Trends in quality of life reporting for radical cystectomy and urinary diversion over the last four decades: A systematic review of the literature

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ABSTRACT

**Objective:** To report the trends in quality of life (QoL) reporting for radical cystectomy (RC) and urinary diversion (UD) over the last four decades, as RC for bladder cancer is associated with significant morbidity and QoL issues.

**Material and methods:** We searched PubMed, Medical Literature Analysis and Retrieval System Online (MEDLINE), Excerpta Medica database (EMBASE), Cumulative Index to Nursing and Allied Health Literature (CINAHL), and the Cochrane library for published studies from January 1980 to January 2017 in the English language. We divided the published articles into three time periods: period-1 (1980–1997), period-2 (1998–2007) and period-3 (2008–2017).

**Results:** A total of 85 QoL studies (8417 patients) were identified, of which 3347 (39.8%) patients had an ileal conduit (IC), 1078 (12.8%) had a continent UD (CD), 3264 (38.8%) had a neobladder (NB), and in the remaining 728 (8.6%) the type of UD was not specified. Whilst there were 15, 24 and 41 studies in period-1, period-2 and period-3 respectively, two (13%), 20 (83%) and 37 (90%) used a validated QoL tool; and none, six (25%) and 23 (56%) used a urology specific QoL tool during these three time periods. Similarly, the number of prospective studies increased from one (7%) to four (17%) and 14 (34%) in these three time periods. The proportion of reported IC patients reduced from 65% (784 patients) to 36% (899) and 35% (1664) from period-1 to period-3, whereas the proportion of NB patients increased from 4.5% (54) to 44% (1105) and 44% (2105). Over the last few years there have been QoL studies on laparoscopic and robotic IC and NB UD.

**Conclusion:** Our review suggests an increasing use of validated, bladder cancer-specific questionnaires with UD-specific constructs.

**Abbreviations:** BCI: Bladder Cancer Index; BDI: Beck Depression Inventory; BIS: Body Image Scale; CD: continent urinary diversion; EORTC QLQ-30C: European Organisation for the Research and Treatment of Cancer Quality of Life 30-item core questionnaire; ERAS: enhanced recovery after surgery; FACT- (BL)(G)(VCI): Functional Assessment of Cancer Therapy-Bladder Cancer(-General)(-Vanderbilt Cystectomy Index); IC: ileal conduit; NB: neobladder; (HR)QoL: health-related quality of life; (RA)RC: (robot-assisted) radical cystectomy; SF-36: 36-item short-form health survey; SIP: Sickness Impact Profile; UD: urinary diversion

**Introduction**

Radical cystectomy (RC) with urinary diversion (UD) is associated with significant morbidity. Once patients recover from this surgery, quality of life (QoL) becomes an important priority having a significant role in their future psychological and emotional well-being [1–3]. UD impacts QoL and there are different types of UD to choose from, including ileal conduit (IC) to continent cutaneous UD (CD) and neobladder (NB) [3–8].

Measuring QoL can help assess the impact of RC and UD, identify patient preference, help in staff training, and be useful for audit and clinical governance [1]. The choice of UD depends on patient suitability and preference, with a possible surgical bias related to the surgical expertise available in the centre. Whilst enthusiasts favour NB, there is little evidence to support that one UD type is better than another [9–12]. It seems that for now, the choice of UD should be individualised and based on patient counselling and expectations, with an active but unbiased surgical input. Measuring QoL in these patients has changed from self-designed to non-validated and now validated tools, including generic and disease-specific measures. Over time the shift has been to use bladder cancer-specific health-related QoL (HRQoL) tools supplemented by patient-reported outcome measures [8,13–18].

**Publication trends reflect clinical practice** [19]. Trends in the type of UD offered could help patients in their choice of UD type, improve counselling and allocation of healthcare resources. The QoL aspect seems to be the most important element in UD once patients have recovered from their initial surgery. There is no bibliometric study looking at the publication trends of reporting QoL in UD patients.
We therefore assessed the trend in QoL reporting after RC and UD over the last four decades.

**Materials and methods**

**Inclusion criteria**

(1) All studies reporting on QoL after UD, irrespective of the type of UD.
(2) Studies published in English language over the last four decades.

**Exclusion criteria**

(1) Animal studies and case reports.
(2) Studies on UD that did not assess QoL.

**Search strategy and study selection**

We performed a systematic review of the world literature to identify original studies reporting on QoL in UD. It was carried out using Cochrane and Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) methodology.

We searched PubMed, Medical Literature Analysis and Retrieval System Online (MEDLINE), Excerpta Medica database (EMBASE), Cumulative Index to Nursing and Allied Health Literature (CINAHL) and the Cochrane library for published studies from January 1980 to January 2017. We used the following search terms ‘urinary diversion’, ‘quality of life’, ‘neobladder’, ‘ileal conduit’, ‘cutaneous diversion’, ‘cystectomy’, ‘health-related quality of life’, and ‘QoL’. All articles from 1980 to 1997, and only articles directly comparing two or more different UD types from 1998 to 2017 were selected for screening. All full-length articles published in the English language were included in the original search and the two reviewers (K.R., B.K.S.) independently identified all studies that fitted the inclusion criteria (Figure 1).

We included all studies where patients underwent UD (1980–1997), and at least two forms of UD were used and QoL was measured using either a validated or non-validated questionnaire (1998–2017). After screening the abstracts (n = 295), 85 studies met the inclusion criteria and were included in our present review (Appendix 1). Each of the 85 studies was then assessed in a standardised fashion. The following information was collected for each study: number of patients, type of UD compared, study design, type of instrument used to assess HRQoL outcome (general vs disease-specific and validated vs non-validated), major findings of the study, and any other characteristics unique to the study.

We divided the last four decades into three time periods: period-1 (1980–1997), period-2 (1998–2007), and period-3 (2008–2017).

**Primary outcome measures**

(1) Trends of QoL reporting over the last four decades.
(2) Number of studies and type of UD done.

**Secondary outcome measures**

(1) Geographical variation in the reporting of the QoL studies.
(2) Journals which published these QoL studies.

![Figure 1. PRISMA flowchart of study inclusion.](image-url)
Data extraction and analysis

Both reviewers (K.R., B.K.S.) independently identified all studies that appeared to fit the inclusion criteria and any disagreement was resolved with mutual consensus. All data were collected in an Excel spreadsheet and then transferred to a Word document. The study was carried out using the Cochrane and PRISMA methodology. Included studies showed a high level of heterogeneity and bias, and data were not suitable for a meta-analysis, and hence have been presented in a descriptive manner.

Results

Over the last 37 years, a total of 85 post-RC QoL studies (8417 patients) have been reported (Tables 1 and 2). Of these UD patients (within the 85 studies), 3347 (39.8%) had an IC, 1078 (12.8%) had a CD, 3264 (38.8%) had a NB, and in the remaining 728 (8.6%) the type of UD was not specified (Tables 1 and 2). Whilst there were 15, 24 and 41 studies in period-1, period-2, and period-3, respectively, two (13%), 20 (83%) and 37 (90%) used a validated QoL tool; and none, six (25%) and 23 (56%) used a urology specific QoL tool during these three time periods. Similarly, the number of prospective studies increased from one (7%) to four (17%) and 14 (34%) in these three time periods.

The overall proportion of reported IC patients reduced from 65% (784 patients) to 36% (899) and 35% (1664) from period-1 to period-3, whereas the proportion of reported NB patients increased from 4.5% (54) to 44% (1105) and 44% (2105). The reporting of both the UD types was broadly similar over the last two decades. Over the last few years there have also been QoL studies on laparoscopic and robot-assisted IC and NB UDAs.

Overall, 43 (51%) studies came from Europe, 22 (26%) from the USA, and 16 (19%) from Asia (Table 3), with 16 studies published in BJU International (British Journal of Urology before 1999) and 10 studies in Urology.

Discussion

Over the last decade, there have been more QoL studies and more validated and prospective studies. Similarly, the proportionate numbers of NBs has also increased over the last two decades, with newer studies now reporting on laparoscopic and robot-assisted UDAs (Tables 1 and 2). There has also been a rise in the number of studies reporting on QoL outcomes in these patients, demonstrating the importance placed on QoL in the last decade.

Change in QoL trends over the last four decades

Whilst publication trends show that better reporting of QoL with more validated questionnaires are now being used, it seems that as long as the patient is well counselled and supported in their decision they learn to cope and adjust with their UD type [1]. Compared to previous decades, the past decade has seen an upsurge in focus on QoL outcomes in bladder cancer. This has occurred in tandem with the development of new and specific HRQoL instruments used in bladder cancer [1,8]. There has also been considerable variability in the use of QoL assessment tools, with a progressive uptake of validated assessment methods in the last decade. Our literature review revealed 13 of the 15 studies between 1987 and 1997 used a non-validated ad hoc (self-designed) instrument to assess QoL outcomes compared to only four in the 2009–2017 period. This suggests that the process of HRQOL measurement is becoming increasingly popular and perhaps clinically responsive.

The ad hoc instruments previously used were potentially poor measures of reliability and qualitative outcomes, and subject to bias due to their inherent non-validated nature [1,8]. In addition, there has been a gradual rise in the globalisation of quality assessment in patients after RC, given that 18 different countries are represented across the studies in 2009–2017 compared to only six in 1987–1997. Only one study across the last three decades accounted for sociocultural influences in health perception and QoL evaluation [11]. Perhaps there is a role for cross-cultural testing of these QoL instruments to ensure the validity and reliability of these tools across patients from other countries and cultures [12].

Generic vs cancer-specific QoL assessment

In the past more generic QoL assessment tools were used. Previously, the Beck Depression Inventory (BDI) and Sickness Impact Profile (SIP) [13] were used to assess HRQOL across a wide range of medical conditions, and therefore these were not responsive to

| Year       | No. of countries (studies*) | No. of patients | Validated scale (urology specific) used, n | Prospective/retrospective, n | IC/CD/NB/unspecifie, n | Open/lap or robotic, n |
|------------|-----------------------------|-----------------|-----------------------------------------|----------------------------|------------------------|------------------------|
| 1980–1997  | 6 (15)                      | 1206            | 2 (8)                                   | 1/14                       | 784/368/54/0           | 1206/0                 |
| 1998–2007  | 11 (24)                     | 2464            | 20 (6)                                  | 4/20                       | 899/428/1105/32        | 2432/0                 |
| 2008–2017  | 18 (41)                     | 4747            | 37 (23)                                 | 14/27                      | 1664/282/2105/696      | 3939/112               |
| Total      | 35 (80)                     | 8417            | 59 (29)                                 | 19/61                      | 3347/1078/3264/728     | 7577/112               |

*lap, laparoscopic.
| Journal                | Author                     | Country | Year | No. of Patients | Scale used – 1          | Scale used 2 | IC   | CD | NB | CD/NB | Study type | Conclusion on QoL                                                                 |
|-----------------------|----------------------------|---------|------|-----------------|-------------------------|--------------|------|----|----|-------|------------|--------------------------------------------------------------------------------|
| Br J Urol             | Jones et al.               | UK      | 1980 | 34              | Self-designed questionnaire |              | 34              |     |    |    |       | Retro. Stoma problems                                                             |
| Scand J Urol Nephrol  | Fossà et al.               | Norway  | 1987 | 59              | Self – psychological/social issues |              | 59              |     |    |    |       | Retro. Good QoL                                                                  |
| J Urol                | Boyd et al.                | USA     | 1987 | 172             | BDI, POMS, physical impact |              | 87              | 85  |    |    |       | Retro. Preop. counselling important, patients overall satisfied but more for CD  |
| Br J Urol             | Månsson et al.             | Sweden  | 1988 | 60              | Self-designed questionnaire |              | 40              | 20  |    |    |       | Retro. Less stoma problems and more freedom for activities in CD                 |
| Scand J Urol Nephrol  | Mømmsen et al.             | Denmark | 1989 | 68              | Self-designed questionnaire |              | 68              |     |    |    |       | Retro. Preop. counselling important but often neglected                         |
| Br J Urol             | Chadwick and Stower        | UK      | 1990 | 41              | Interview – appliance management |              | 41              |     |    |    |       | Retro. 83% improved QoL, 90% continue household duty, leakage problem           |
| Scand J Caring Sci    | Månsson et al.             | Sweden  | 1991 | 34              | Interview              |              | 20              | 14  |    |    |       | Retro. Sexual problems postop., lack of psychological support from health services – irrespective of UD |
| Br J Urol             | Nordström et al.           | Sweden  | 1992 | 66              | Interview – sexual function |              | 66              |     |    |    |       | Retro. 90% men had erectile dysfunction, 5/6 females had lower sexual activity  |
| Scand J Urol Nephrol  | Nordström et al.           | Sweden  | 1992 | 66              | Interview – psychological function |              | 66              |     |    |    |       | Retro. 80% overall good health, 70% unchanged social activity, leak, body image in females |
| Br J Urol             | Bjerre et al.              | Denmark | 1994 | 76              | Self-designed questionnaire |              | 50              | 26  |    |    |       | Retro. Global satisfaction high and similar in both groups                      |
| Br J Urol             | Bjerre et al.              | Denmark | 1995 | 67              | Interview + questionnaire |              | 29              | 38  |    |    |       | Retro. High global satisfaction with both UD, Urinary leak more frequent in NB, but IC patients affected more |
| J Urol                | Gerharz et al.             | Germany | 1997 | 192             | Self-designed questionnaire |              | 131             | 61  |    |    |       | Retro. Less stoma problems in CD, overall scores similar                         |
| Int J Urol            | Okada et al.               | Japan   | 1997 | 137             | Self-designed questionnaire |              | 63              | 74  |    |    |       | Retro. Less stoma problems in CD, but more night catheterisations, more satisfied patients in CD, counselling/consent |
| Eur Urol              | Filipas et al.             | Germany | 1997 | 81              | Interview + questionnaire |              | 27              | 54  |    |    |       | Retro. No difference in global satisfaction and health, UD type must consider psychological and employment status |
| Scand J Urol Nephrol  | Bjerre et al.              | Denmark | 1997 | 37              | Self-designed questionnaire |              | 20              | 17  |    |    |       | Retro. No difference in two groups                                             |
| Br J Urol             | Månsson et al.             | Sweden  | 1997 | 50              | SIP                    | MCT           | 17              | 17  | 16 |    |       | Pros. Defensive strategies and philosophical outlook generally did not influence the psychosocial outcome of intervention |
| Scand J Urol Nephrol  | Bjerre et al.              | Denmark | 1998 | 76              | Self-designed questionnaire |              | 27              | 49  |    |    |       | Retro. No difference in two groups                                             |
| Urology               | Weijerman et al.           | The Netherlands | 1998 | 56              | SIP                    |              | 23              | 33  |    |    |       | Retro. Overall QoL favourable in both groups                                     |
| Br J Urol             | Sullivan et al.            | Canada  | 1998 | 86              | Urinary symptoms, activity level, overall well being |              | 42              | 44  |    |    |       | Retro. Good overall QoL, significant effect on sex life, 70% patients had no limit on activities |
| Br J Urol             | Månsson et al.             | Sweden  | 1998 | 57              | Interview + questionnaire | MCT + VAS    | 17              | 22  | 18 |    |       | Pros. Patients with wet stoma did not do less well than continent procedures, and the adjustment improved with time |
| J Urol                | Hart et al.                | USA     | 1999 | 224             | 4 self-reporting questionnaire |              | 24              | 93  | 103|    |       | Retro. Good overall QoL in all groups                                          |

(Continued)
| Study Type | Conclusion on QoL |
|------------|------------------|
| **Retro.** | Little difference in all groups, patients accepted and adapted to present general quality status |
| **Pros.** | High global satisfaction with both UDs, 75% would choose same UD again |
| **Retro.** | IC patients have decreased mental QoL but continent UDs do not, compared to population norms |
| **Retro.** | No difference in two groups |
| **Retro.** | QoL better with NB in all domains |
| **Pros.** | Psychological and HRQoL measures come to baseline values and stabilise after the 12th-month period |
| **Retro.** | No difference overall between groups (NB – more incontinence, but better appreciation of appearance and erectile function) |
| **Retro.** | Patients satisfied with overall QoL and health status in both groups |
| **Retro.** | NB marginally better when adjusted for age, stage and sex |
| **Retro.** | Compromised sexual function main source of distress in RC patients, addressing self-assessed distress may improve patient care |
| **Retro.** | QoL same in both groups. Higher emotional function compared to NB population but more urinary + sexual problems |
| **Retro.** | ONB substitution has acceptable impact on patient’s everyday life. |
| **Retro.** | No difference in HRQoL between patients and controls |
| **Retro.** | No difference in IC vs continent UD; no major difference between non-RC and RC patients |
| **Retro.** | QoL – no difference; body image and urinary function affected. 10/13 IC, 7/9 CD, 6/7 NB would choose same operation again |
| **Retro.** | HRQoL in the NB group and those in the CD group were similar |
| **Retro.** | More urinary leak in NB |
| **Retro.** | No difference in HRQoL, more patients disappointed with NB – preop. counselling |
| **Pros.** | Swedish men had better FACT-BL and HADS scores, patient assessed outcome differ with different populations |
| **Retro.** | No significant difference in scores between IC and NB. Compared to control population – physical, social and emotional functioning worse in both IC and NB groups |
| **Pros.** | Pre- and post-RC QoL, postop. QoL scores similar at 3 months and exceeded baseline at 6 months |
| Study type | Conclusion on QoL |
|------------|------------------|
| Patients with all UDs rated their QoL as high with no significant difference between them. More patients in NB group experienced practical problems compared to IC. Influence on everyday life was significantly better in favour of IC compared to NB. | |
| NB patients were younger and more fit. HRQoL was favourable in both UDs, with physical functioning significantly better in NB group. Conclude – body image issues persist although no formal body image measures used. | |
| No difference in scores between IC and NB | |
| HRQoL similar except physical health, emotional problems and bodily pain, which were worse in NB patients. No difference between men and women. | |
| Longest FU – 8 years. Initial worsening of body image in both UDs. Earlier return of body image to baseline for IC, with NB never returning to baseline. Age but not sex associated with body image with older patients having better body image | |
| Patients with UUC surprisingly presented at least equal QoL than the presumably less debilitating ONB | |
| Many arguments in favour of NB rather than IC as the UD of choice. | |
| Patients with IC had VCI scores that averaged 5 points > than those who had an ONB UD at 1-year postop | |
| HRQoL with NB is generally favourable irrespective of the type of NB | |
| Initial decline in QoL after surgery but approached preoperative baseline levels at <90 days | |
| Cutaneous ureterostomy represents a valuable alternative for elderly patients with high surgical risk | |
| NB provides significantly better QoL than IC | |
| NB was associated with significantly better body image than IC | |
| SF-36 scores were significantly greater following NB than non-NB – total health scores were higher | |
| No statistically significant association between the type of UD and QoL | |
| Global satisfaction was higher with CD and NB compared with IC. Continent UD provides better results in terms of QoL compared to IC | |
| No. | Journal                | Author                      | Country | Year | No. of Patients | Scale used – 1                                                                 | Scale used 2                                      | IC | CD | NB | CD/NB | Study type | Conclusion on QoL                                                                 |
|-----|------------------------|-----------------------------|---------|------|-----------------|-------------------------------------------------------------------------------|--------------------------------------------------|----|----|----|-------|------------|---------------------------------------------------------------------------------|
| 61  | Cent Eur J Urol        | Aboumarzouk et al.          | Poland  | 2013 | 63              | Assessment based on psychological, social, sexual and physical states (no particular scale used) | 39 | 24 |    |       | Pros.      | No difference between the groups regarding QoL; no difference between either UD in all comparative aspects e.g. length of hospital stay, complications etc., except that the NB had a longer operative time |
| 62  | Health Qual Life       | Gacci et al.                | Italy   | 2013 | 37              | EORTC QLQ-C30, FACT-BL and QLQ-BLM30 | 16 | 12 | 9  |       | Retro.     | Patients with cutaneous ureterostomy had worse HRQoL compared to those who underwent IC or NB, primarily due to physical/emotional perception of body image. |
| 63  | J Urol                 | Parekh et al.              | USA     | 2013 | 40              | FACT-BI                                                                       | 2   | 19 | 3  |       | Pros.      | Ureterosigmoidostomy may be a good choice for UD in selected patients, with similar QoL to other types of UD |
| 64  | Arch Esp Urol          | Fuentes et al.             | Spain   | 2014 | 25              | FACT-BI                                                                       | 2   | 19 | 3  |       | Retro.     | Both types resulted in satisfactory outcomes; sigmoid NB group appeared to be more favourable than ileal NB group in terms of long-term voiding function |
| 65  | Urol Oncol             | Miyake et al.              | Japan   | 2014 | 234             | SF-36                                                                         | 2   | 19 | 3  |       | Retro.     | Ileal NB reconstruction provides long-term satisfaction with maintained HRQoL |
| 66  | Ann Surg Oncol         | Rouanne et al.             | France  | 2014 | 31              | SF-12, Urinary symptom profile/Contilife questionnaire                     | 31  |    |    |      | Retro.     |                                                                                  |
| 67  | BJU Int                | Singh et al.               | India   | 2014 | 164             | EORTC QLQ-C30, FACT-VCI                                                     | 80 | 34 |    |       | Pros.      | Better QoL outcomes than IC                                 |
| 68  | Urology                | Large et al.               | USA     | 2014 | 73              | EORTC QLQ-C30, FACT-VCI                                                     | 27 | 16 |    |       | Pros.      | Scores did not statistically differ from baseline to 6-month follow-up between UD types |
| 69  | Urology                | Aboumohamed et al.         | USA     | 2014 | 182             | BCI                                                                           | 5   | 10 |    |       | Retro.     | RARC has comparable HRQoL outcomes to open RC; UD technique does not appear to affect QoL |
| 70  | BJU Int                | Poch et al.                | USA     | 2014 | 43              | BCI, EORTC-BIS                                                               | 5   | 10 |    |       | ? HRQoL outcomes after RARC show recovery of urinary and bowel domains at ≤6 months |
| 71  | Int J Urol             | Zahran et al.              | Egypt   | 2014 | 74              | EORTC QLQ-C30, FACT-BI                                                       | 74  |    |    |      | Retro.     | After ONB in women, HRQoL is lower than that of the normal population – night time incontinence being a particular issue |
| 72  | World J Urol           | Mischinger et al.          | Germany | 2014 | 56              | SF-36, QLQ-C30, QLQ-BLM30, TNQ                                               | 56  |    |    |      | Pros.      | Contradictory results – suggest that the questionnaires are not useful to evaluate HRQoL in patients with different NbS |
| 73  | BJU Int                | Messer et al.              | USA     | 2014 | 40              | FACT-VCI                                                                     | 37  | 3  |    |       | Pros.      | HRQoL returns to baseline 3 months post-RC, with no significant difference in HRQoL between open RC and RARC |
| 74  | BMC Urol               | Huang et al.               | China   | 2015 | 294             | EORTC-QOL, BIS, BCI                                                         | 39  |    |    |      | Retro.     | The mean BIS score in ileal ONB group patients was significantly better than that in IC group patients at the 1-year follow-up, but there was no significant difference at the long-term follow-up. |
| 75  | Urol Oncol             | Goldberg et al.           | Israel  | 2015 | 95              | BCI                                                                           | 49  | 3  | 46 |       | Retro.     | Increased risk of urinary incontinence and sexual dysfunction for NB reconstruction vs IC |
| 76  | Eur Urol               | Bochner et al.             | USA     | 2015 | 124             | Self-designed questionnaire, Global health, side effects, emotional         | 33 (r) 32 (o) |    |    |      | Pros.      | There were no clinical or statistical differences between the two arms in QoL, change from baseline to 3 month or from 3 to 6 months in any of the evaluated domains |
| Journal     | Author            | Country | Year | No. of Patients | Scale used 1                        | Scale used 2                                      | IC | CD | NB | CD/NB | Study type | Conclusion on QoL                                                                 |
|-------------|-------------------|---------|------|-----------------|-------------------------------------|-------------------------------------------------|-----|----|-----|-------|------------|--------------------------------------------------------------------------------|
| Eur Urol    | Satkunasivam et al. | USA     | 2016 | 107             | Modified BCI, SF-36                 | mucus- and pad-related questions included       | 28  | 79 |     |       | Retro.     | Ileal ONB had comparable bladder cancer-specific HRQOL scores to open ONB. However, pad size and daytime wetness were worse for ileal ONB, albeit over a significantly shorter follow-up. |
| BJU Int     | Longo et al.       | Italy   | 2016 | 70              | BCI – translated to Italian        | Likert scale, BCI assessed stoma and appliance function | 35  | 35 |     |       | Retro.     | Chronic ureteric stenting does not affect the QoL of patients with bladder cancer undergoing CD compared with those undergoing IC UD. |
| Oncol Lett  | Liu et al.         | China   | 2016 | 85              | Karnofsky performance scale (functional), FACT-G, BSS | 27  | 28 (traditional), 30 (tubeless) | Retro. | The HRQOL scores of the patients in the improved group were significantly higher than those of the patients in the other two groups, and the difference was statistically significant. |
| Eur Urol    | Khan et al.        | UK      | 2016 | 164             | FACT-BI                            | BCa; Bladder Cancer Subscale                    | 17  | 3 (o), 3 (r), 18 (l) | 3 (o), 2 (r), 1 (l) | Pros. | There were no statistically significant relationships in QoL according to surgical arm (o, open; r, robotic; l, laparoscopic). |
| J Urol      | Winters et al.     | USA     | 2018 | 166             | FACT-BI                            | EORTC-QLQ-C30 (translated to Arabic) BCI       | 64  |     |     |       | Retro.     | In women, HRQoL is better after ONB than IC as long as continence status is preserved. If incontinence is expected, IC may be a better option for UD. |
| Minerva Urol Nefrol | Zahran et al. | Egypt | 2017 | 145             | FACT-BI                            | EORTC-QLQ-C30 (translated to Arabic) BCI       | 44  |     |     |       | Retro.     | Urinary function but not urinary bother was significantly better in IC and IP compared to NB UD. Older men with NC had better function than older men with NB. In younger men, IP patients had significantly better urinary function than NB patients. |
| Urology     | Gellhaus et al.    | USA     | 2017 | 128             | FACT-BI                            | EORTC–QLQ-C30 – German translation ICQ-SF questionnaire | 50  |     |     |       | Retro.     | No significant differences in postoperative bowel disorders were found between both NB types. |
| Eur J Surg Oncol | Mischinger et al. | Germany | 2017 | 56              | GIQLI                              | GIQLI                                           | 23  |     |     |       | Retro.     | ONB is an independent predictor for better overall HRQoL at 3 months, but not 12 months after RC (global health score, physical functioning, role functioning) |
| World J Urol | Kretschmer et al.  | Germany | 2017 | 121             | EORTC–QLQ-C30 – German translation ICQ-SF questionnaire | 50  |     |     |       | Retro.     |                                                                                                  |
finer, qualitative, postoperative changes pertinent to bladder cancer and UD. Similarly, the 36-item short-form health survey (SF-36) [14], which was commonly used in this time period did not incorporate post-operative concerns specific to bladder surgery, including issues such as erectile dysfunction or urinary incontinence. Indeed, even cancer-specific scales [European Organisation for the Research and Treatment of Cancer Quality of Life 30-item core questionnaire (EORTC QLQ-30C) [15] and Functional Assessment of Cancer Therapy-General (FACT-G) [16)] failed to address specific domains of importance to patients with bladder cancer.

The importance of developing instruments that measure specific outcomes for patients with bladder cancer is slowly being addressed as demonstrated by the fact that 23 studies from 2009 onwards used a bladder-specific QoL tool. Tools such as the FACT-Bladder Cancer (FACT-BL), Bladder Cancer Index (BCI) [17], Body Image Scale (BIS), FACT-Vanderbilt Cystectomy Index (FACT-VCI) [18], suggest a greater appreciation for having a responsive tool that can identify specific concerns in post-RC patients and hopefully act as a framework to compare outcomes and validate more specific tools.

Despite several retrospective studies reporting no clear superiority for NB surgery [17,20–23], recent data suggest that NB is increasingly being offered to patients. Although the type of UD should be individualised, the surgeon or centre should be able to offer both types of UDs for surgical equipoise, based on patient preference.

Table 1 suggests a progressive increase in the number of prospective studies being performed in the last decade, along with a rise in the reported numbers of NB UDs. We can perhaps postulate that the shift towards NBs has predominantly been driven by improved surgical training in a more complex procedure and better patient counselling, offering a choice of UD rather than the QoL outcomes [24].

### Role of laparoscopic and robot-assisted surgery in post-RC QoL

The advent of minimally invasive surgery, such as robot-assisted RC (RARC) and laparoscopic surgery, has led to decreased length of stay and morbidity, and faster recovery. Multicentre data from the USA has suggested a significant rise in its use from 0.6% in 2004 to 12.8% in 2010 [2,3,25]. Poch et al. [26] assessed QoL before and after RARC and reported no significant QoL advantage for RARC. However, the authors found quicker return of urinary function and better body image postoperatively with intracorporeal vs extracorporeal UDs. Studies have failed to show a QoL benefit of RARC compared to open RC [2,27]. A recent meta-analysis also suggests post-operative HRQoL to be similar in patients undergoing RARC and open RC [28]. With the advent of enhanced recovery after surgery (ERAS) protocols, there is now a reduction in postoperative morbidity and hospital stay, with a recent study reporting higher emotional well-being in patients who underwent ERAS [29].

### Strengths and limitations of the review

Despite the current trend of QoL studies moving in the right direction with the increased use of validated and specific HRQoL measures; the fact remains that there are still significant challenges in measuring QoL in UD patients. Sexual dysfunction although common is perhaps poorly captured. Conversely, although disease-specific questionnaires are more responsive than generic questionnaires to subtle changes within disease-specific domains, the high disease-specific sensitivity of these questionnaires may limit the ability to account for unexpected events. For example, an unanticipated neurological adverse event may not be addressed in the disease-specific instrument’s questions and as a result this may not be reflected in an accurate QoL change. Of the newer QoL tools, the Bladder Utility

### Table 3. Geographical density and impact of studies over the last four decades.

| Year       | Number and country | Number and continent | Number and Journal |
|------------|--------------------|----------------------|--------------------|
| 1980–1997  | 5 – Sweden         | 14 – Europe          | 5 – Br J Urol (BJU Int) |
|            | 4 – Denmark        | 1 – USA              | 3 – J Urol          |
|            | 2 – UK, Germany    | 6 – USA              | 1 – Eur Urol, Int J Urol |
|            | 1 – USA, Japan, Norway |                   |                   |
| 1998–2007  | 7 – Japan          | 11 – Europe          | 5 – BJU Int         |
|            | 5 – USA            | 7 – Asia             | 3 – Urology, J Urol |
|            | 4 – Sweden         | 6 – USA              | 2 – Int J Urol, Eur Urol, Cancer |
|            | 1 – Germany, Denmark, Netherlands, Canada, Austria, Turkey, Greece, Belgium | | |
| 2008–2017  | 14 – USA           | 18 – Europe          | 7 – Urology         |
|            | 5 – Italy          | 15 – USA             | 6 – BJU Int         |
|            | 4 – Germany        | 8 – Asia             | 3 – Eur Urol, Eur J Surg Oncol |
|            | 3 – UK, Japan, China | 2 – Africa          | 2 – World J Urol, Urol Oncol |
|            | 2 – Egypt          |                      |                   |
|            | 1 – Norway, Greece, Bosnia, South Korea, Canada, Iran, Poland, Spain, France, India, Israel | | |
Symptom Scale (BUSS) seems to be a novel patient-reported outcome instrument and measures HRQoL for all patients with bladder cancer regardless of treatment received or stage of the disease [30].

Various studies have been published investigating QoL after RC and UD. However, there is an extensive deal of heterogeneity amongst these studies with regards to methodology, the use of non-validated QoL instruments, and the underpowered and retrospective nature of the majority of data make interpretation difficult. Based on the present studies, QoL has not shown to be significantly variable across the different types of UD. As the majority of them are retrospective in nature, there also remains the risk of inherent selection bias. Furthermore, QoL is only measured postoperatively in most of these studies, and in the absence of preoperative QoL data, it is not truly possible to determine the effect of UD. With different approaches to UD and in the absence of any randomised trials, results from the ongoing prospective, multicentre, randomised trial of open vs robotic radical cystectomy (RAZOR) trial may provide an answer in the near future [31].

Conclusion

The last four decades has seen gradual but significant improvements in the way QoL assessment is conducted in RC patients, with the implementation of several validated, bladder cancer-specific questionnaires and UD-specific constructs. The emergence of more prospective studies with validated QoL instruments has improved our ability to identify their QoL and to understand the differences between various UD types.

Disclosure statement

No potential conflict of interest was reported by the authors.

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