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Original Article

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Health-related quality of life after a diagnosis of bladder cancer: a longitudinal survey over the first year

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Objectives

To describe the health-related quality of life (HRQoL) of patients in a prospective 12-month observational cohort study of new bladder cancer diagnoses and compare with national cancer and general population surveys.

Patients and Methods

A prospective UK study in patients with new bladder cancer diagnoses at 13 NHS Trusts. The HRQoL data were collected at 3, 6, 9 and 12 months. Questionnaires used included: the EuroQoL five Dimensions (EQ-5D), European Organisation for Research and Treatment of Cancer quality of life questionnaire (EORTC QLQ)-30-item core, EORTC QLQ-24-item non-muscle-invasive bladder cancer, and EORTC QLQ-30-item muscle-invasive bladder cancer. Results were compared with the Cancer Quality of Life Survey and Health Survey for England.

Results

A total of 349 patients were recruited, 296 (85%) completed the first (baseline) and 233 (67%) the final survey. The patients underwent transurethral resection of bladder tumour (TURBT) ± intravesical therapy (238 patients, 80%), radical cystectomy/radiotherapy (51, 17%) or palliation (seven, 2%). At baseline, patients needing radical treatment reported worse HRQoL including lower social function (74.2 vs 83.8, $P = 0.002$), increased fatigue (31.5 vs 26.1, $P = 0.03$) and more future worries (39.2 vs 29.4, $P = 0.005$) than patients who underwent TURBT. Post-treatment surveys showed no change/ improvements for patients who underwent TURBT but deterioration for the radically treated cohort. At final survey, reports were similar to baseline, regardless of treatment. Radically treated patients continued to report poorer HRQoL including issues with body image (23.4 vs 12.5, $P = 0.007$) and male sexual function (75.8 vs 40.4, $P < 0.001$) compared to those who underwent TURBT. Radically treated patients reported lower EQ-5D utility scores and more problems with usual activities than the general population.

Discussion

Patients undergoing TURBT can be reassured regarding HRQoL following treatment. However, those requiring radical treatment report greater changes in HRQoL with the need for appropriate clinical and supportive care to minimise the impact of treatments.

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Keywords

bladder cancer, health-related quality of life, radical treatment, transurethral resection, survey

Introduction

Bladder cancer is a common malignancy and one of the most expensive to manage [1]. Over 128 000 individuals were diagnosed with bladder cancer in England between 2013 and 2019 [2]. The disease is best divided by stage into non-muscle-invasive (NMIBC) and muscle-invasive (MIBC) bladder cancers. These have markedly different prognoses and require different treatments [3,4]. In the UK, ~25% of patients present with MIBC, which requires radical treatment for cure [5]. NMIBC is more common and includes both indolent low-grade cancer [6] and high-grade tumours with a propensity to progress to invasion [7].

Treatments for bladder cancer include local therapies to the bladder, intravesical chemo/immunotherapy, radical pelvic surgery, or radiotherapy (RT), and systemic chemo/immunotherapy. Bladder-sparing approaches include surveillance cystoscopies over several years. We have previously detailed the impact of the disease and its treatment upon health-related quality of life (HRQoL) using a single assessment up to 10 years after diagnosis [8]. We observed most respondents had one or more problem with HRQoL, with sexual problems being common [9], exercise levels being low [10,11] and overall HRQoL after bladder cancer being worse than for other pelvic cancers. These observations mirrored findings from other groups [12–15] and question whether more supportive measures, targeted to issues that matter, could help affected individuals.

Collecting HRQoL over time, using validated patient-reported outcome measures (PROMs) tools, plays an important role in understanding treatment outcomes and improving care (by addressing the needs of patients). A recent systematic review highlighted the benefits of this approach, such as fewer hospital visits during prolonged treatments, meaningful improvements in satisfaction with care and HRQoL, and better patient-physician discussions, although there was wide variation in trial designs [16]. Little is known about the trajectory of changes in HRQoL following a diagnosis of bladder cancer, how symptoms evolve during treatment and compare to other cancers. To determine these, we report a prospective 12-month observational cohort study of HRQoL in patients with a new bladder cancer diagnosis and compare with national data on patients with pelvic cancers and the general population.

Patients and Methods

Study Design and Setting

The Life after Bladder Cancer (LABC) longitudinal patient-reported outcome study has been described fully elsewhere [8,10,12]. In brief, surveys were collected at baseline (~3 months), and at 6, 9, and 12 months after diagnosis. Eligible patients were aged ≥18 years, no more than 3 months post-diagnosis and treated in NHS hospitals serving the Yorkshire and Humber, North Derbyshire, or South Tees regions. This area covers ~5.9 million persons (11% of English population) with 22 hospitals providing urological services. The study received the following approvals: Yorkshire and Humber, South Yorkshire Research Ethics Committee (17/YH/0095), Health Research Authority Confidentiality Advisory Group (17/CAG/0054); Office for Data Release (ODR1718_137 and ODR1920_114). Recruitment began 01/03/2019 and ended 19/03/2020. Participants were consented at the recruiting NHS hospital and provided written informed consent. PROMs collection (by post and on-line) was co-ordinated by an NHS England approved independent survey provider (Quality Health Ltd., Chesterfield, UK now part of IQVIA).

Clinical information (date of diagnosis/treatment received) was collected by each site's research nurses. The 5-year age band, sex, and area-based socioeconomic deprivation status (Index of Multiple Deprivation [IMD]) were obtained from the National Disease Registration Service (NDRS) [17]. The income domain quintile of the IMD 2019 (1 = least deprived to 5 = most deprived) was obtained for each participant.

Questionnaire Content

Surveys captured self-reported information on ethnicity, other long-term health conditions (LTCs), relationship status, employment status, and tobacco use (Appendix S1–S4). Physical activity was assessed using the Godin Leisure-Time Exercise Questionnaire (GLTEQ) [10,18], with scores classified as 'active', 'moderately active', or 'inactive/sedentary'.

The HRQoL was measured using the following validated instruments (Appendix S1):

1. The EuroQoL five Dimensions (EQ-5D) [19] at all timepoints collected the five-level health profile in domains of mobility, self-care, usual activities, pain/discomfort and anxiety/depression, and the visual analogue scale (VAS)

subjective judgement of overall health (0–100, with 100 representing best possible health).

2. The European Organisation for Research and Treatment of Cancer quality of life questionnaire (EORTC QLQ)-30-item core (C30) [20] collected information at 3, 6 and 12 months on overall Global Health, Physical, Role, Emotional, Cognitive and Social function, and seven symptoms of Fatigue, Pain, Nausea/Vomiting, Dyspnoea, Insomnia, Lack of Appetite, Constipation, Diarrhoea and Financial Issues.
3. Treatment-specific information was collected at 3, 6 and 12 months using the merged EORTC QLQ-24-item non-muscle-invasive bladder cancer (NMIBC24) [14] and EORTC QLQ-30-item muscle-invasive bladder cancer (BLM30) [21] modules on items relevant to both patients with NMIBC and MIBC.

Survey Categorisation

To facilitate mapping results onto the care pathway, surveys were categorised as 'Baseline', 'Post-treatment', and 'Recovery'. 'Baseline' was the first completed survey in the transurethral resection of bladder tumour (TURBT) pathway and the first survey for patients that was returned prior to receiving radical cystectomy (RC) or starting/just beginning radical RT (regardless of neoadjuvant chemotherapy). 'Post-treatment' was the 6-month return for TURBT patients (regardless of adjuvant intravesical treatment) and the nearest completion after the finish date of radical treatment (regardless of which time this survey was returned). 'Recovery' was the 12-month return for TURBT patients (regardless of adjuvant intravesical treatment) and for patients who had completed radical treatment at least 6 months previously.

Comparisons with Other Populations

The 'Recovery' HRQoL data were compared with (i) cancer survey data: outcomes from patients in the North East and Yorkshire NHS region who had completed the Cancer Quality of Life Survey 18 months after diagnosis for common pelvic cancers (3007 patients with colorectal cancer and 333 with bladder cancer, as of April 2023) [22] and (ii) general population data: EQ-5D VAS and Utility score (originally sourced from the Health Survey for England [HSE] 2018 and age-adjusted for the Cancer Quality of Life Survey) and EQ-5D restricted to adults aged ≥55 years (to align with our bladder cancer cohort) from the HSE 2018 [23].

Statistical Analysis

Age was categorised as <65, 65–74, 75–84, and ≥85 years. Number of LTCs were grouped into none, one, two, three and four or more. Patients were categorised by treatment into TURBT ± BCG/mitomycin C (MMC) or radical treatment (RC or RT ± other treatments). The EQ-5D domains were categorised as 'No problems' and 'Any problems' for comparisons [24]. Mean (SD) VAS scores were calculated. The EQ-5D utility scores were derived using the Van Hout cross-walk for STATA to map the EQ-5D-5L to the available EQ-5D-3L value set for the UK [25]. The EORTC Summary score (SumSc; 0–100 with higher scores indicating better health) was calculated as the mean of 13 of 15 EORTC subscale scores (Global Health and Financial Issues excluded) with symptoms scales reversed to obtain uniform direction of all scales and only calculated if all 13 subscale scores were not missing [26].

Comparisons of Post-treatment vs Baseline and Recovery vs Baseline were carried out within each treatment group using Wilcoxon sign-rank test for continuous repeated measures, and McNemar's test for categorical repeated measures. Comparisons of TURBT Recovery vs Radical Recovery were carried out using the independent samples Wilcoxon rank-sum test for continuous data, and chi-square test for categorical data/Fisher's exact test for frequencies of <10.

The mean values of continuous data from the national Cancer Quality of Life survey were compared with radical Recovery using the one-sample Wilcoxon sign-rank test and chi-square test/Fisher's exact test for categorical data. Published percentages and weighted bases of the HSE 2018 data on HRQoL of healthy adults were used to calculate frequencies within each age category over the age of 55 years (55–64, 65–74, and ≥75 years) and combine them. Reported frequencies of under five were suppressed and adjacent percentages suppressed if ≤2%. Missing data were excluded from analysis. Statistical Analysis was performed using STATA (Version 17.0 for Windows; Stata Corp., College Station, TX, USA).

Results

Patients and Response Rates

From an estimated 1082 new bladder cancer diagnoses (based on NDRS registrations of International Classification of Diseases [ICD]-10 code C67), 698 patients at 13 participating NHS Trusts were approached by research staff. Of these, 362 (51.9%) patients consented to enter the study, of which 13 were ineligible and 349 were included (50.0% of those approached). The first survey, at 3 months, was completed by 296 (85%) patients (Table 1, Fig. 1). Most respondents were aged 65–84 years (218 patients, 74%), male (234, 79%), had one or more LTC (72%), and 57% belonged to the two most affluent social quintiles (IMD Income Domains 1 and 2). Treatments received included TURBT ± intravesical therapy (238 patients, 80%), RC or RT ± systemic therapy (51, 17%) or palliation (seven, 2%). Subsequent surveys were received from 270/296 (91%) participants at 6 months, 247/270 (91%)

Table 1 Population characteristics of participants.

Characteristic	All treatments (*N* = 296)	
	N	**%**
Sex		
Male	234	79
Female	62	21
Age at diagnosis, years		
<65	62	21
65–74	118	40
75–84	100	34
≥85	16	5
Treatment		
TURBT only	116	39
TURBT ± BCG/MMC	122	41
RC ± other	33	11
RT ± other	18	6
Palliative	7	2
Other LTCs, *n*		
None	84	28
1	92	31
2	61	21
3	44	15
≥4	15	5
IMD income quintile		
1 (least deprived)	88	30
2	81	27
3	51	17
4	39	13
5 (most deprived)	36	12
Not known	1	≤1
Current employment status		
Employed	58	20
Unemployed	9	3
Retired	215	73
Other	5	2
Not known	9	3
Marital status		
Married/civil partnership	216	73
Separated/divorced	23	8
Widowed/surviving partner	36	12
Single	15	5
Other	*	*
Not known	*	*
Smoking		
Never smoker	94	32
Ex-smoker	167	56
Current smoker	26	9
Not known	9	3
Physical activity		
Insufficiently active	179	61
Moderately active	27	9
Active	89	30
Not known	1	≤1
Carer status		
No	223	75
Yes	63	21
Not known	10	3
Ethnicity		
White	287	97
Non-White	*	*
Not known	*	*

**Suppressed due to small counts.*

at 9 months, and 233/247 (94%) at the 12-month timepoint. Respondents appeared generally representative of the whole cohort, although lower response rates were seen in patients receiving palliative treatment (58% [seven/12] vs 86% curative, *P* = 0.04; Table S1).

Baseline HRQoL

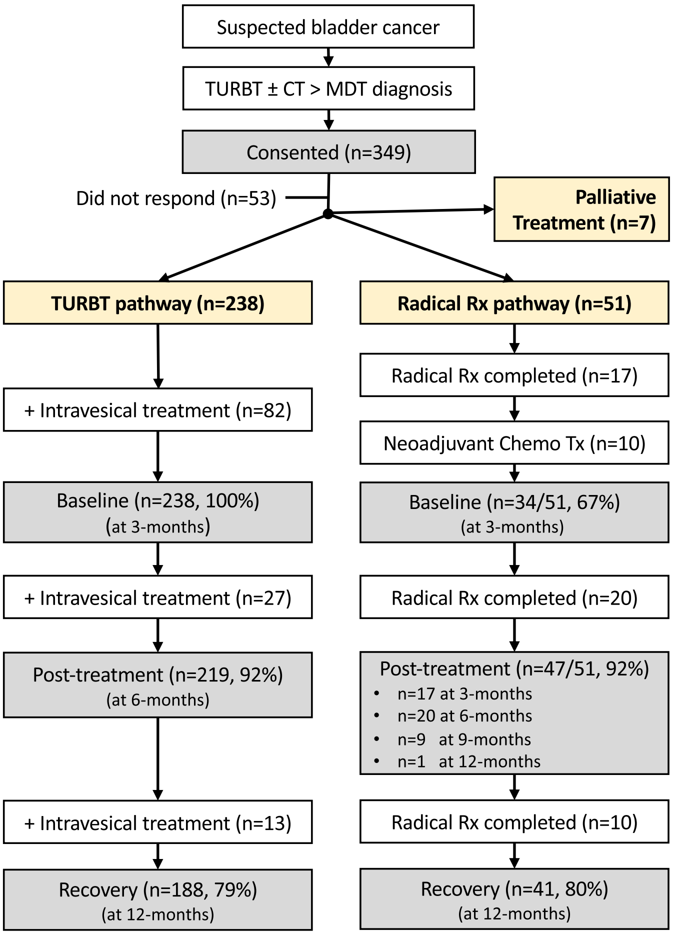
Baseline surveys were received from 238 patients undergoing TURBT and 34 undergoing radical treatment (Fig. 1, Table S2). Radically treated patients included two participants who self-reported having started RT on their baseline survey (they only received 4–5 days of treatment from the 4-week course of RT) and 10 who had started neoadjuvant chemotherapy. In all, 82/238 patients who underwent TURBT had started intravesical chemotherapy or immunotherapy before the baseline survey. The mean (SD) VAS self-assessed health was 78.0 (16.5) for those undergoing TURBT and 75.6 (12.4) for the radical treatment cohort (Table 2, Fig. S1). Patients receiving radical treatment reported more problems with anxiety/depression at Baseline (56%) than the TURBT cohort (36%, *P* = 0.03). Both cohorts reported problems with pain/discomfort (49% TURBT, 53% radical). With regards to cancer-specific HRQoL (EORTC QLQ-C30), patients receiving radical treatment reported lower social function (74.2 vs 83.8 TURBT, *P* = 0.002) and increased fatigue (31.5 vs 26.1 TURBT, *P* = 0.03; Table S2) at Baseline compared to patients who underwent TURBT. With regards to bladder cancer-specific HRQoL, the only significant difference was that patients receiving radical treatment had higher rates of worries about the future (39.2 vs 29.4 TURBT, *P* = 0.005).

Post-Treatment HRQoL

Post-treatment surveys were received from 219 (92%) patients who underwent TURBT and 47 (92%) who had radical treatment (Fig. 1). Within the TURBT cohort, there were few differences between Baseline and Post-treatment HRQoL for both general (EQ-5D) and cancer-specific outcomes (EORTC QLQ-C30; Table 2, Figs S1–S3). The exception was lower rates of anxiety/depression reported post-treatment (36% at Baseline vs 31% Post-treatment, *P* = 0.02). A further 27/219 patients had started intravesical chemo-/immunotherapy after TURBT. With regards to bladder cancer-specific HRQoL, patients who underwent TURBT reported improvements in urinary symptoms (31.4 Baseline vs 27.8 Post-treatment, *P* = 0.006), future worries (29.4 Baseline vs 25.6 Post-treatment, *P* = 0.003), and sexual enjoyment (58.1 Baseline vs 68.9 Post-treatment, *P* = 0.02) after treatment (Table 2, Fig. S4).

In contrast to improvements seen in the TURBT cohort, radically treated patients reported a decline in HRQoL in the Post-treatment phase (Table 2, Figs S1–S3). The EQ-5D utility scores fell from 0.79 at Baseline to 0.73 Post-treatment (*P* = 0.005), with a similar fall for EORTC QLQ-C30 SumSc (82.6 Baseline to 76.1 Post-treatment, *P* = 0.04). For

Fig. 1 Consolidated Standards of Reporting Trials (CONSORT) diagram showing recruitment according to patient pathways at study time points. MDT, multidisciplinary team; Rx, treatment (cystectomy/radiotherapy); Tx, therapy.



individual domains/areas of function, the EQ-5D responses revealed more problems with mobility (32% at Baseline vs 48% Post-treatment, *P* = 0.02) and usual activities (47% vs 78%, *P* = 0.004). The EORTC QLQ-C30 responses showed worsening physical function (84.1 vs 71.0, *P* = 0.002), role function (77.8 Baseline vs 56.8 Post-treatment, *P* = 0.04), and pain scores (11.3 vs 19.4, *P* = 0.02) after treatment. Responses to the bladder cancer-specific measures revealed radically treated patients had worsened sexual function (24.7 Baseline vs 15.1 Post-treatment, *P* = 0.03) and more male sexual problems (35.8 vs 66.7, *P* = 0.02) than at Baseline (Table 2, Fig. S4). Low sample size for the radical treatment cohort meant that urinary symptoms and some sexual items could not be compared before and after treatment.

Recovery HRQoL – With Respect to Baseline

Recovery surveys were received from 188 patients who underwent TURBT and 41 who underwent radical treatment (Fig. 1). Regardless of treatment, there was no difference in general HRQoL at Recovery when compared to Baseline (using the EQ-5D or EORTC global health and SumSc; Table 2, Figs S1, S2). For cancer-specific outcomes, pain scores remained high for radically treated patients on the EORTC symptom scale (11.3 Baseline vs 23.9 Recovery, *P* = 0.003; Fig. S3) but not with the EQ-5D. Dyspnoea scores were worse than at Baseline in patients who underwent TURBT (Baseline 16.2 vs Recovery 19.4, *P* = 0.002) using the EORTC QLQ-C30. The merged EORTC NMIBC24/BLM30 modules revealed further improvements in urinary symptoms (31.4 Baseline vs 25.7 Recovery, *P* = 0.002), malaise (6.9 Baseline vs 4.7 Recovery, *P* = 0.01) and future worries (29.4 Baseline vs 23.8 Recovery, *P* = 0.001) in the TURBT cohort (Table 2, Fig. S4). Future worries decreased for radically treated patients (39.2 Baseline vs 24.8 Recovery, *P* < 0.001) but male sexual problems increased (35.8 Baseline vs 75.8 Recovery, *P* = 0.008).

Recovery HRQoL – With Respect to Treatment Received

We compared outcomes at Recovery between the treatment cohorts (Table 3) and found no differences in general HRQoL using the EQ-5D. Using the EORTC QLQ-C30, we did observe radically treated patients had lower SumSc (81.4 vs 85.9 TURBT, *P* = 0.03), lower role function (74.2 vs 83.5 TURBT, *P* = 0.02), lower social function (79.2 vs 86.5 TURBT, *P* = 0.004) and higher insomnia scores at Recovery (30.8 vs 23.3 TURBT, *P* = 0.04) than patients who underwent TURBT. Merged EORTC QLQ-NMIBC24/-BLM30 modules also revealed poorer perceived body image (23.4 vs 12.5 TURBT, *P* = 0.007) and lower sexual function for males after radical treatment (75.8 vs 40.4 TURBT, *P* < 0.001) at Recovery.

Comparisons with Other Cancers and the General Population

We compared our findings with the national Cancer Quality of Life Survey for patients with bladder cancer (*n* = 333) and colorectal cancer (*n* = 3007) 18 months after diagnosis in the NHS region of the North East and Yorkshire (Table 3). With regards to the bladder cancer population, the radically treated cohort had higher EQ-5D utility and VAS scores than seen in the national Cancer Quality of Life Survey (Utility: 0.71 National vs 0.76 Recovery, *P* = 0.03, and VAS score: 71.8 National vs 76.7 Recovery, *P* = 0.01). Similarly, the national patients with bladder cancer had lower SumScs than our radically treated cohort (*P* = 0.02), lower physical function (*P* = 0.03) and lower social function (*P* = 0.003), using the EORTC QLQ-C30. With regards to patients with colorectal cancer, few differences were seen, apart from lower social function (73.4 National vs 79.2 Recovery, *P* = 0.003). We

Table 2 The HRQoL trajectory for the TURBT cohort and the radically treated cohort.

	TURBT ± BCG/MMC								
	Baseline survey (*n* = 238)			**Post-treatment survey (*n* = 219)**			***P*[§]**	**Recovery survey (*n* = 188)**	
	N	**Mean or %**	**SD**	***N***	**Mean or %**	**SD**		***N***	**Mean or %**
EQ-5D[*]									
VAS score	234	78.0	16.54	216	79.1	18.02	0.29	183	79.3
Utility score	236	0.81	0.19	216	0.81	0.21	0.79	187	0.81
EORTC[*]									
Global health	227	74.4	17.90	214	74.0	20.83	0.74	181	73.9
SumSc	211	84.7	15.42	196	84.7	15.10	0.73	172	85.9
EQ-5D domains									
Mobility									
No problems	161	68%		149	68%			120	64%
Any problems	75	32%		69	32%		0.85	67	36%
Self-care									
No problems	214	90%		191	88%			166	89%
Any problems	23	10%		26	12%		0.11	21	11%
Usual activities									
No problems	146	62%		140	64%			120	64%
Any problems	91	38%		79	36%		0.77	67	36%
Pain/discomfort									
No problems	121	51%		115	53%			99	53%
Any problems	116	49%		104	47%		0.51	88	47%
Anxiety/depression									
No problems	150	64%		151	69%			121	65%
Any problems	86	36%		68	31%		0.02	66	35%
EORTC QLQ-C30 functions[*]									
Physical	236	83.8	19.57	213	82.8	20.81	0.07	183	82.9
Role	233	83.0	26.46	208	82.5	25.97	0.30	178	83.5
Emotional	232	82.5	21.01	217	82.6	21.63	1.00	182	84.3
Cognitive	228	82.8	21.30	214	82.7	21.17	0.78	181	82.8
Social	230	83.8	24.48	216	82.7	26.01	0.07	180	86.5
Symptom scales/items[†]									
Fatigue	234	26.1	25.00	212	25.3	23.86	0.72	180	24.5
Nausea/vomiting	230	3.2	8.21	212	2.7	8.32	0.25	180	2.7
Pain	229	17.0	24.28	207	16.7	24.11	0.62	178	16.4
Dyspnoea	234	16.2	25.32	213	17.5	26.61	0.14	180	19.4
Insomnia	234	24.5	27.59	213	25.2	26.63	0.94	182	23.3
Appetite loss	234	9.5	21.38	212	7.7	18.31	0.26	181	6.8
Constipation	235	15.0	23.89	213	15.3	25.79	0.99	182	15.0
Diarrhoea	231	6.9	17.03	218	5.5	14.32	0.73	183	6.0
Financial problems	229	5.4	17.80	217	4.9	13.85	0.72	182	3.5
EORTC QLQ merged NMIBC24_BLM30[†]									
Urinary symptoms	223	31.4	23.99	213	27.8	21.94	0.006	180	25.7
Urostomy symptoms	6	20.4	14.34	6	6.5	7.38	na	<5	0.0
Catheter problems	19	3.5	10.51	14	4.8	17.82	na	9	33.3
Malaise	228	6.9	12.19	214	5.8	10.76	0.10	178	4.7
Intravesical issues	229	7.6	17.41	210	5.9	14.67	0.22	175	5.9
Future worries	231	29.4	23.71	215	25.6	23.62	0.003	178	23.8
Bloating/flatulence	231	18.3	19.80	213	19.3	20.62	0.48	177	20.7
Body image issues	231	9.9	19.18	215	10.9	18.90	0.23	179	12.5
Sexual function	217	21.5	23.81	200	22.8	25.36	0.22	171	23.2
Male sexual probs	151	37.7	34.89	135	38.6	35.83	0.57	125	40.4
Intimacy issues[‡]	68	20.1	30.00	60	12.2	24.52	0.25	55	17.6
Risk of contaminating partner[‡]	67	17.9	29.20	62	11.8	22.66	0.55	55	9.7
Sexual enjoyment[‡]	66	58.1	30.56	60	68.9	25.20	0.02	54	68.5
Female sexual problems[‡]	7	33.3	33.33	13	46.2	39.76	na	10	56.7

[*]*Higher scores for measures of VAS, Utility, Global health, SumScs, and functional scales indicate better health.* [†]*Higher scores for symptom scales/items indicate worse symptom effect on patients.* [‡]*Question applied to only those who were sexually active.* [§]*Comparison with baseline using Wilcoxon's sign-rank for continuous variables and McNemar's test for categorical variables.* [¶]*n = 47 post-treatment surveys for radical pathway (n = 46 available for EQ-5D and n = 38 for EORTC due to lack of EORTC measurement at 9 months). na, not available.*

		Radical RC/RT ± other treatments										
	P[§]	Baseline survey (n = 34)			Post-treatment survey (n = 47)[¶]			P[§]	Recovery survey (n = 41)			P[§]
SD		N	Mean or %	SD	N	Mean or %	SD		N	Mean or %	SD	
17.50	0.32	33	75.6	12.37	46	72.2	17.79	0.30	40	76.7	18.54	0.19
0.22	0.71	34	0.79	0.16	45	0.73	0.19	0.005	41	0.76	0.28	0.14
19.92	0.16	31	71.5	17.58	38	63.8	19.59	0.09	40	67.7	22.34	0.93
14.94	0.72	29	82.6	11.92	37	76.1	16.20	0.04	37	81.4	14.71	0.86
		23	68%		24	52%			25	61%		
	0.26	11	32%		22	48%		0.02	16	39%		0.25
		28	82%		32	70%			32	78%		
	0.58	6	18%		14	30%		0.25	9	22%		0.38
		18	53%		10	22%			20	49%		
	0.58	16	47%		35	78%		0.004	21	51%		0.63
		16	47%		20	43%			17	41%		
	0.54	18	53%		26	57%		0.77	24	59%		0.34
		15	44%		24	52%			25	61%		
	0.75	19	56%		22	48%		1.00	16	39%		0.69
21.88	0.07	34	84.1	16.15	38	71.0	22.78	0.002	40	78.2	22.66	0.15
25.24	0.59	33	77.8	25.23	37	56.8	36.32	0.04	40	74.2	27.72	0.22
19.62	0.50	31	80.4	18.07	38	81.4	17.27	0.46	39	81.0	22.04	0.31
21.37	0.29	31	87.6	12.89	38	86.0	17.56	0.57	40	80.8	23.43	0.09
24.08	0.26	31	74.2	21.87	38	67.1	27.26	0.21	40	79.2	24.39	0.07
24.97	0.40	34	31.5	17.97	38	36.5	19.66	0.75	40	30.6	25.26	0.28
10.59	0.58	34	4.9	12.67	38	10.5	21.37	1.00	40	5.0	14.71	0.92
25.33	0.77	31	11.3	18.95	37	19.4	23.41	0.02	39	23.9	28.04	0.003
26.34	0.002	33	18.2	25.13	37	18.9	26.69	0.19	39	21.4	22.28	1.00
29.56	0.42	34	28.4	29.74	38	35.1	28.94	0.10	39	30.8	26.91	0.53
18.16	0.33	34	8.8	17.03	38	21.1	29.43	0.28	40	12.5	22.25	0.77
25.87	0.96	34	20.6	29.60	38	28.1	31.51	1.00	40	20.0	25.93	0.63
15.44	0.74	31	6.5	15.91	38	12.3	22.49	1.00	40	6.7	18.80	0.75
12.88	0.56	31	8.6	19.18	38	4.4	13.80	1.00	40	5.8	19.81	0.19
21.79	0.002	26	29.1	18.78	17	28.5	22.08	na	15	27.0	22.02	na
0.00	na	<5	11.1	n/a	26	19.7	17.72	na	26	13.9	9.33	na
44.10	na	<5	33.3	n/a	0	na	na	na	0	na	na	na
10.48	0.01	34	5.4	7.91	36	7.4	12.24	1.00	40	6.3	12.90	0.29
14.63	0.17	33	8.1	14.51	33	14.1	18.69	0.22	39	4.3	11.29	1.00
23.15	0.001	33	39.2	18.62	36	32.4	22.85	0.24	40	24.8	19.47	<0.001
21.63	0.10	33	20.2	18.52	36	28.2	22.12	0.20	40	26.3	22.29	0.47
22.98	0.17	33	17.2	27.93	36	24.7	28.25	0.06	39	23.4	29.15	0.37
25.27	0.49	33	24.7	28.60	32	15.1	21.73	0.03	37	19.4	23.08	0.61
37.22	0.45	20	35.8	29.26	17	66.7	33.33	0.02	20	75.8	33.97	0.008
28.58	0.53	10	6.7	14.05	6	33.3	29.81	na	10	23.3	16.10	na
23.72	0.45	10	3.3	10.54	5	6.7	14.91	na	9	3.7	11.11	na
29.26	0.30	9	70.4	20.03	6	33.3	29.81	na	10	50.0	23.57	na
35.31	na	<5	50.0	23.57	<5	100.0	0.00	na	<5	41.7	50.00	na

Table 3 The HRQoL at Recovery (TURBT vs radical therapy) and comparison with other populations.

	Life after bladder cancer (LABC)							**General population**
	TURBT ± BCG/MMC at Recovery (*n* = 188)			**Radical RC/RT ± other at Recovery (*n* = 41)**				**Healthy adults (age-adjusted) (*n* = 7382; *n* = 2698)**[¶]
	N	**Mean or %**	**SD**	***N***	**Mean or %**	**SD**	***P***[§]	***N***
EQ-5D[*]								
VAS score	183	79.3	17.50	40	76.7	18.54	0.30	7213
Utility score	187	0.81	0.22	41	0.76	0.28	0.21	7244
EORTC[*]								
Global health	181	73.9	19.92	40	67.7	22.34	0.09	NK
SumSc	172	85.9	14.94	37	81.4	14.71	0.03	
EQ-5D domains								
Mobility								
No problems	120	64%		25	61%			1719
Slight/moderate problems	54	29%		14	34%		0.70	768
Severe problems	13	7%		<5	5%			211
Self-care								
No problems	166	89%		32	78%			2360
Slight/moderate problems	18	10%		8	20%		0.07	287
Severe problems	<5	≤2%		<5	≤2%			51
Usual activities								
No problems	120	64%		20	49%			1892
Slight/moderate problems	56	30%		19	46%		0.07	642
Severe problems	11	6%		<5	5%			164
Pain/discomfort								
No problems	99	53%		17	41%			1077
Slight/moderate problems	78	42%		22	54%		0.18	1383
Severe problems	10	5%		<5	5%			238
Anxiety/depression								
No problems	121	65%		25	61%			1903
Slight/moderate problems	61	32%		14	34%		0.65	717
Severe problems	5	3%		<5	5%			78
EORTC QLQ-C30 functions[*]								
Physical	183	82.9	21.88	40	78.2	22.66	0.08	NK
Role	178	83.5	25.24	40	74.2	27.72	0.02	
Emotional	182	84.3	19.62	39	81.0	22.04	0.39	
Cognitive	181	82.8	21.37	40	80.8	23.43	0.68	
Social	180	86.5	24.08	40	79.2	24.39	0.004	
EORTC symptom scales/items[†]								
Fatigue	180	24.5	24.97	40	30.6	25.26	0.12	NK
Nausea/vomiting	180	2.7	10.59	40	5.0	14.71	0.21	
Pain	178	16.4	25.33	39	23.9	28.04	0.07	
Dyspnoea	180	19.4	26.34	39	21.4	22.28	0.35	
Insomnia	182	23.3	29.56	39	30.8	26.91	0.04	

		National Cancer Quality of Life Survey (North East and Yorkshire)							
		Colorectal cancer at 18 months (n = 3007)				**Bladder cancer at 18 months (n = 333)**			
SD	***P*********	***N***	**Mean or %**	**SD**	***P*********	***N***	**Mean or %**	**SD**	***P*********
na	0.37	2693	74.4	20.22	0.06	296	71.8	20.49	0.01
na	<0.001	2870	0.73	0.24	0.13	315	0.71	0.25	0.03
		2978	69.8	22.15	0.77	332	67.7	22.14	0.77
		2861	78.6	17.93	0.08	318	76.6	17.68	0.02
		1603	54%			149	46%		
	0.72	1097	37%		0.40	147	45%		0.07
		245	8%			29	9%		
		2315	79%			239	74%		
	0.09	554	19%		0.85	73	23%		0.70
		72	2%			10	3%		
		1380	47%			124	38%		
	0.003	1279	43%		0.81	166	51%		0.18
		286	10%			36	11%		
		1176	40%			130	40%		
	0.84	1582	53%		0.82	168	52%		0.89
		202	7%			24	7%		
		1536	52%			174	54%		
	0.18	1293	44%		0.25	137	42%		0.39
		123	4%			12	4%		
		2971	75.5	24.28	0.17	330	72.1	23.74	0.03
		2992	71.7	30.68	0.26	329	67.3	30.36	0.26
		2993	76.7	23.54	0.05	330	78.6	22.59	0.05
		2996	80.3	22.34	0.11	331	78.0	23.89	0.11
		2982	73.4	30.10	0.003	330	68.8	30.55	0.003
		NK				NK			

Table 3 (Continued).

	Life after bladder cancer (LABC)							General population
	TURBT ± BCG/MMC at Recovery (n = 188)			Radical RC/RT ± other at Recovery (n = 41)				Healthy adults (age-adjusted) (n = 7382; n = 2698)[¶]
	N	Mean or %	SD	N	Mean or %	SD	P[§]	N
Appetite loss	181	6.8	18.16	40	12.5	22.25	0.05	
Constipation	182	15.0	25.87	40	20.0	25.93	0.13	
Diarrhoea	183	6.0	15.44	40	6.7	18.80	0.97	
Financial problems	182	3.5	12.88	40	5.8	19.81	0.68	
EORTC merged NMIBC24_BLM30[†]								
Urinary symptoms	180	25.7	21.79	15	27.0	22.02	0.72	NK
Urostomy symptoms	na	0.0	0.00	26	13.9	9.33	na	
Catheter problems	9	33.3	44.10	0	na	na	na	
Malaise	178	4.7	10.48	40	6.3	12.90	0.60	
Intravesical issues	175	5.9	14.63	39	4.3	11.29	0.65	
Future worries	178	23.8	23.15	40	24.8	19.47	0.42	
Bloating and flatulence	177	20.7	21.63	40	26.3	22.29	0.09	
Body image issues	179	12.5	22.98	39	23.4	29.15	0.007	
Sexual function	171	23.2	25.27	37	19.4	23.08	0.41	
Male sexual problems	125	40.4	37.22	20	75.8	33.97	<0.001	
Intimacy issues[‡]	55	17.6	28.58	10	23.3	16.10	0.13	
Risk of contaminating partner[‡]	55	9.7	23.72	9	3.7	11.11	0.77	
Sexual enjoyment[‡]	54	68.5	29.26	10	50.0	23.57	0.04	
Female sexual problems[‡]	10	56.7	35.31	<5	41.7	50.00	na	

**Higher scores for measures of VAS, Utility, Global health, SumSc, and functional scales indicate better health. [†]Higher scores for symptom scales/items indicate worse symptom effect on patients. [‡]Question applied to only those who were sexually active. [¶]n = 7382 EQ-5D VAS and Utility score (age-adjusted) from national Cancer Quality of Life Survey (release date 13 April 2023), n = 2698 EQ-5D five domains (aged ≥55 years) from the HSE 2018. **Wilcoxon one-sample sign-rank test used to compare continuous data with mean only data. Chi-square and Fisher's exact tests used for categorical data; Slight/moderate and Severe problems combined for comparison due to small numbers. All comparisons made with the LABC radically treated cohort. [§]Wilcoxon rank-sum test used for continuous non-parametric independent samples. Chi-square and Fisher's exact tests used for categorical data; Slight/moderate and Severe problems combined for comparison due to small numbers. na, not available; NK, not known.*

compared our findings with general population data from the HSE 2018 (Table 3). In our radically treated cohort, the EQ-5D utility scores were significantly lower than seen in the general population (0.90 Healthy adults vs 0.76 Recovery, $P < 0.001$) and they were more likely to report problems with usual activities (30% Healthy adults vs 51% Recovery, $P = 0.003$).

Discussion

In this comprehensive study mapping of HRQoL in the first year after a diagnosis of bladder cancer, significant differences were identified for those requiring radical therapy vs those requiring TURBT ± intravesical therapy. At baseline, patients needing radical treatment reported more anxiety/depression and fatigue, worse social function, and more future worries. In contrast to improvements seen in the TURBT cohort, radically treated patients reported declines in HRQoL in the Post-treatment phase with increasing problems with mobility and carrying out usual activities, worse physical, role and sexual function and higher pain scores. At Recovery (12 months after TURBT and 6–12 months after radical treatment), there was no difference in general HRQoL when compared to Baseline, regardless of treatment, but radically treated patients continued

			National Cancer Quality of Life Survey (North East and Yorkshire)							
			Colorectal cancer at 18 months (*n* = 3007)				**Bladder cancer at 18 months (*n* = 333)**			
Mean or %	**SD**	***P*****	***N***	**Mean or %**	**SD**	***P*****	***N***	**Mean or %**	**SD**	***P*****
			NK				NK			

to report more issues with role function, social function, insomnia, body image, and male sexual function compared to the TURBT cohort. Radically treated patients reported lower EQ-5D utility scores and more problems with carrying out usual activities than the general population.

Findings of increased anxiety/depression and fatigue, with worse social function and worries about the future (at Baseline) in the cohort requiring radical treatment is understandable given the severity of their diagnosis and their prognosis, compared to those facing less aggressive therapy. Similarly, findings of improved urinary symptoms, fewer future worries, and lower anxiety/depression for those following TURBT ± intravesical therapy, along with unchanged sexual function and enjoyment, is understandable. However, it is concerning that radically treated patients report physical and role function that has not fully recovered 1 year on from diagnosis, experiencing significantly worse HRQoL in some domains than the general population. Our radically treated cohort reported better HRQoL (overall health, physical and social function) than patients from a wider geographic area in the North of England included in the national Cancer Quality of Life Survey. This maybe artefactual due to small numbers, or potentially reflect differences in the populations or care received. A potential study weakness is that 57% of respondents belonged to the two most affluent income quintiles. This bias might explain why our outcomes appear better than for the national Cancer Quality of Life Survey cohort.

Radically treated patients reported worsening of pain at Post-treatment (8.1 points on average) compared to Baseline. Pain had not resolved by Recovery and had increased further (4.5 points average). This may suggest that the Recovery time window defined by the study did not capture the apex of pain for radically treated patients. It is worth noting that this group is heterogeneous consisting of RC and RT patients thereby leading to complex but differing spectra of late morbidity burden. As with pain, an increase in male sexual problems was found Post-treatment in this cohort (30.9 points average) with a further increase at Recovery (9.1 points increase average).

Strengths and Weaknesses

Study strengths include the depth and breadth of enquiry utilising generic and specific validated measures wherever possible. Good response rates and continued participation (with limited drop-off with each survey round) suggest that, despite the length, our collection was found to be acceptable to respondents. Additionally, we have been able to compare results with other malignancies and use comparative national population data. There were several study limitations. First, relatively few respondents received radical treatment. To maximise the sample size, we used a method whereby patients who were not included in Baseline scores (having already finished radical treatment at the 3-month survey) were included as Post-treatment. Hence, some Post-treatment scores do not match a corresponding Baseline score and so may artificially inflate/deflate outcomes. Second, we identified participants after a diagnosis of bladder cancer was made (i.e., after TURBT). Our Baseline scores do not reflect true diagnostic baselines (i.e., prior to any treatment with the cancer in situ). The nature of the clinical pathway made it very difficult to recruit patients at an earlier timepoint. Additionally, we were limited by inability to describe a true Baseline for radically treated patients due to small numbers; 17 had already completed radical treatment and were excluded from the Baseline and 10 had already started neoadjuvant chemotherapy. Differences in social function observed at Baseline could be due to this limitation rather than patient/disease factors. Finally, our Recovery outcomes (collected at 12 months) were compared with 18 month data from the national Cancer Quality of Life Survey for patients with bladder cancer and colorectal cancer. These timings differ and so may explain some findings, such as reduced social function reported by patients with colorectal cancer; however, the national Cancer Quality of Life Survey represents the largest available comparative English pelvic cancer cohort and offers valuable insights.

Conclusion

This study provides intelligence to reassure patients undergoing TURBT ± intravesical therapy regarding their HRQoL following treatment. However, for those requiring radical treatment, a different picture has emerged that mandates clinical services to further develop the provision of symptom and supportive care to enhance their HRQoL. Future work should address these issues with targeted information and supportive programmes and compare our findings with those from the Netherlands [27].

Author Contributions

James W.F. Catto, Adam Glaser and Amy Downing conceived the study and along with Sarah Bottomley and Kate Absolom designed the study. Zoe Rogers and Amy Downing analysed the data. All authors helped in interpretation and analysis and were involved in drafting and editing of the manuscript. The corresponding author had full access to the data and takes final responsibility for the decision to submit for publication.

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Disclosure of Interests

James W.F. Catto has received reimbursement for consultancy from Astra Zeneca, Ferring, Ipsen, Roche, and Janssen; speaker fees from BMS, MSD, Janssen, Astellas, Nucleix, and Roche; honoraria for membership of advisory boards for Ferring, Roche, Gilead, Photocure, BMS, QED therapeutics and Janssen; and research funding from Roche. The remaining authors declare no potential conflicts of interest.

Ethics Approvals

The study received the following approvals: Yorkshire and Humber, South Yorkshire Research Ethics Committee (17/YH/0095), Health Research Authority Confidentiality Advisory Group (17/CAG/0054); Office for Data Release (ODR1718_137 and ODR1920_114). Recruitment began 01/03/2019 and ended 19/03/2020.

Consent to Participate

Participants were consented at the recruiting NHS hospital and provided written informed consent.

Data Availability Statement

All relevant data are included in the article and its supplementary information files.

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Abbreviations: EORTC QLQ(-C30)(-NMIBC24) (-BLM30), European Organisation for Research and Treatment of Cancer quality of life questionnaire (-30-item core) (-24-item non-muscle-invasive bladder cancer) (-30-item muscle-invasive bladder cancer); EQ-5D, EuroQoL five Dimensions; HRQoL, health-related quality of life; HSE, Health Survey for England; IMD, Index of Multiple Deprivation; LTC, long-term health condition; MIBC, muscle-invasive bladder cancer; MMC, mitomycin C; NDRS, National Disease Registration Service; NMIBC, non-muscle-invasive bladder cancer; PROM, patient-reported outcome measure; RC, radical cystectomy; RT, radiotherapy; SumSc, Summary scores; TURBT, transurethral resection of bladder tumour; VAS, visual analogue scale.

Supporting Information

Additional Supporting Information may be found in the online version of this article:

Table S1. Completers vs non-completers at 3-month (baseline) survey.

Table S2. Baseline HRQoL comparison of treatment groups.

Fig. S1. Overall HRQoL using the EQ-5D questionnaire.

Fig. S2. The EORTC QLQ-C30 global health and functional scales (mean) in participants with bladder cancer on the TURBT and radical treatment pathways.

Fig. S3. The EORTC QLQ-C30 symptom scores (mean) in participants with bladder cancer on the TURBT and radical treatment pathways.

Fig. S4. Merged EORTC QLQ-NMIBC24 and EORTC QLQ-BLM30 score in participants with bladder cancer on the TURBT and radical treatment pathways.

Appendix S1. Life and Bladder Cancer Survey T1.

Appendix S2. Life and Bladder Cancer Survey T2.

Appendix S3. Life and Bladder Cancer Survey T3.

Appendix S4. Life and Bladder Cancer Survey T4.