



Published in final edited form as:

Psychooncology. 2017 February ; 26(2): 206–213. doi:10.1002/pon.4025.

Idiographic Quality of Life Assessment before Radical Cystectomy

Christopher B. Anderson¹, Bruce Rapkin², Brieyona C. Reaves¹, Arony J. Sun¹, Bradley Morganstern³, S. Guido Dalbagni¹, Machele Donat¹, Harry W. Herr¹, Vincent P. Laudone¹, and Bernard H. Bochner¹

¹Urology Service, Department of Surgery, Memorial Sloan-Kettering Cancer Center, New York, NY

²Department of Epidemiology and Population Health, Albert Einstein College of Medicine, Bronx, NY

³The Smith Institute for Urology, North Shore-LIJ Health System, New Hyde Park, NY

Abstract

Background—We sought to determine if idiographic, or self-defined, measures added to our understanding of bladder cancer patients' quality of life (QOL) prior to radical cystectomy (RC). We tested whether idiographic measures increased prediction of global QOL beyond standard (nomothetic) measures of QOL components.

Methods—We administered the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaires (QLQ)-C30 and QLQ-BLM30, and our own idiographic Quality of Life Appraisal Profile prior to RC. Idiographic measures included number of goal statements, distance from goal attainment, and ability to complete goal attainment activities. Multivariate linear regression was used to predict measures of global QOL and related constructs of life satisfaction and mental health.

Results—215 patients reported a median of 8 (interquartile range [IQR] 6, 11) goals and half had an average goal attainment rating above 6.9 out of 10 (IQR 5.5, 8.2). On multivariable analysis, QLQ-C30 role functioning and QLQ-BLM30 future perspective explained 15.7% of the variability in preoperative global QOL. Including goal attainment and activity difficulty explained an additional 12% of global QOL variance. Smaller gains were seen on measures of global health, life satisfaction, mental health and activity, suggesting that idiographic measures capture aspects of QOL distinct from health and functional status defined by nomothetic scales.

Conclusions—Idiographic assessment of QOL added to prediction of global QOL above and beyond health-related components measured using nomothetic instruments. This self-defined information may be valuable in communicating with cancer patients about their QOL.

MESH terms

radical cystectomy; quality of life; bladder cancer

Background

Radical cystectomy (RC) and urinary diversion is the gold-standard treatment for high-risk bladder cancer. However, RC can be a morbid procedure associated with changes in body image and urinary, sexual and bowel function, which impact quality of life (QOL). Quality of life is a person's "appraisal of and satisfaction with their current level of functioning as compared to what they perceive to be possible or ideal" or, simply, the gap between a person's expectations and experiences.[1, 2] It is a complex, subjective, multi-dimensional concept that is influenced by health and non-health related factors. QOL informs decisions regarding treatment selection, patient counseling, and survivorship, and has also been used as an outcome in clinical trials, comparative effectiveness research, and a metric in value-based healthcare.[3, 4]

Several standard (or nomothetic) instruments have been developed to quantify QOL after RC.[5–8] These instruments capture patient-reported assessments of general and condition-specific domains that are thought to impact QOL. Although nomothetic instruments are relatively easy to administer, score and compare, they do not assess individual concerns, account for differences in patient perspective, or consider the effects of response shift.[9] Due to these inherent limitations, interpretation of QOL based on nomothetic instruments alone can be difficult.[10] For example, patients with objectively poor health and many symptoms may nonetheless report good QOL. Standard measures provide little insight in such situations.

An alternative method to quantify QOL is through individualized (or idiographic) patient assessments.[9, 11, 12] These assessments generate a self-defined, internally calibrated QOL definition and rating. They add valuable QOL information not captured with nomothetic instruments, including concerns about lifestyle, relationships and family.[9] Still, idiographic assessments are used infrequently because data collection, coding and interpretation are more difficult and labor intensive.

As part of a prospective QOL study, we administered both nomothetic and idiographic QOL assessments on patients prior to RC. Our objective was to evaluate whether idiographic measures could increase the ability to explain preoperative global QOL beyond standard general and bladder cancer specific measures of health-related functioning and symptoms. We hypothesized that idiographic measures would improve the ability to predict global QOL over what was possible using nomothetic instruments alone. To examine the generality or specificity of the relationship of idiographic measures to global QOL, we also conducted parallel analyses to predict standard measures of global health status, life satisfaction, mental health and daily activity.

Methods

This study was approved by the Memorial Sloan Kettering Cancer Center Internal Review Board patient enrollment began in 2008 and was completed in 2014. Patients with non-metastatic bladder cancer scheduled for RC and urinary diversion, at least 18 years of age, English speaking and able to provide written informed consent were eligible for recruitment.

QOL was evaluated using idiographic and nomothetic methods preoperatively and at 3, 6, 12, 18 and 24 months after RC (table 1). All preoperative assessments occurred within three weeks of surgery, and only post-chemotherapy preoperative assessments were considered for patients receiving neoadjuvant chemotherapy. Because study follow-up is currently ongoing and we have yet to accrue all postoperative assessments, the analytic cohort included all patients who completed preoperative nomothetic and idiographic QOL assessments.

Dependent variables

All dependent variables considered in this study were assessed using standard, nomothetic instruments. The primary outcome was preoperative global QOL, defined by a single item in the idiographic assessment: “How do you rate your quality of life at this time?” scored from 0–10, with 10 being the highest QOL possible. We chose this as the primary outcome because it was the most straightforward, measure of general QOL available in this study. Use of single-item measures of global quality of life has been recommended as a valid, straightforward alternative to the use of multi-item scales.[13, 14]

Additional outcome measures reflecting other assessments of overall well-being were also considered, including the two-item Global Health Status subscale assessed as part of the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (QLQ)-C30, the five-item Satisfaction with Life scale, the five-item Mental Health Inventory, and single-item measures of days engaged in activity outside the home and days of activity missed due to illness within the past month.[15, 16]

Nomothetic Measures of Symptoms and Health-Related Functioning

A broad set of standard measures of health-related QOL domains were used to account for their association with global constructs. Specifically, we used the EORTC QLQ-BLM30, consisting of the EORTC QLQ-C30 with the BLM30 module.[7] The EORTC QLQ-C30 has been validated to assess general QOL in cancer patients. In addition to global functioning (used as a dependent measure) it consists of five specific functional domains (physical, role, emotional, social, cognitive), three symptom domains (fatigue, pain and nausea), six single item symptom questions (dyspnea, insomnia, appetite loss, diarrhea, constipation and financial concerns), and two questions regarding global QOL. The two questions about global QOL were not used as independent variables. The BLM30 measures unique muscle invasive bladder cancer-specific QOL items, and consists of seven domains (urinary symptoms, urostomy problems, bloating/flatulence, body image, future perspectives, catheter problems and sexual function). Since urostomy and catheter problems were not relevant prior to surgery, they were omitted. At the time of this study, the validity of the BLM30 had not yet been reported; however it had been used in prior clinical studies.[17–19]

Idiographic QOL assessment

Idiographic measures were obtained from the Quality of Life Appraisal Profile, a structured interview to elicit patients’ personal priorities and concerns. All patients were interviewed by a trained investigator, in clinic or by telephone. This idiographic QOL instrument has been validated in RC patients and successfully used in other patient populations.[11, 20–23] The Quality of Life Appraisal Profile consists of three main parts.[9] First, patients list up to

three goals important to their QOL in each of seven motivational categories: goals to accomplish, problems to solve, things to prevent or avoid, things to maintain or keep unchanged, commitments to let go of, things to accept and milestones to reach. Second, patients rate how much progress they have made toward attaining each goal from 0–10, with 10 indicating the goal has been attained. Finally, patients list activities they have attempted over the past month to reach their goal. Their ability to perform each activity was rated on six criteria: degree of difficulty (1–5, 5 being most difficult), amount of help received (1–5, 5 being most help received), if additional help was needed (yes vs. no), presence of discomfort or pain (yes vs. no), if the activity causes fatigue (yes vs. no) and if the activity takes longer than expected (yes vs. no). The interview took approximately 30 minutes.

We calculated the distance from goal attainment for all goals (average goal attainment rating, minimum goal attainment rating) and the total number of goal statements. We also calculated the average degree of activity difficulty and help received, as well as the percentage of activities that required help, were associated with pain and fatigue, and took too long.

Statistical Analysis

The goal of this study was to determine whether aspects of quality of life measured using an idiographic procedure helped to explain variance in global measures of quality of life, health status and well being, above and beyond standard nomothetic predictors. This analytic approach sets a particularly high bar for assessing the value of idiographic measures, because of shared method variance between nomothetic dependent measures and nomothetic health-related functioning and symptoms.[24]

We described idiographic and nomothetic independent variables using medians, interquartile ranges (IQR), frequencies and percentages. We examined zero order correlations between all independent and dependent variables. We used multivariable linear regression to predict single-item global QOL using a four-tiered hierarchical forward selection process. In order, the model included the EORTC QLQ-C30 domains, the BLM30 domains, the idiographic goal variables and the idiographic activity variables. Entering the nomothetic independent variables first allowed us to examine whether and to what extent any remaining variance in QOL could be explained by self-defined idiographic measures. Model goodness-of-fit was assessed using the adjusted R^2 , representing the amount of variance in the dependent variable explained by the independent variables, correcting for the number of predictors in the equation.

To determine whether the variables selected into the base model were unique predictors of global QOL or if there was redundancy among the independent variables, we explored model fit after excluding these variables. As a sensitivity analysis, we adjusted our base model for patient demographic and clinical characteristics. Demographic covariates included patient age, gender, employment status, and marital status. Clinical data included the age-adjusted Charlson Comorbidity Index, body mass index, clinical tumor stage, number of prior transurethral resections, receipt of prior intravesical therapy, history of pelvic radiation therapy and use of neoadjuvant chemotherapy. Statistical analysis was performed using SPSS v20.0.0 (IBM) and two-tailed $p < 0.05$ was considered significant.

Results

The analytic cohort included 215 patients with bladder cancer scheduled for RC. Forty-one percent received neoadjuvant chemotherapy and median age was 67 (IQR 62, 72) (table 2). Most patients reported high function and low symptom scores on the QLQ-C30, and most reported some urinary symptoms and concern for the future on the BLM30 (table 3). The median number of goals per patient was 8 (IQR 6, 11) and average goal attainment rating was 6.9 (IQR 5.5, 8.2). Patients reported relatively few activities that were associated with difficulty, discomfort, fatigue or taking too long. The median single-item preoperative global QOL rating was 8 (IQR 6, 9).

Analysis to Explain Global Quality of Life

On hierarchical multivariable linear regression, role functioning entered first and accounted for 13% of model variance, and future perspective entered second and accounted for an additional 2.5% of variance (table 4). After accounting for these two nomothetic measures, average goal attainment entered third, was positively correlated with single-item global QOL ($\beta=0.264$, $p<0.001$) and improved model fit by explaining an additional 8.6% of the variance ($p<0.001$). Average activity difficulty entered last, was inversely associated with single-item global QOL ($\beta=-0.190$, $p=0.01$) and explained an additional 3.4% of model variance ($p=0.004$). Due to significant multicollinearity between future perspectives and average goal attainment ($r=0.2$, $p=0.005$), future perspectives was not significant in the final model after the addition of average goal attainment. After adjusting the model for clinical and demographic covariates the results were unchanged (data not shown).

Additional analyses were conducted to further examine the impact of multicollinearity among predictors. Several nomothetic and idiographic variables were significantly correlated with each other and with single-item global QOL (data not shown). We repeated the regression analysis after excluding the four significant variables from the base model and found that fatigue, urinary symptoms and minimum goal attainment were significantly associated with single-item global QOL. This model explained less variance than the base model (adjusted $R^2 = 0.136$), indicating the four original variables were the best predictors of global QOL.

Analysis to Explain Additional Global Measures of Health and Well-Being

The median EORTC QLQ-C30 Global Health Status was 83.3 (IQR 66.6, 83.3; range 0 to 100). The median Mental Health Inventory and Satisfaction with Life scores were 22 (IQR 19, 26; range is 5 to 30) and 28.2 (IQR 24, 31; range is 5 to 35), respectively. Median number of days spent engaging in activities outside the home was 20 (IQR 8, 28; range 0 to 30) and the median number of days missed due to illness was 0 (IQR 0, 4; range 0 to 30).

On multivariable linear regression, the nomothetic EORTC QLQ-C30 and BLM30 variables were strongly associated with each of these global measures of health and well being, in the expected directions (table 4). Idiographic measures demonstrated small but significant associations with EORTC QLQ-C30 Global Health Status (average goal attainment), Mental Health Inventory (average goal attainment), number of days engaged in activity (number of

goals, percentage of activities that took too long), and days missed due to illness (percentage of activities that took too long, percentage of activities associated with discomfort). None of the idiographic measures were associated with the Satisfaction with Life scale.

To consider the predictive power of idiographic measures alone, we repeated the regression analysis for single-item global QOL, as well as the five alternative dependent variables, using the idiographic measures as the only independent variables. Idiographic measures were significantly associated with all dependent measures in the expected directions: global QOL (adjusted $R^2 = 13.2\%$, $p < 0.001$); EORTC Global Health Status (adjusted $R^2 = 10.5\%$, $p < 0.001$); Mental Health Inventory score (adjusted $R^2 = 7.3\%$, $p < 0.001$); Satisfaction with Life Scale (adjusted $R^2 = 4.0\%$, $p < 0.002$); number of days engaged in activity (adjusted $R^2 = 5.7\%$, $p < 0.001$); and number of days missed due to illness (adjusted $R^2 = 4.8\%$, $p < 0.001$). In no case did the idiographic measures explained as much variance as the combination of nomothetic and idiographic predictors together. Idiographic measures were independently associated with global QOL and the number of days engaged in activity, with variance explained in these models similar to the increment in variance over nomothetic measures presented in table 4. Alternatively, in models predicting Global Health Status, Mental Health Inventory score and Life Satisfaction Scale score, the variance explained by idiographic measures alone was greater than the increment in variance explained beyond nomothetic measures. For these dependent variables, idiographic measures explained some of the same variance as nomothetic predictors, such that their overall associations were partially obscured in the hierarchical regressions reported on table 4. This overlap in prediction suggesting that idiographic measures may partially mediate associations of functional status and symptoms with these aspects of well-being.

Discussion

We measured preoperative QOL in RC patients using idiographic and nomothetic instruments, and found that patients who reported more progress achieving important goals and who had less difficulty performing goal attainment activities had higher single-item global QOL. These idiographic variables significantly improved the ability to predict QOL over what was achieved using nomothetic instruments alone. Furthermore, when predicting global QOL defined by alternative dependent variables, idiographic measures added valuable predictive power that was not captured by the nomothetic instruments.

In a study of 50 patients, the Quality of Life Appraisal Profile was validated to measure QOL prior to RC.[9] Patients reported several goals that were unrelated to their disease or treatment, such as lifestyle, relationships and family. Progress in goal attainment correlated poorly with the EORTC QLQ-C30, suggesting the idiographic and nomothetic assessments measured different elements of QOL. We have expanded on these prior findings by comparing idiographic assessments to a condition-specific nomothetic instrument in a larger cohort.

Our findings also support the construct validity of idiographic QOL assessments. Since progress in goal accomplishment is considered a definition of QOL, we found that average goal attainment independently predicted global QOL.[1, 2] In addition, the idiographic

measures were typically consistent with the dependent variables they were predicting. For instance, idiographic activity variables predicted days engaged in activity and number of days of activity missed.

Physicians often suspect that patients in different health states have meaningful differences in QOL. Interestingly, many studies in bladder cancer patients have failed to demonstrate these differences. For instance, despite an external stoma, patients with incontinent diversions have similar body image and QOL compared to patients with continent diversions.[10, 25] Furthermore, RC patients can have similar QOL to patients with preserved bladders and healthy controls, and post-RC QOL returns to preoperative levels after one year despite permanent changes in urinary function, sexual function, and body image.[25–29]

One explanation for the inability to identify certain QOL differences is that no differences exist. In fact, people in very poor health states can have surprisingly high QOL, highlighting the importance of differentiating objective health status from a patient's subjective assessment of their health.[30, 31] Another explanation may be limitations in study design, as many studies in RC patients were not prospective and did not use validated instruments. [10] Finally, nearly all studies that measure QOL used nomothetic instruments, which may have limitations making it difficult to identify meaningful QOL differences.

RC-specific nomothetic QOL instruments are developed via expert and patient input, and include items salient to general and condition-specific QOL for most patients.[5, 6] They are widely used and are easy to administer and score. However, measuring a subjective concept with a standard instrument is complex. Nomothetic instruments may not include specific concerns that impact QOL, and not all items are applicable to all patients at all times. Furthermore, nomothetic instruments do not account for differences in patient perspective, making interpretation difficult. For example, patients may rate QOL in comparison to themselves in perfect health, their friends, or what they perceive to be normal. Finally, it is difficult to determine if longitudinal changes in QOL are real or represent adaption to a new health state, known as response shift.

Idiographic instruments generate a highly personal QOL definition and rating that may be less susceptible to some of these limitations. The only other study to measure QOL in RC patients with an idiographic instrument administered the Schedule for the Evaluation of Individual Quality of Life Direct Weighting (SEIQoL-DW) to 32 patients prior to RC.[12] Patients commonly identified family, health, relationships and finance as important factors that impacted overall QOL, many of which are not assessed with nomothetic instruments. The Quality of Life Appraisal Profile differs from the SEIQoL-DW by capturing a more detailed assessment of personal goals and activities.

Several limitations should be noted. Our findings are not generalizable to the postoperative setting. However, we intend to measure the responsiveness of the Quality of Life Appraisal Profile to changes after RC. We selected a single-item question about global QOL as our primary end-point, however it may be worthwhile to investigate the role of idiographic measures to predict a more detailed measure of global QOL. Still, we tested our hypothesis

against several alternative dependent variables that may be considered proxies for global QOL and our conclusions were similar. Our results suggest idiographic measures are associated with global quality of life independent of measures of health and functioning, however further research is required to determine the relationships between idiographic measures and measures of symptoms, health and functioning. It may be that some people adopt a broad perspective when rating global QOL which leads to more positive ratings than would be suggested by simply considering their symptom and functioning alone. Conversely, idiographic measures of personal goal attainment may help to explain associations between health-related measures of functioning and symptoms and measures of global health, life satisfaction and mental health. Our findings suggest that, in part, functional problems and symptoms affect certain aspects of general well-being through their impact on goal attainment. Alternatively, people may downgrade nomothetic ratings in these areas because they have encountered difficulties in pursuing valued goals and activities. Prospective studies that go beyond analyses presented here would help to clarify the causal links underlying these statistical results. Finally, while we demonstrated the ability of idiographic measures to add predictive power to that of nomothetic variables alone, our findings do not support replacing nomothetic assessments with idiographic assessments, but rather using them as complimentary measures. In its current form the idiographic assessment is lengthy, time-consuming and burdensome for most urologists to use as an outcome measure in routine clinical practice. We hope to develop a practical and useful idiographic assessment that can add valuable QOL information about RC patients.

We believe that further research that offers a more complete and in-depth understanding of patients' quality of life beyond that which can be attained from a limited set of standard items is worthwhile. With a growing emphasis on patient-reported outcomes in modern cancer care, more accurate measures are needed. [32] Our findings show that idiographic assessments provide unique and valuable QOL information that has potential to become a practical and more accurate patient-centric QOL instrument for RC patients. Asking questions about personal goals and goal attainment may provide a valuable way for clinicians to engage patients and gain an understanding about how illness and treatment fit into their overall sense of QOL. Further research will help to determine whether idiographic QOL measures add to our understanding of patients' responses to treatment regimens and therapeutic trials.

Conclusions

Prior to RC, idiographic variables describing the amount of progress towards goal attainment and activity difficulty improved the ability to predict single-item global QOL. While idiographic assessments may not be able to replace nomothetic instruments, they can provide valuable supplemental information that improves the ability to quantify patient-reported global QOL.

Acknowledgments

Grant Number: P30 CA008748

Funding source: Michael and Zena Wiener Family Bladder Cancer Fund; Pin Down Bladder Cancer Foundation; Sidney Kimmel Cancer Center for Prostate and Urologic Cancers

References

1. Calman KC. Quality of life in cancer patients--an hypothesis. *J Med Ethics*. 1984; 10(3):124–7. [PubMed: 6334159]
2. Cella DF, Tulsky DS. Quality of life in cancer: definition, purpose, and method of measurement. *Cancer Invest*. 1993; 11(3):327–36. [PubMed: 8485655]
3. Whalen GF, Ferrans CE. Quality of life as an outcome in clinical trials and cancer care: a primer for surgeons. *J Surg Oncol*. 2001; 77(4):270–6. [PubMed: 11473376]
4. Anderson JL, et al. ACC/AHA Statement on Cost/Value Methodology in Clinical Practice Guidelines and Performance Measures: A Report of the American College of Cardiology/American Heart Association Task Force on Performance Measures and Task Force on Practice Guidelines. *Circulation*. 2014
5. Anderson CB, et al. Psychometric characteristics of a condition-specific, health-related quality-of-life survey: the FACT-Vanderbilt Cystectomy Index. *Urology*. 2012; 80(1):77–83. [PubMed: 22608798]
6. Gilbert SM, et al. Development and validation of the Bladder Cancer Index: a comprehensive, disease specific measure of health related quality of life in patients with localized bladder cancer. *J Urol*. 2010; 183(5):1764–9. [PubMed: 20299056]
7. [accessed 3/10/2013] EORTC QLQ-BLM-30. Available from: <http://groups.eortc.be/qol/bladder-cancer-eortc-qlq-bls24-eortc-qlq-blm30>
8. [accessed 3/10/2013] FACT-BL. Available from: <http://www.facit.org/FACITOrg/Questionnaires>
9. Morganstern BA, et al. The psychological context of quality of life: a psychometric analysis of a novel idiographic measure of bladder cancer patients' personal goals and concerns prior to surgery. *Health Qual Life Outcomes*. 2011; 9:1–18. [PubMed: 21223594]
10. Porter MP, Penson DF. Health related quality of life after radical cystectomy and urinary diversion for bladder cancer: a systematic review and critical analysis of the literature. *J Urol*. 2005; 173(4): 1318–22. [PubMed: 15758789]
11. Rapkin BD, et al. Development of the Idiographic Functional Status Assessment - a Measure of the Personal Goals and Goal Attainment Activities of People with Aids. *Psychology & Health*. 1994; 9(1–2):111–129.
12. Somani BK, et al. Quality of life and body image for bladder cancer patients undergoing radical cystectomy and urinary diversion--a prospective cohort study with a systematic review of literature. *Urology*. 2009; 74(5):1138–43. [PubMed: 19773042]
13. Bowling A. Just one question: If one question works, why ask several? *J Epidemiol Community Health*. 2005; 59(5):342–5. [PubMed: 15831678]
14. de Boer AG, et al. Is a single-item visual analogue scale as valid, reliable and responsive as multi-item scales in measuring quality of life? *Qual Life Res*. 2004; 13(2):311–20. [PubMed: 15085903]
15. Diener E, et al. The Satisfaction With Life Scale. *J Pers Assess*. 1985; 49(1):71–5. [PubMed: 16367493]
16. Berwick DM, et al. Performance of a five-item mental health screening test. *Med Care*. 1991; 29(2):169–76. [PubMed: 1994148]
17. Erber B, et al. Morbidity and Quality of Life in Bladder Cancer Patients following Cystectomy and Urinary Diversion: A Single-Institution Comparison of Ileal Conduit versus Orthotopic Neobladder. *ISRN Urol*. 2012; 2012:1–8.
18. Gacci M, et al. Quality of life in women undergoing urinary diversion for bladder cancer: results of a multicenter study among long-term disease-free survivors. *Health Qual Life Outcomes*. 2013; 11:43. [PubMed: 23497292]
19. Mansson A, et al. Neutral third party versus treating institution for evaluating quality of life after radical cystectomy. *Eur Urol*. 2004; 46(2):195–9. [PubMed: 15245813]
20. Bloem EF, et al. Clarifying quality of life assessment: do theoretical models capture the underlying cognitive processes? *Quality of Life Research*. 2008; 17(8):1093–1102. [PubMed: 18704756]

21. Li Y, Rapkin B. Classification and regression tree uncovered hierarchy of psychosocial determinants underlying quality-of-life response shift in HIV/AIDS. *J Clin Epidemiol*. 2009; 62(11):1138–47. [PubMed: 19595576]
22. Schwartz CE, et al. Changing values, changing outcomes: the influence of reprioritization response shift on outcome assessment after spine surgery. *Quality of Life Research*. 2013; 22(9):2255–2264. [PubMed: 23519975]
23. Schwartz CE, et al. Cognitive reserve and patient-reported outcomes in multiple sclerosis. *Multiple Sclerosis Journal*. 2013; 19(1):87–105. [PubMed: 22546847]
24. Podsakoff PM, et al. Common method biases in behavioral research: a critical review of the literature and recommended remedies. *J Appl Psychol*. 2003; 88(5):879–903. [PubMed: 14516251]
25. Hedgepeth RC, et al. Body image and bladder cancer specific quality of life in patients with ileal conduit and neobladder urinary diversions. *Urology*. 2010; 76(3):671–5. [PubMed: 20451964]
26. Allareddy V, et al. Quality of life in long-term survivors of bladder cancer. *Cancer*. 2006; 106(11): 2355–62. [PubMed: 16649218]
27. Autorino R, et al. Health related quality of life after radical cystectomy: comparison of ileal conduit to continent orthotopic neobladder. *Eur J Surg Oncol*. 2009; 35(8):858–64. [PubMed: 18824319]
28. Somani B, MacLennan S, N'Dow J. Quality of Life with Urinary Diversion. *Eur Urol Suppl*. 2010; 9(10):763–771.
29. Kulaksizoglu H, et al. When should quality of life be measured after radical cystectomy? *Eur Urol*. 2002; 42(4):350–5. [PubMed: 12361900]
30. Lule D, et al. Life can be worth living in locked-in syndrome. *Prog Brain Res*. 2009; 177:339–51. [PubMed: 19818912]
31. Temel JS, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010; 363(8):733–42. [PubMed: 20818875]
32. Cella DF, et al. Integrating health-related quality of life into cross-national clinical trials. *Qual Life Res*. 1993; 2(6):433–40. [PubMed: 8161977]

Table 1

Quality of life assessment schedule.

	Preoperative		Postoperative			
	3 months	6 months	12 months	18 months	24 months	24 months
EORTC QLQ-C30	x	x	x	x	x	x
EORTC QLQ-BLM30	x	x	x	x	x	x
Quality of life appraisal	x	x	x	x	x	x
Satisfaction with life scale	x	x	x	x	x	x
Mental health inventory	x	x	x	x	x	x
Activity level	x	x	x	x	x	x

EORTC QLQ-C30: European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C30

EORTC QLQ-BLM30: European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C30 with BLM30 module

Table 2

Clinical and demographic characteristics of the cohort.

Characteristic	Median (IQR)
Age	67 (62, 72)
Charlson comorbidity index	2 (0, 4)
Number prior TURs	2 (2, 4)
	N (%)
Marital status	
Married or partnered	164 (76)
Unmarried	51 (24)
Employment status	
Employed	103 (48)
Unemployed	112 (52)
Clinical stage	
T1	102 (47)
T2	110 (51)
Tx	2 (1)
Prior IVC	
Yes	79 (37)
No	136 (63)
Prior pelvic radiation therapy	
Yes	15 (7)
No	199 (93)
Missing	1 (0)
Neoadjuvant chemotherapy	
Yes	89 (41)
No	125 (58)
Missing	1 (0)

IQR – interquartile range

TUR – transurethral resection

IVC – intravesical chemotherapy

Table 3

Summary of preoperative nomothetic and idiographic variables.

	Variable	Number	Median (IQR)
EORTC QLQ-C30	Physical function	215	100 (87, 100)
	Role functioning	215	100 (83, 100)
	Cognitive function	215	100 (83, 100)
	Emotional function	215	75 (67, 92)
	Social function	215	83 (67, 100)
	Fatigue	214	11 (0, 33)
	Nausea/vomiting	215	0 (0, 0)
	Pain	215	0 (0, 17)
	Dyspnea	215	0 (0, 0)
	Appetite loss	215	0 (0, 0)
	Constipation	214	0 (0, 33)
	Diarrhea	215	0 (0, 0)
	Financial problems	214	0 (0, 33)
	Insomnia	215	33 (0, 33)
	BLM30	Urinary symptoms	209
Bloating/flatulence		187	17 (0, 33)
Sexual functioning		149	43 (29, 61)
Future perspective		186	56 (33, 67)
Body image satisfaction		183	89 (67, 100)
Idiographic	Number of goals	215	8 (6, 11)
	Goals		
	Minimum goal attainment rating	213	2 (0, 6)
	Average goal attainment rating	213	6.9 (5.5, 8.2)
	Average activity difficulty	209	1.3 (1, 1.8)
	Average activity help received	209	1.0 (1.0, 1.5)
	Percent of an individual's activities associated with:		
	Activities		
	Needing (additional) help	209	0% (0%, 20%)
	Discomfort	209	0% (0%, 0%)
Fatigue	209	0% (0%, 30%)	
Taking too long	208	0% (0%, 12%)	

EORTC QLQ-C30: European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C30

BLM30: BLM30 module

Table 4

Multivariable linear regression output for the base and exploratory models. Incremental R² represents the amount of model variability explained by the sequential addition of variables from each domain.

Model	Variable domain	Standardized β coefficient	Incremental R ²	Adjusted R ²
Single-item global QOL				0.257 ^{***}
Role functioning	EORTC	0.286 ^{***}	0.132 ^{***}	
Future perspectives	BLM	0.106	0.025 [*]	
Average goal attainment	Goals	0.264 ^{**}	0.086 ^{***}	
Average activity difficulty	Activity	-0.190 [*]	0.034 ^{**}	
EORTC Global Health Status				0.515 ^{***}
Fatigue	EORTC	-0.242 ^{**}	0.495 ^{***}	
Social functioning	EORTC	0.127		
Constipation	EORTC	-0.167 ^{**}		
Physical functioning	EORTC	0.178 ^{**}		
Role functioning	EORTC	0.188 [*]		
Future perspective	BLM	0.124 [*]	0.021 ^{**}	
Average goal attainment	Goals	0.155 [*]	0.022 ^{**}	
Mental health inventory score				0.464 ^{***}
Emotional functioning	EORTC	0.457 ^{***}	0.399 ^{***}	
Future perspective	BLM	0.255 ^{***}	0.053 ^{***}	
Average goal attainment	Goals	0.158 [*]	0.023 [*]	
Satisfaction with life scale				0.148 ^{***}
Physical functioning	EORTC	0.235 ^{**}	0.165 ^{***}	
Emotional functioning	EORTC	0.215 ^{**}		
Constipation	EORTC	-0.164 [*]		
Days engaged in activities outside of home				0.217 ^{***}
Fatigue	EORTC	-0.258 ^{**}	0.118 ^{***}	
Sexual functioning	BLM	-0.180 [*]	0.073 ^{**}	
Future perspective	BLM	0.221 ^{**}		
Number goals	Goals	0.203 ^{**}	0.029 [*]	
Proportion of activities that took too long	Activity	-0.158 [*]	0.024 [*]	
Days of activities missed due to illness				0.298 ^{***}
Role functioning	EORTC	-0.392 ^{***}	0.251 ^{***}	
Social function	EORTC	-0.193 [*]		
Proportion of activities that took too long	Activity	0.297 ^{***}	0.066 ^{***}	
Proportion of activities associated with discomfort	Activity	-0.187 [*]		

Significance level of variable entry

*
p<0.05

**
p<0.01

p<0.001

EORTC: European Organization for Research and Treatment of Cancer

BLM: BLM30 module

QOL: Quality of life

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript