing radical cystectomy and urinary stoma: still many gaps

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Provenance: This is a Guest Editorial commissioned by Section Editor Xiao Li (Department of Urologic Surgery, the Affiliated Cancer Hospital of Jiangsu Province of Nanjing Medical University, Nanjing, China).

Comment on: Winters BR, Wright JL, Holt SK, *et al.* Health Related Quality of Life Following Radical Cystectomy: Comparative Analysis from the Medicare Health Outcomes Study. *J Urol* 2017.

Submitted Nov 20, 2017. Accepted for publication Dec 01, 2017.

doi: 10.21037/tau.2017.12.02

View this article at: <http://dx.doi.org/10.21037/tau.2017.12.02>

Health-related quality of life (HRQoL), defined by the World Health Organization as “*Individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns*”, has recently gained increasing interest in the field of uro-oncology and is considered a relevant treatment-related outcome together with survival (1,2). It represents a dynamic, highly subjective, theoretical construct with multiple domains that can be influenced by cultural, demographic, and social variables. Radical cystectomy (RC) is one of the most traumatic cancer operations in terms of HRQoL impairment and the impact of the type of urinary diversion on this outcome has become the subject of intense debate in recent years (3,4). Orthotopic neobladder reconstruction, which is the preferred method for urinary diversion in suitable patients, may provide potential advantages in terms of HRQoL (5). However, in everyday clinical practice, the number of patients with relative or absolute contra-indications to orthotopic neobladder reconstruction is often high and an incontinent urinary diversion is consequently required. Indeed, ileal conduit (IC) has been reported to be the most commonly performed urinary diversion (33–72% of cases in some series), and cutaneous ureterostomy (CU) is often required in elderly patients with high comorbidity status in order to reduce surgical stress, operative time, blood loss and incidence of complications (3,6). Both IC and CU require wearing of an external appliance and, theoretically,

may distort the body image with potential negative sequelae in several HRQoL domains: physical, mental, emotional, social, sexual, and economical (6). Although the number of publications addressing the topic of HRQoL in BCa patients undergoing RC and stoma creation has grown exponentially in recent years, the level of evidences is still sub-optimal as many issues remain under-investigated and some gaps still exist between scientific evidence and everyday clinical practice. Some limitations of available literature deserve consideration. First, most data about HRQoL in BCa patients undergoing RC comes from clinical studies conducted in highly selected populations that may be not completely representative of the everyday clinical practice. Few studies exist evaluating HRQoL on population level, an information that may be useful to guide policies for health. Second, many studies aim to compare HRQoL among patients undergoing different types of urinary diversions in a cross-sectional fashion while longitudinal data is lacking in many series. The knowledge of HRQoL variation over time is of special interest as it has been hypothesized that a long coexistence with a urinary diversion may be able to change the attitude of patients towards it, becoming part of themselves, establishing a longer practice for the management of it, and affecting the degree of adaptation to their new life with the urinary diversion itself (7). Third, the knowledge of factors that can improve HRQoL in urinary stoma patients is inadequate. Available evidences about factors that may improve HRQoL

in stoma patients derive mainly from studies enrolling patients with fecal diversions. These studies suggest that satisfaction with the care received, confidence in changing the appliance, and the relationship with the enterostomal therapist can affect HRQoL (8). Moreover, Danielsen *et al.* demonstrated that educational activities aimed at increase knowledge and focusing on patients' psychosocial needs may improve HRQoL of patients with a stoma (9). To date, it is largely unknown if analogies exist between patients with fecal and urinary stoma in terms of HRQoL and if evidence from studies on fecal stoma patients could be translated to urinary stoma patients. Regarding discrepancies between scientific evidence and everyday clinical practice, the following aspects deserve consideration. First, although guidelines recommend the use of validated questionnaires to assess HRQoL in patients with muscle invasive BCa and many urologists recognize HRQoL assessment an important part of the clinical routine, only a small percentage of them routinely perform this investigation in everyday clinical practice with standardized instruments (4,10,11). Indeed, a recent survey conducted by Schmick *et al.* demonstrated that less than 50% of German urologists assessed HRQoL in BCa patients (11). Insufficient methodological knowledge of HRQoL assessment, excessive questionnaire length, and lack of financial and time resources are recognized as major barriers to HRQoL assessment (11). Second, although several tools have been validated including generic, disease-specific, and urinary diversion-specific questionnaires, to date there are no specific recommendations about the type of questionnaire to be used in clinical practice (4,10,11). Winters *et al.* recently published the results of a study aimed at investigating HRQoL in BCa patients undergoing RC and IC urinary diversion (12). Findings from their study contribute to the knowledge of HRQoL in BCa patients undergoing RC and urinary stoma creation at population level and provide us with important takeaways and directions for future research. Authors identifies 166 BCa patients undergoing RC and IC urinary diversion from the Surveillance, Epidemiology, and End Results-Medicare Health Outcomes Survey (SEER-MHOS) dataset and matched them 1:5 to 830 non-cancer controls (12). HRQoL was measured using Physical Component Summary (PCS) scores and Mental Component Summary (MCS) scores based on validated SF-36 and VR-12 surveys (12). Moreover, unlike many published studies, authors calculated separately the mean change in MCS and PCS for the group

of 40 BCa patients with both pre- and post-surgery data available and compared data with their propensity-matched non-cancer controls to evaluate longitudinal changes in HRQoL over time (12). In line with published data, BCa patients exhibited significantly lower mean PCS scores and near significantly lower mean MCS scores with respect to non-cancer controls (12). Based on the longitudinal analysis performed by the authors, PCS scores declined significantly more in RC patients while only a trend toward a significant decline in terms of MCS scores was evident (12). This finding should be considered preliminary as the number of patients evaluated was low and multiple HRQoL evaluations should be performed over time in order to better capture the evolution of this parameter. Interestingly, authors compared for the first time HRQoL of patients undergoing RC and IC with HRQoL of patients undergoing colorectal cancer surgery with ostomy creation (12). They found no differences in terms of mean PCS and MCS scores as well as in terms of individual component subscores between the two groups thus hypothesizing that the HRQoL effects in patients having a stoma are independent of the underlying disease or stoma contents (12). This finding suggests the possibility to translate some published evidences about HRQoL obtained in patients with fecal stomas to patients with urinary stomas. Future directions of clinical research and practice in the field of HRQoL include the identification and adoption of proactive strategies aimed to actively improve this outcome in patients with stoma. Moreover, wider adoption of HRQoL measurement in urinary stoma patients in everyday clinical practice is advocated in order to improve the knowledge of this parameter on population level in different social and geographical settings. Finally, the role of mental adaptation strategies to disease adopted by BCa patients undergoing RC and urinary stoma creation deserve investigations. In details two distinct attitudes have been described: the constructive one, manifesting as active, optimistic, and highly self-sufficient struggle with the illness, and the destructive one, characterized by feelings of helplessness and hopelessness, anxiety, a fatalistic attitude, a low sense of self-sufficiency, and a complete withdrawal into the self (1). The possibility to favorably interfere with these psychological responses deserves future investigations by multidisciplinary teams.

### Acknowledgements

None.

## Footnote

*Conflicts of Interest:* The authors have no conflicts of interest to declare.

## References

1. Sosnowski R, Kulpa M, Ziętałewicz U, et al. Basic issues concerning health-related quality of life. *Cent European J Urol* 2017;70:206-11.
2. Imbimbo C, Creta M, Gacci M, et al. Patients' desire to preserve sexual activity and final decision for a nerve-sparing approach: results from the MIRROR (Multicenter Italian Report on Radical Prostatectomy Outcomes and Research) Study. *J Sex Med* 2011;8:1495-502.
3. Longo N, Imbimbo C, Fusco F, et al. Complications and quality of life in elderly patients with several comorbidities undergoing cutaneous ureterostomy with single stoma or ileal conduit after radical cystectomy. *BJU Int* 2016;118:521-6.
4. Imbimbo C, Mirone V, Siracusano S, et al. Quality of Life Assessment With Orthotopic Ileal Neobladder Reconstruction After Radical Cystectomy: Results From a Prospective Italian Multicenter Observational Study. *Urology* 2015;86:974-9.
5. Cerruto MA, D'Elia C, Siracusano S, et al. Is Health-Related Quality of Life after Radical Cystectomy Using Validated Questionnaires Really Better in Patients with Ileal Orthotopic Neobladder Compared to Ileal Conduit: A Meta-Analysis of Retrospective Comparative Studies. *Curr Urol* 2017;10:57-68.
6. Siddiqui KM, Izawa JI. Ileal conduit: standard urinary diversion for elderly patients undergoing radical cystectomy. *World J Urol* 2016;34:19-24.
7. Cerruto MA, D'Elia C, Cacciamani G, et al. Behavioural profile and human adaptation of survivors after radical cystectomy and ileal conduit. *Health Qual Life Outcomes* 2014;12:46.
8. Marquis P, Marrel A, Jambon B. Quality of life in patients with stomas: the Montreux Study. *Ostomy Wound Manage* 2003;49:48-55.
9. Danielsen AK, Rosenberg J. Health related quality of life may increase when patients with a stoma attend patient education--a case-control study. *PLoS One* 2014;9:e90354.
10. Witjes JA, Compérat E, Cowan NC, et al. EAU guidelines on muscle-invasive and metastatic bladder cancer: summary of the 2013 guidelines. *Eur Urol* 2014;65:778-92.
11. Schmick A, Juergensen M, Rohde V, et al. Assessing health-related quality of life in urology - a survey of 4500 German urologists. *BMC Urol* 2017;17:46.
12. Winters BR, Wright JL, Holt SK, et al. Health Related Quality of Life Following Radical Cystectomy: Comparative Analysis from the Medicare Health Outcomes Study. *J Urol* 2017. [Epub ahead of print].

**Cite this article as:** Creta M, Longo N, Imbimbo C, Imperatore V, Mirone V, Fusco F. Health-related quality of life in bladder cancer patients undergoing radical cystectomy and urinary stoma: still many gaps. *Transl Androl Urol* 2018;7(Suppl 1):S111-S113. doi: 10.21037/tau.2017.12.02