



Original Article

Role performance and factors affecting quality of life in bladder cancer survivors with ileal orthotopic neobladder

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ABSTRACT

Objective: Bladder cancer survivors with neobladder experience changes in role performance and quality of life (QoL) due to various symptoms and problems, but related studies are limited. Therefore, this study attempted to explore the QoL and factors influencing it in bladder cancer survivors with neobladder.

Methods: A cross-sectional descriptive design was used. Data were collected from 100 bladder cancer survivors with a neobladder using the European Organisation for Research and Treatment of Cancer QLQ-C30 and Muscle-Invasive Bladder Cancer Module, the Patient Activation Measure 13, the Enforced Social Dependency Scale, and the Multidimensional Scale of Perceived Social Support. Factors affecting the QoL were identified using multiple regression analysis.

Results: QoL significantly differed by daily pad usage, need for clean intermittent catheterization, and role performance. QoL was correlated with urinary symptoms and problems, future perspective, abdominal bloating and flatulence, body image, role performance, and social support. Role performance, body image, and the need for clean intermittent catheterization were identified as the factors affecting QoL.

Conclusions: The study highlights the importance of bladder cancer survivors continuing their roles at home, at work, and in society after neobladder reconstruction. Specifically, continuing recreational and social activity positively affects QoL, even if the activity range is modified. To help with their role performance, institutional support and changes in social perception are needed. Additionally, education and interventions, including body image enhancement, symptom management, and self-care, should be developed and applied to improve their QoL.

Introduction

Radical cystectomy and urinary diversion are standard treatment approaches for muscle-invasive bladder cancer, with ileal conduit and orthotopic neobladder reconstruction is typically performed for urinary diversion.¹ An ileal conduit is relatively quick, easy to perform, and associated with few complications; however, it can negatively impact body image due to the presence of a stoma and external appliances.² In contrast, the ileal orthotopic neobladder may preserve body image as the intestine is utilized to create a reservoir connected to the urethra.² Given this advantage, the use of neobladder reconstruction is increasing.³ In South Korea, the number of cases undergoing orthotopic neobladder reconstruction rose from 194 in 2010 to 382 in 2020.⁴

Following cystectomy and neobladder reconstruction, complications such as urinary tract infections, urinary incontinence, incomplete voiding, and metabolic problems may occur,⁵ and bladder cancer survivors

may experience various symptoms such as sexual dysfunction, sleep disorders, anxiety, and fatigue.⁶ Additionally, fear of recurrence and role functioning problems such as retirement and limited leisure activity are common concerns among bladder cancer survivors after neobladder reconstruction.^{7,8} These symptoms and problems significantly impact their quality of life (QoL).

In contrast, bladder cancer survivors with ileal orthotopic neobladder adapt to changes following radical cystectomy. They undergo bladder training to void through a neobladder and learn self-catheterization and pelvic floor muscle exercises to cope with urinary retention and incontinence.⁸ With support from family and friends, they maintain social relationships and continue performing activities at home, at work, and in society, although difficulties may arise due to lower urinary tract symptoms such as urinary frequency and incontinence.⁸ Accordingly, patient activation, role performance, and social support during the adaptation process following neobladder reconstruction are expected to influence QoL.

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Patient activation refers to believing in the importance of the patient's role in maintaining and promoting health, having the confidence and knowledge necessary for health behavior, actively engaging in health behavior, and sustaining health behavior despite stress.⁹ To adapt to change after neobladder reconstruction, patients must understand that acquiring neobladder management skills is not an easy process, be motivated to overcome the difficulty, and be cognitively and physically able and persistent to continue with bladder training and pelvic floor muscle exercise.¹⁰ The relationship between patient activation and QoL in bladder cancer survivors is still unknown; however, bladder cancer survivors with a neobladder who frequently perform pelvic floor muscle exercises reported a higher QoL than those who did not.¹¹

A role is the expected behavior in one's given position and is defined within the context of relationships with others.¹² Each individual has diverse roles, and health and disease affect the individual's role performance.¹² Social functioning was reported to decrease in bladder cancer survivors more than in the general population, due to urinary incontinence.¹³ The relationship between role performance and QoL in bladder cancer survivors with a neobladder is unknown. However, cancer survivors who continued working reported a higher QoL than those who did not,¹⁴ and colorectal cancer survivors who performed leisure, housework, and social activities showed a higher QoL than their counterparts.¹⁵

Social support refers to the diverse resources individuals can have in interpersonal relationships.¹⁶ Social support has an impact on health behaviors and adherence to medical regimens.^{17,18} Furthermore, social support reduces psychological distress in bladder cancer survivors and affects their QoL.^{19,20}

Studies identify age, follow-up duration, comorbidities, urinary incontinence, activities of daily living (ADL) performance level before surgery, the surgeon's experience, and sexual activity as predictors of QoL in bladder cancer survivors with a neobladder.^{11,21–23} As QoL is a concept implicating physical, psychological, social, and role functioning,²⁴ it cannot be sufficiently explained based on previously identified factors alone.

This study aimed to investigate symptoms and problems, patient activation, role performance, social support, and QoL following neobladder reconstruction and identify the factors influencing their QoL.

Methods

Study design and participants

This study employed a cross-sectional design and adhered to the STROBE guidelines for reporting observational studies. A convenience sample of 100 Korean bladder cancer survivors who had undergone orthotopic neobladder reconstruction was selected from a tertiary hospital outpatients in Seoul, Korea, spanning the period from March 2019 to February 2021. Patients with mental illnesses were excluded from the study. To determine an appropriate sample size, a power analysis was conducted using G*power 3.1.9,²⁵ based on a prior study investigating factors influencing the QoL in bladder cancer patients.²⁰ The minimum required sample size was calculated to be 83, assuming a two-tailed test in multiple regression analysis, a significance level of 0.05, a power of 0.95, an effect size of 0.33, and 15 predictors. To account for potential dropouts, data were collected from 101 patients. One patient was excluded due to incomplete responses, resulting in the analysis of data from 100 participants.

Instruments

Sociodemographic and cancer characteristics

Demographic and disease-related characteristics were gathered using questionnaires. Demographic data included age, gender, current employment status, religion, marital status, and education level, while disease-related information encompassed time elapsed since surgery, operation method, recurrence, current treatment for bladder cancer, and comorbidities.

Quality of life

QoL was assessed using the Korean version of the EORTC Core Quality of Life Questionnaire (EORTC-QLQ-C30). This questionnaire consists of 30 items and incorporates functional scales, symptom scales/items, and a global health status/QoL scale.²⁶ All scales/items were examined in this study, with the global health status/QoL scale utilized as the dependent variable for multiple regression analysis. Scores ranged from 0 to 100, with higher scores indicating better functioning, higher QoL, or a higher level of symptoms for the three scales. Cronbach's alpha coefficients ranged from 0.51 to 0.86 in this study.

Symptom and problem

Symptoms and problems were evaluated using the Korean version of the EORTC-QLQ Muscle-Invasive Bladder Cancer Module (BLM30), as well as the presence and severity of urinary incontinence and the need for clean intermittent catheterization (CIC). The QLQ-BLM30 includes symptom scales/items (urinary symptoms and problems, urostomy problems, catheter use problems, future perspective, abdominal bloating and flatulence, body image) and a functional scale (sexual functioning). While the BLM30 comprises 30 items, this study utilized 24 items, excluding urostomy problems. Scores range from 0 to 100, with higher scores indicating greater symptomatology or problems, or better functioning. Urinary incontinence was classified into daytime and nighttime categories. A study defined participants with no incontinence in the last month or incontinence with a few drops of urine within two times as having no incontinence.²⁷ The severity of incontinence was measured by the number of pads used per day and classified into one-two, three-four, and five or more based on a previous study.²⁸ The need for CIC was assessed based on the implementation of CIC due to urinary retention within the last month.

Patient activation

Patient activation was evaluated using the Korean version of Patient Activation Measure 13 (PAM 13),⁹ which incorporates concepts such as a health locus of control and self-efficacy in managing health behaviors. Each item is rated on a four-point scale from 1 (strongly disagree) to 4 (strongly agree), with an additional "not applicable" option. A raw score is computed by summing the responses to the 13 items, yielding a total scores ranging from 13 to 52. These raw scores were converted to a 0–100 interval scale, where higher scores indicate higher levels of patient activation. Activation levels were categorized into four groups: level 1 (score \leq 47.0), level 2 (score 47.1–55.1), level 3 (score 55.2–67.0), and level 4 (score \geq 67.1) representing varying degrees of patient involvement. Level 1 patients believe they have no important role in their health; level 2 patients lack confidence and knowledge to act; level 3 patients start to take action; level 4 patients are characterized by active involvement. Considering the small sample size, levels 1 and 2 were combined into a low activation group.²⁹ Level 3 was the higher activation group, and level 4 the highest activation group. The Cronbach's alpha coefficient for this study was 0.88.

Role performance

Role performance was assessed using the social competence domain of the Enforced Social Dependency Scale (ESDS).³⁰ This scale consists of two subscales: personal competence and social competence. Social competence includes three items: activity in the home, work activity, and recreational and social activity, each rated on a four-point scale (1 = usual activity, 2 = modified activity, 3 = restricted activity, 4 = no activity). A higher score indicates a lower role performance. Cronbach's alpha for the social competence domain was 0.79.

Social support

Social support was measured using the Multidimensional Scale of Perceived Social Support (MSPSS),³¹ a 12-item scale employing a 7-point Likert-type response format (1 = very strongly disagree; 7 = very strongly agree). Higher scores on this scale reflect higher levels of perceived social support. The MSPSS consists of three four-item

subscales: family, friends, and significant others. A significant other is defined as a spouse or main caregiver. The scale demonstrated high internal consistency with a Cronbach's alpha of 0.94.

Data analysis

Demographic, disease-related characteristics, and research variables were analyzed using descriptive statistics. Group comparisons on the QoL was conducted using nonparametric methods such as the Mann–Whitney, Kruskal–Wallis, and Jonckheere–Terpstra tests. Pearson's correlation was utilized to examine relationships between variables. Variables showing significant associations were included in a hierarchical multiple linear regression model to identify the relationship between QoL and independent variables. Missing data were addressed through listwise deletion. All statistical analyses were performed with a significance level of $\alpha = 0.05$ (two-tailed) using the SPSS 26.0 software (IBM, Armonk, USA).

Ethical considerations

This study was conducted after obtaining approval from the Research Ethics Review Committee of the Samsung Medical Center (IRB No. 2019-02-037-002). One of the authors introduced the study to patients who visited the clinic for outpatient treatment after neobladder reconstruction and directed them to meet with the first author if they were interested in participating. The first author, a doctoral student at the time, was responsible for explaining the study to patients, obtaining consent forms, and distributing questionnaires during data collection. Patients completed the questionnaire independently in the waiting room of the clinic, with the process typically taking approximately 20–30 minutes to complete. All participants provided written informed consent.

Results

Demographic and disease-related participants' characteristics

The study comprised predominantly male participants (92.0%), most of whom were married (90.0%), and employed (50 participants; 50.0%). The median age was 64.50 years (interquartile range [IQR]: 58.00–68.75). Fifty-two survivors had graduated from college (52.0%), and 55 had a religion (55.0%). In terms of disease-related characteristics, 70 survivors had robot-assisted laparoscopic surgery (70.0%), 87 did not have cancer recurrence (87.0%), and 58 had no comorbidities (58.0%). The median time elapsed since surgery was 14 months (IQR: 5.00–26.00). Further details are presented in [Table 1](#).

Descriptive statistics for study variables

The mean QoL score was 66.83 (standard deviation [SD] = 22.81; range = 0.00–100.00). Among QoL functional scales, social functioning exhibited the lowest score. Insomnia emerged as the most severe symptom ([Table 2](#)). The symptoms and problems are shown in [Tables 2 and 3](#). Future perspectives were the most problematic symptom, with sexual functioning scoring at 24.50 (SD = 21.93; range = 0.00–80.95). Only 14 survivors reported no urinary incontinence (14.3%), and 47 used 1–2 pads per day due to urinary incontinence (48.0%). Additionally, 23 survivors performed CIC in the last month due to difficulty in urinary retention (23.5%).

The overall mean score for patient activation was 60.19 (SD = 13.33; range = 38.10–100.00), with 61 survivors (61.0%) having a higher or highest level of activation. Role performance had a mean score of 5.63 (SD = 2.28; range = 3.00–11.00), with work activity scoring the lowest. Perceived social support scored a mean of 5.52 (SD = 1.29; range = 1.00–7.00), with support from friends being the lowest.

Table 1

Demographic and disease-related characteristics (N = 100).

Characteristics	n (%)	Median (IQR)
Age (years)		64.50 (58.00–68.75)
Gender		
Male	92 (92.0)	
Female	8 (8.0)	
Current employment		
Employed	50 (50.0)	
Unemployed	50 (50.0)	
Religion		
No religion	45 (45.0)	
Have religion	55 (55.0)	
Marital status		
Married	90 (90.0)	
Not married	10 (10.0)	
Education		
≤ High school	48 (48.0)	
≥ College	52 (52.0)	
Time elapsed since surgery (months)		14.00 (5.00–26.00)
Operation method		
Open surgery	30 (30.0)	
Robot-assisted laparoscopic surgery	70 (70.0)	
Recurrence		
Has not recurred	87 (87.0)	
Recurred	13 (13.0)	
Current treatment ^a		
Yes	10 (10.0)	
No	90 (90.0)	
Comorbidity		
Yes	42 (42.0)	
No	58 (58.0)	

IQR, Interquartile range.

^a Current treatment: radiotherapy, chemotherapy, immunotherapy.

Differences in quality of life according to symptoms and problems, patient activation, and role performance

[Table 3](#) presents differences in QoL according to symptoms and problems, patient activation, and role performance. QoL varied based on the severity of urinary continence, specifically the number of pads used per day (H (3) = 7.81, $P = 0.048$). The Jonckheere–Terpstra test revealed a decreasing trend in QoL with an increase in the number of pads used. A significantly lower QoL was observed in the group using five or more pads per day compared to those not using pads ($z = -2.57$, $P = 0.030$). Similarly, the group performing CIC exhibited lower QoL compared to the group that did not ($z = -2.67$, $P = 0.007$).

QoL significantly differed according to patient activation level (H (2) = 6.18, $P = 0.045$), although the post hoc test did not reveal significant differences between groups. Analysis of role performance across three domains (at home, at work, and in recreational and social activities) showed significant differences in QoL. For role performance at home, QoL was higher in the usual activity group compared to the modified activities ($z = 5.10$, $P < 0.001$) and restricted activities groups ($z = 4.12$, $P < 0.001$). Similarly, for role performance at work, the usual activity group exhibited higher QoL than the modified activities ($z = 3.72$, $P = 0.001$), restricted activities ($z = 4.41$, $P < 0.001$), and no activity groups ($z = 3.96$, $P < 0.001$). In recreational and social activities, QoL was higher in the usual activities group compared to the restricted activities ($z = 4.71$, $P < 0.001$) and no activity groups ($z = 2.99$, $P = 0.017$). Furthermore, QoL was higher in the modified activities group than in the restricted activities group ($z = 2.93$, $P = 0.021$).

Correlations among study variables

Correlation analysis revealed significant associations between QoL and various study variables. QoL exhibited negative correlations with urinary symptoms and problems ($r = -0.433$, $P < 0.001$), future perspective ($r = -0.506$, $P < 0.001$), abdominal bloating and flatulence ($r = -0.361$, $P < 0.001$), and body image ($r = -0.619$, $P < 0.001$).

Table 2
Descriptive statistics of the measured variables (N = 100).

Variables	n	Mean ± SD	Min	Max
QoL				
Global health status/QoL	100	66.83 ± 22.81	0.00	100.00
Functional scales				
Physical functioning	100	82.92 ± 16.53	33.33	100.00
Role functioning	100	78.00 ± 23.91	0.00	100.00
Emotional functioning	100	79.83 ± 19.29	8.33	100.00
Cognitive functioning	100	82.67 ± 18.03	33.33	100.00
Social functioning	100	71.67 ± 28.18	0.00	100.00
Symptom scales/items				
Fatigue	100	31.89 ± 22.26	0.00	100.00
Nausea and vomiting	100	5.33 ± 11.33	0.00	50.00
Pain	100	15.00 ± 20.72	0.00	100.00
Dyspnea	100	14.67 ± 23.84	0.00	100.00
Insomnia	100	37.67 ± 31.30	0.00	100.00
Appetite loss	100	13.00 ± 25.47	0.00	100.00
Constipation	100	26.33 ± 28.15	0.00	100.00
Diarrhea	100	14.67 ± 23.84	0.00	100.00
Financial difficulties	100	29.33 ± 30.81	0.00	100.00
Symptoms and problems				
Symptom scales/items				
Urinary symptoms and problems	99	39.96 ± 18.98	4.76	95.24
Future perspective	100	41.89 ± 23.04	0.00	100.00
Abdominal bloating and flatulence	100	17.67 ± 24.02	0.00	100.00
Body image	100	34.39 ± 26.83	0.00	100.00
Catheter use problem ^a	42	17.46 ± 22.38	0.00	66.67
Functional scale				
Sexual functioning	90	24.50 ± 21.93	0.00	80.95
Patient activation	100	60.19 ± 13.33	38.10	100.00
Role performance				
Home activities	100	1.61 ± 0.83	1.00	4.00
Work activities	97	2.06 ± 1.00	1.00	4.00
Recreational and social activities	99	2.02 ± 0.93	1.00	4.00
Social support				
Spouse or primary caregiver	100	5.94 ± 1.46	1.00	7.00
Family	100	5.86 ± 1.41	1.00	7.00
Friends	100	4.75 ± 1.73	1.00	7.00

SD, standard deviation; QoL, quality of life.

^a The catheter use problem is conditional item and must only be scored if it is applicable to the patient.

indicating that more severe symptoms and problems were associated with lower QoL. In contrast, QoL showed positive correlations with role performance ($r = -0.658, P < 0.001$) and social support ($r = 0.236, P = 0.030$), suggesting that better role performance and higher levels of perceived social support were associated with higher QoL (Table 4).

Factors influencing quality of life in bladder cancer survivors with a neobladder

A hierarchical multiple regression analysis was conducted to investigate factors influencing QoL in bladder cancer survivors with a neobladder (Table 5). Assumptions of the statistical model, including the ratio of cases to independent variables, normality, independence of errors, homoscedasticity, linearity, and absence of multicollinearity were confirmed.

In Model 1, demographic and disease-related characteristics were included as independent variables, but this model did not reach statistical significance. Model two examined the effects of symptoms and problems on QoL while controlling for demographic and disease-related characteristics. Body image and the need for CIC emerged as significant predictors of QoL ($\beta = -0.45, P < 0.001$; $\beta = -0.21, P = 0.025$, respectively). In Model 3, patient activation, role performance, and social support were investigated, adjusting for demographic and disease-related characteristics as well as symptoms and problem variables. This model achieved statistical significance ($F = 7.82, P < 0.001$), with body image ($\beta = -0.31, P = 0.006$), the need for CIC ($\beta = -0.20, P = 0.016$), and role performance ($\beta = -0.45, P < 0.001$) significantly influencing QoL. Collectively, the variables in this model accounted for

Table 3
Difference in quality of life according to measured variables (N = 100).

Variables	n (%)	Mean ± SD	z or H	Pairwise comparisons
Symptoms and problems				
Presence of incontinence (n = 98)				
None	14 (14.3)	73.81 ± 21.65	3.06	
Night only	43 (43.9)	68.80 ± 23.15		
Day and night	41 (41.8)	63.21 ± 22.90		
Severity of incontinence (No. Pads/24 hrs) (n = 98)				
a: Do not use	19 (19.4)	74.56 ± 24.92	7.81*	a > d ^a
b: 1–2	47 (48.0)	68.26 ± 20.83		
c: 3–4	15 (15.3)	66.11 ± 27.00		
d: ≥ 5	17 (17.3)	56.86 ± 20.46		
Clean intermittent catheterization (n = 98)				
No	75 (76.5)	70.44 ± 21.93	-2.67*	
Yes	23 (23.5)	56.52 ± 23.29		
Patient activation				
Low activation	39 (39.0)	60.26 ± 23.76	6.18*	
Higher activation	42 (42.0)	69.84 ± 20.66		
Highest activation	19 (19.0)	73.68 ± 23.12		
Role performance				
Home activities				
a: Usual activity	58 (58.0)	78.74 ± 15.15	37.75**	a > b, c
b: Modified activity	26 (26.0)	51.92 ± 20.86		
c: Restricted activity	13 (13.0)	48.08 ± 25.04		
d: No activity	3 (3.0)	47.22 ± 12.73		
Work activities (n = 97)				
a: Usual activity*	33 (34.0)	82.83 ± 13.49	29.08**	a > b, c, d
b: Modified activity**	36 (37.1)	65.05 ± 19.30		
c: Restricted activity	17 (17.5)	53.92 ± 23.22		
d: No activity	11 (11.3)	50.00 ± 26.61		
Recreational and social activities (n = 99)				
a: Usual activity*	34 (34.3)	79.90 ± 12.50	25.72**	a > c, d, b > c
b: Modified activity**	36 (36.4)	68.29 ± 23.39		
c: Restricted activity ^a	22 (22.2)	51.14 ± 19.47		
d: No activity	7 (7.1)	47.62 ± 29.15		

Participants with foley catheter or percutaneous nephrostomy were excluded in the symptom and problem. An unequal sign indicates a significant difference by a Bonferroni post hoc test.

* $P < 0.05$, ** $P < 0.001$.

^a Jonckheere–Terpstra test.

55.0% of the variance in QoL among bladder cancer survivors with a neobladder (Table 5).

Discussion

This study investigated the QoL of bladder cancer survivors with a neobladder and identified factors influencing their QoL. The adaptation process for bladder cancer survivors with a neobladder involves significant lifestyle adjustments due to the loss of bladder function, which directly impacts their QoL outcomes. Adaptation is influenced by various personal contexts such as mental health, personality, social support, coping strategies, and physical health.³² This study is significant as it explores QoL and its determinants within the context of change and adaptation experienced by patients following neobladder reconstruction.

The mean QoL score among bladder cancer survivors with a neobladder closely resembled those of bladder cancer patients observed in studies using the EORTC-QLQ-C30 instrument.^{21,33} However, despite differences in the elapsed time since surgery, ranging from 14 months in this study, compared to 37–38 months in previous studies, the QoL level remained consistent.^{21,33} This suggests that QoL may not improve with the passage of time after neobladder reconstruction. Notably, social and

Table 4
Correlation between the quality of life and variables ($N = 85$).

	Urinary symptoms and problems	Future perspective	Abdominal bloating and flatulence	Body image	Sexual functioning	Patient activation	Role performance ^a	Social support	Quality of life
Urinary symptoms and problems	1								
Future perspective	0.490**	1							
Abdominal bloating and flatulence	0.426**	0.284*	1						
Body image	0.388**	0.609**	0.421**	1					
Sexual functioning	0.045	-0.029	-0.052	-0.196	1				
Patient activation	0.003	-0.072	0.205	-0.040	0.078	1			
Role performance	0.322*	0.461**	0.319*	0.508**	-0.155	0.058	1		
Social support	-0.069	-0.085	-0.021	-0.155	-0.014	0.263*	-0.137	1	
Quality of life	-0.433**	-0.506**	-0.361*	-0.619**	0.032	0.082	-0.658**	0.236*	1

* $P < 0.05$, ** $P < 0.001$.

^a A higher score indicates lower role performance.

Table 5
Hierarchical regression analysis for quality of life in bladder cancer survivors with neobladder ($N = 85$).

Variables	Model 1				Model 2				Model 3			
	B	S.E.	β	P	B	S.E.	β	P	B	S.E.	β	P
(Constant)	82.07	18.52			97.95	15.92			89.44	17.70		
Age	-0.21	0.29	-0.08	0.472	-0.03	0.24	-0.01	0.911	0.16	0.22	0.06	0.453
Time elapsed since surgery	0.06	0.08	0.08	0.469	-0.01	0.08	-0.01	0.929	-0.05	0.07	-0.07	0.466
Female (reference: male)	-11.13	11.65	-1.11	0.342	5.13	9.92	0.05	0.607	1.66	8.77	0.02	0.850
Current treatment (ref: no)	-14.66	8.41	-0.19	0.085	4.80	7.32	0.06	0.514	5.13	6.47	0.07	0.431
Urinary symptoms and problems					-0.15	0.13	-0.13	0.236	-0.16	0.11	-0.14	0.165
Future perspectives					-0.17	0.13	-0.17	0.206	-0.06	0.12	-0.06	0.616
Abdominal bloating and flatulence					-0.08	0.10	-0.08	0.442	-0.03	0.09	-0.03	0.730
Body image					-0.38	0.10	-0.45	< 0.001	-0.26	0.09	-0.31	0.006
Sexual functioning					-0.02	0.10	-0.02	0.801	-0.06	0.08	-0.06	0.503
Pad usage: 1-4 (ref: no)					3.11	5.46	0.07	0.570	-1.90	4.97	-0.04	0.703
Pad usage: ≥ 5 (ref: no)					-5.12	7.82	-0.08	0.515	-1.73	6.99	-0.03	0.805
Need for CIC (ref: no)					-12.14	5.31	-0.21	0.025	-11.57	4.66	-0.20	0.016
Patient activation									0.14	0.14	0.08	0.307
Role performance									-4.32	0.97	-0.45	< 0.001
Social support									1.39	1.33	0.09	0.300
R^2	0.07				0.50				0.63			
Adjusted R^2	0.02				0.42				0.55			
F(P)	1.45 (0.226)				5.97 (< 0.001)				7.82 (< 0.001)			

Ref, reference; S.E., standard error.

role functioning scores were lower compared to other domains, consistent with existing literature.^{21,33} Bladder cancer survivors exhibit lower role functioning compared to the general population, as well as lower social functioning compared to both the general population and kidney cancer survivors.^{13,34} This is attributed to the challenges they face in maintaining a social life, including work, due to issues like urinary incontinence and retention.⁸ Regarding symptom scales/items, the score was the highest in insomnia, followed by fatigue and financial difficulty. Studies have also reported that insomnia, fatigue, and financial difficulties were more severe than other symptoms.^{21,33} Sleep quality decreases in bladder cancer survivors with a neobladder due to nighttime incontinence and nocturia.³⁵ In this study, insomnia and fatigue were also correlated with urinary symptoms and problems (Appendix A). The financial difficulty of bladder cancer survivors may be associated with a loss of income and a lack of universal health care coverage.³⁶ In this study, 50.0% of participants did not have a job. Of those, 56.0% stopped working after the bladder cancer diagnosis and surgery and experienced more significant financial difficulties than those who had retired before the diagnosis or those with a job (Appendix B). In South Korea, despite the policy for national health insurance coverage expansion for cancer patients, the financial household burden of a cancer patient is significant due to income loss.³⁷ Accordingly, systemic measures to cope with job loss and reduced income for cancer patients are required.³⁷

Role performance, body image, and the need for CIC emerged as significant factors influencing QoL. This implies that QoL tends to be higher among patients exhibiting high levels of role performance, possessing a positive body image, and not requiring CIC. Notably, role

performance exerted the most substantial impact on QoL. The level of role performance observed in this study, conducted among participants who underwent neobladder reconstruction—a procedure typically reserved for individuals without metastasis and who can self-manage—was notably higher compared to previous research conducted with advanced cancer patients.^{38,39} We discovered significant differences in QoL based on role performance levels at home, work, and in recreational and social activities. Activities at home contribute to cancer survivors' perceptions of themselves as family members⁸ and are associated with higher QoL akin to physical activities.¹⁵ Engagement in work facilitates socialization, fosters social relationships and plays a pivotal role in identity formation.⁴⁰ Similarly, involvement in recreational activities promotes the development of social bonds, positive emotions, and overall improvement in QoL.⁴¹ Therefore, active participation at home, work, recreational, and social activities, within health constraints, hold promise for enhancing QoL. Particularly noteworthy is the finding that the group engaged in modified recreational and social activities exhibited higher QoL compared to those with restricted activities. Adjusting recreational and social activities to accommodate postneobladder reconstruction challenges could foster continued participation and ultimately lead to improved QoL, especially when maintaining prereconstruction participation levels proves challenging.

However, the ability of cancer survivors to perform their roles isn't solely determined by their willingness. A study examining Korean adults' attitudes toward cancer survivors found that 30.9% of participants expressed a tendency to avoid working with cancer survivors, while 28.1% indicated they would avoid socializing with a neighbor who is a cancer survivor.⁴² Another

study involving Koreans revealed negative attitudes toward cancer survivors' return to work.⁴³ Conversely, studies in other countries have reported relatively favorable public perceptions regarding cancer survivors' return to work. Nonetheless, cancer survivors often report experiencing discrimination in the workplace and may refrain from disclosing their survivor status due to fears of discrimination.⁴⁴ Therefore, to support bladder cancer survivors with a neobladder in their role performance, it is imperative to address and rectify the negative perceptions surrounding cancer survivors' social activities. Additionally, institutional support such as return-to-work programs, counseling services, legal assistance, and the expansion of health care facilities are crucial for promoting the social activities of cancer survivors.

Body image emerged as the second-most influential factor affecting QoL. Interestingly, participants in this study exhibited more negative body image compared to findings from previous research.^{21,33} Previous studies, with a longer postsurgery duration, ranging from 37 to 38 months^{21,33} (longer than the 14-month period of this study) reported potentially improved body image over time. The disparity in results could be attributed to the gradual recovery of body image over the postsurgery period. Notably, neobladder reconstruction is renowned for its potential to preserve body image.² The significance of body image as a determinant of QoL underscores its multifaceted nature, encompassing perceptions, thoughts, and emotions related to various factors such as body size, abilities, and functions.⁴⁵ Even subtle changes or the perception of loss of control over one's body can significantly impact body image.⁴⁶ For bladder cancer survivors with a neobladder, issues like erectile dysfunction and reliance on diapers may exacerbate body image concerns. Despite these observations, empirical evidence on this matter remains limited, warranting further investigation. Given the substantial influence of body image on interpersonal relationships,⁴⁵ and its documented impact on QoL in this study, the development of interventions aimed at enhancing body image is warranted.

The need for CIC emerged as another factor influencing QoL, with 23.5% of participants in this study engaging in CIC due to urinary retention within the last month. This prevalence rate exceeded proportions reported in prior studies (ranging from 3.4% to 11.0%).^{11,23,47} The primary challenge associated with CIC revolves around access to restroom facilities, particularly in public settings where space constraints make self-catheterization cumbersome.⁴⁸ This underscores the impact of CIC on patients' ability to participate in social activities. Various factors can contribute to dysfunctional voiding necessitating catheterization, including progressive enlargement of the neobladder. To mitigate neobladder enlargement, patient education on regular voiding is essential.⁴⁹ Additionally, given that a high body mass index is predictive of urinary retention,⁴⁷ patients should be encouraged to maintain regular physical activity. Institutional support in the form of increased accessibility to restrooms and health care facilities is crucial to alleviate the challenges associated with performing CIC.

Sexual functioning, patient activation, and social support were not found to significantly affect QoL in this study. This result contrasts with prior research indicating that sexual activity impacts the QoL of bladder cancer survivors with a neobladder.²³ The difference in findings might stem from cultural disparities concerning sexual attitudes and practices, as Korean bladder cancer survivors tend to accept and resign themselves to diminished sexual function postcystectomy.⁸ The disparity in findings may stem from cultural variations in attitudes toward sexual life. Additionally, patient activation was not deemed significant as a factor influencing QoL. Nevertheless, individuals with the highest activation levels were significantly more likely to cope with complications, adopt a healthy diet, and engage in exercise compared to cancer patients with low activation levels. Specifically, those with the highest activation were 4.5 times more likely to cope with complications, 3.3 times more likely to adopt a healthy diet, and 4.7 times more likely to exercise.⁵⁰ Therefore, interventions aimed at enhancing patient activation among cancer survivors should be considered. Although social support did not significantly influence QoL, it exhibited a positive correlation with it. Family and

friends play a crucial role in supporting bladder cancer survivors as they adapt to changes in voiding mechanisms, symptoms, and learn new skills such as CIC.⁵¹ Consequently, including families in perioperative education programs could facilitate the provision of adequate support to bladder cancer survivors.

Implications for nursing practice and research

This study on male bladder cancer survivors with a neobladder sheds light on factors influencing their QoL, such as urinary symptoms and problems, body image, the need for CIC, and role performance. Despite consistent QoL levels over time postsurgery, challenges such as social functioning, insomnia, and financial difficulties persist. Addressing negative perceptions about cancer survivors' social activities and providing institutional support is crucial. Body image concerns, influenced by factors such as erectile dysfunction and reliance on diapers, underscore the need for interventions to improve body image. The prevalence of CIC and its impact on social participation underscore the importance of patient education, physical activity, and enhanced restroom accessibility. While sexual functioning and social support did not significantly affect QoL in this study, cultural variations may influence these findings. Enhancing patient activation and involving families in perioperative education programs could further support bladder cancer survivors. This study underscores the need for tailored nursing interventions and further research to address the multifaceted challenges encountered by bladder cancer survivors with a neobladder.

Limitations

This study has several limitations. First, the generalizability of the findings may be limited as data were collected from only one hospital, and participants were in relatively good condition, able to independently complete a questionnaire for 20–30 minutes. Second, the cross-sectional design of the study prevents establishing causal relationships between QoL and relevant variables. Third, the relatively short time that has elapsed since surgery may not reflect long-term QoL outcomes. Lastly, the use of self-administered questionnaires may introduce participant bias into the data. However, this study is the first of its kind to investigate QoL and its determinants in the context of changes and adaptation following neobladder reconstruction. The findings offer valuable insights for developing interventions and policies aimed at improving the QoL of the bladder cancer survivors with a neobladder.

Conclusions

This study sheds light on the QoL and its influencing factors amidst the process of change and adaptation following neobladder reconstruction. Findings underscore the pivotal roles of role performance, body image, and the necessity for CIC in shaping the QoL of bladder cancer survivors with neobladder, with role performance emerging as the most impactful factor. It emphasizes the significance of patients' determination and support from their social networks in sustaining their roles post-neobladder reconstruction. Practically, nurses can play a crucial role in aiding bladder cancer survivors by providing education on ongoing role performance and symptom management while involving families in the caregiving process. Furthermore, future research should aim to address social stigmas and provide institutional support to facilitate the effective reintegration of cancer survivors into society, enabling them to fulfill their roles more effectively.

Ethics statement

The study was approved by the Institutional Review Board of the Samsung Medical Center (IRB No. 2019-02-037-002). All participants provided written informed consent.

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CRedit authorship contribution statement

So Hee Kim: Conceptualization, Methodology, Formal analysis, Investigation, Writing – original draft, review & editing. **Eunjung Ryu:** Conceptualization, Methodology, Validation, Resources, Writing – review & editing, Project administration, Funding acquisition. **Byong Chang Jeong:** Investigation, Resources, Supervision, Writing – review & editing. All authors had full access to all the data in the study, and the corresponding author had final responsibility for the decision to submit the article for publication. The corresponding author attests that all listed authors meet the authorship criteria and that no others meeting the criteria have been omitted.

Declaration of competing interest

The authors declare no conflict of interest.

Data availability statement

The data that support the findings of this study are available from the corresponding author, upon reasonable request.

Declaration of Generative AI and AI-assisted technologies in the writing process

No AI tools/services were used during the preparation of this work.

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Appendix A. Supplementary data

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