

1 **Title Page**

2 **Title: The patients' experience of a bladder cancer diagnosis: a systematic review of the qualitative evidence**

3 **Amanda J. Edmondson¹, PhD, Jacqueline C. Birtwistle², MSc, James W. F. Catto^{3*}, MBChB PhD, and**
4 **Maureen Twiddy^{2*}, PhD,**

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6 **Affiliations:**

- 7 1. **Centre for Applied Research in Health, University of Huddersfield**
- 8 2. Institute of Health Sciences, University of Leeds
- 9 3. Academic Urology Unit, University of Sheffield

10 * MT and JWFC share senior authorship

11

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13 The authors declare that they have no conflict of interest with this work.

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¹ **Corresponding author:** Amanda Edmondson, School of Human and Health Sciences, University of Huddersfield, Queensgate, Huddersfield HD1 3DH a.edmondson@hud.ac.uk 01484 473857

23 **Abstract**

24

25 **Purpose:** Bladder cancer (BC) is a common disease with disparate treatment options and variable outcomes.
26 Despite the disease's high prevalence, little is known of the lived experience of affected patients. National patient
27 experience surveys suggest that those with BC have poorer experiences than those with other common cancers.
28 The aim of this review is to identify first-hand accounts of the lived experiences of diagnosis through to
29 survivorship.

30

31 **Method:** A systematic review of the qualitative evidence reporting first-hand accounts of the experiences of being
32 diagnosed with, treated for and surviving bladder cancer. A thematic analysis and 'best fit' framework synthesis
33 was undertaken to classify the experiences.

34

35 **Results:** The inconsistent nature of symptoms contributes to delays in diagnosis. Post diagnosis, many patients
36 are not actively engaged in the treatment decision making process, and rely on their doctor's expertise. This can
37 result in patients not adequately exploring the consequences of these decisions. Learning how to cope with a 'post-
38 surgery body', changing sexuality and incontinence is distressing. Much less is known about the quality of life of
39 patients receiving conservative treatments such as Bacillus Calmette-Guerin (BCG).

40

41 **Conclusions:** The review contributes to a greater understanding of the lived experience of bladder cancer.
42 Findings reflect a paucity of relevant literature, and a need to develop more sensitive Patient Reported Outcome
43 Measures (PROMs) and incorporate patient reported outcomes in BC care pathways.

44

45 **Implications for Cancer Survivors:** Collective knowledge of the patients' self-reported experience of the cancer
46 care pathway will facilitate understanding of the outcomes following treatment.

47

48 **Introduction**

49 Bladder cancer (BC) is the seventh most common cancer in the world [1] and is one of the most expensive to
50 manage [2]. The disease is more common in males than females, reflecting the main etiological risk factors, i.e.
51 cigarette smoking and occupational carcinogen exposure [3]. Despite advances in the epidemiology and treatment,
52 relatively little is known about the experience of patients' diagnosed with BC [4, 5]. Patient surveys have shown
53 the experience of those with BC is one of the poorest when compared to other cancers. Potential explanations for
54 this include absence of care planning, emotional support and poor post discharge care [6]. These factors may be
55 compounded by the male predominance of BC and the tendency of men to internalise their illness behaviour [7].

56

57 Whilst most cancers affect the well-being and quality of life (QoL) of diagnosed individuals and their caregivers,
58 the QoL for BC patients is not well known due to a lack of disease and treatment specific validated measure(s),
59 and a lack of large scale analyses [8-13]. Where data are available, reports are often restricted to small samples,
60 post-treatment [14, 15] and so limit understanding of the BC patients experience following diagnosis and pre-
61 treatment experience of care (reviewed in [4]). Developing new measures which identify care needs across the
62 patient pathway will help improve clinical practice and assist patients in the early stages of their diagnosis and
63 treatment decision making [16]. Given that recent reviews have focussed upon quantitative data (e.g. [4]), we
64 undertook a systematic review of the current status of qualitative data in patients with BC.

65

66 In 2010, the National Cancer Survivor Initiative (NCSI) published a 'Vision' document [5] that reported a number
67 of key shifts required in the approach to care for people living with and beyond cancer. One key vision was moving
68 the focus from measuring clinical activity to measuring experience, concerns and outcomes for cancer survivors
69 through routine use of patient reported outcome measures (PROMs). The value of qualitative research in the
70 development of PRO measures has been recognised for some time. For example, Duncan et al. [17] recently
71 conducted a synthesis of the qualitative evidence to examine the quality of life domains from the patient
72 perspective to facilitate PROM development in five specific health conditions. This article also presents a
73 systematic search of the qualitative literature and a 'best fit' framework synthesis [18] to classify and enhance
74 understanding of the experiences of BC from the patients' perspective. Findings may also assist future PROM
75 development.

76

77 **Method**

78 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed,
79 including reference to the 27 item checklist (where applicable) and four phase item flow diagram [19] – see figure
80 1.

81

82 *Literature Search*

83 Medline, Psycinfo, Embase, Cinahl, Cochrane Library, Global Health, Scopus, Pro Quest (Health & Medicine)
84 and Google Scholar were searched for articles published between January 2000 and January 2016. A combination
85 of key words to describe the patient, patient experience, BC, treatment, and research method were used. For
86 example to describe the patient (patient, cancer patient, surgical patient, hospitalised patient); their experience
87 (acceptance, attitude, beliefs, opinion, satisfaction, quality of life, quality of care, understanding, feelings); the
88 cancer (BC, urinary bladder neoplasms, bladder, carcinoma); the treatment (intravesical immunotherapy, BCG
89 vaccine, cystectomy, surgery) and research method (interview, case studies, observations, focus group, thematic
90 analysis), see online resource 1 for example search strategy. In addition, reference lists and citations of included
91 studies were scanned, specific urology journals were hand searched (Current Opinion in Urology, European
92 Urology, Urology Practice, Journal of Urology, Urology, Scandinavian Journal of Urology and Nephrology and
93 Scandinavian Journal of Urology and Asian Journal of Urology). Lead authors (identified from the searches /
94 included studies) and conference abstracts (APOS, BPOS) were searched. English language restriction was
95 applied to the search.

96

97 *Study Selection*

98 All primary studies detailing self-reported accounts of the experience of being diagnosed and treated for BC
99 (primary cancer) were included in the review, meaning that results are based upon the narratives of individuals
100 with BC. Studies that reported survey data only or hypothetical data were excluded. Two authors (AE and JB)
101 reviewed the titles and abstracts to apply the inclusion criteria and potentially eligible full text articles were
102 evaluated by AE, JB and MT for eligibility and quality. Each article was assessed for quality using the Critical
103 Appraisal Skills Programme (CASP) assessment tool for qualitative research [20]. All studies were included in

104 the review regardless of their quality rating, but the rating was used as an indication of the strength of the evidence
105 and to inform standards required for future research into the qualitative experiences of people diagnosed with BC.
106 Disagreements were resolved by discussion.

107

108 *Data synthesis*

109 Data regarding population, age range, participant numbers, diagnosis, treatment, data collection approach, and
110 derived themes were extracted using a standardised form. A thematic analysis of all the identified lived
111 experiences of BC, using a 'best fit framework synthesis' [18] was undertaken starting with very similar themes
112 to those described by Beitz and Zuzelo [21], which were experience of diagnosis; acute care & treatment; post
113 treatment, and the new normal. These informed the framework as they encompassed the patients' pathway from
114 diagnosis to survivorship and adapting (or not) to life and thereby fit with the aims of this review. Initial allocation
115 of experiences to the framework was undertaken by AE aided by discussion with JB and MT in uncertain cases.

116

117 **Results**

118 *Manuscript selection*

119 In total, 2,198 manuscripts were identified, from which 14 eligible studies were selected (figure 1 and online
120 resource 2). Most studies were North American (n=9) or British (n=3), with 1 from Italy and Sweden. Accounts
121 of 270 participants, of which 188 (70%) were male and 76 (30%) were female (gender missing in one study, n=6),
122 with an age range from 33-86 years are reported. Diagnoses included non-muscle invasive, muscle invasive and
123 metastatic BC. Treatments included radical cystectomy with various urinary diversions, systemic chemotherapy,
124 radical radiation, transurethral resection and intravesical Bacillus Calmette-Guerin (BCG). At least half of the
125 studies focus on the experiences of radical surgery patients, other papers did not report treatments provided and
126 only two papers focussed exclusively on BCG patients. Articles were scored for quality; with a mean quality score
127 of 7 (range 5-9/9 points). Lower scores reflected an absence of ethical standard statements and risk or presence of
128 bias during the process.

129

130

131 Figure 1: flow chart of included and excluded studies *about here*

132

133 *Patients' experience of diagnosis*

134 This theme captures patients' reported experience of being diagnosed with BC; including presenting symptoms,
135 diagnostic process, pre-treatment consultations and the treatment decision-making process.

136

137 *Diagnosing BC:*

138 Typical symptoms of BC were visible haematuria and altered urination patterns (urgency, frequency and dysuria)
139 [21, 22]. Patients described haematuria as deceptive due to its painless and inconsistent nature [21]. The lack of
140 pain and understanding about BC led to a delay in seeking help [23, 21, 24]. When help was sought, some felt
141 frustrated that their symptoms were trivialised and misdiagnosed. For example, women presenting with blood in
142 their urine were often met with "*are you sure it's not just your menstrual cycle?*" [21], reflecting the typical delay
143 in referral for female patients with BC [25].

144

145 A typical response to diagnosis was shock, upset [21, 23], and devastation [26], followed by a fear of treatment
146 [26] and an intense desire for a speedy intervention [21]. Some described feeling 'scared to death' and thought of
147 their diagnosis as a death sentence [21, 26, 23] "*you're sitting there thinking I'm going to die*"[23]. Hilton and
148 Henderson [24] described this experience as 'unknowing' – everything a patient knows about their health is
149 suddenly called into question and they may now worry their overall health will deteriorate [26].

150

151 *Treatment Decision making:*

152 Making treatment decisions was perceived as very challenging. Patients described difficulty understanding
153 medical explanations, treatment options and potential side effects [27] and felt uncomfortable making such
154 decisions [21]. Cancer information became important and patients reported receiving insufficient information
155 about self-care after treatment (surgery), finances and insurance; and subsequently many sought information via
156 the internet and /or support groups [27]. Worries about survival, pain, reduced sexual function and change in body
157 image (after surgery) were often not addressed. In one recent study, only 6 out of 30 patients reported discussing

158 likely changes in sexual function following surgery during the treatment consultation [27]. Some patients also
159 reported receiving conflicting treatment recommendations and felt there was a bias toward particular treatments
160 depending on the health care professional they spoke to [21].

161

162 Berry and colleagues [28] explored how patients perceived and engaged in treatment decision making. They found
163 patients expended significant effort in identifying the best healthcare provider *“one of the things I’ve always kept*
164 *as a reference point is where are the centers of excellence for various treatments?”* [28], even if this meant
165 travelling a significant distance for treatment. In contrast, when considering treatment choice, almost half of
166 patients’ were passive in the decision making process and accepted the clinicians’ treatment recommendation
167 without question, but this was not constructed as problematic by patients *“it’s like, no you [clinician] tell me*
168 *what to do”* [28] and was most common in patients with early stage disease. Other patients sought information
169 from the internet, family, friends, and others with knowledge / personal experience to inform discussions with
170 their clinician. A small number reported having complete control over the decision *“at the end I [patient] was the*
171 *only one who would make the decision”* [28]. Treatment choice was largely influenced by survival statistics but
172 other factors , such as treatment preferences [29], age and level of recreational and work activity played an
173 important role [28] : *“I based it on the fact I’m 59 so it’s not like I’m 20 and I have to live with this bag for a*
174 *hundred years”*; *“I’ve never had a period in my life where I wasn’t exercising so an ostomy bag was really not*
175 *an option for me”* [28].

176

177 Unsurprisingly, open communication was a critical and reoccurring theme throughout the patient pathway, but
178 particularly so in diagnosis and treatment consultations [28, 23, 30]. Early impressions of interpersonal aspects
179 of patient care are important to the patient; in particular whether they feel that they are being treated as someone
180 who matters and is worthy of care, and being recognised and responded to as a unique individual with a particular
181 social context [30] - *“I say yes it’s like being on first name terms with some of them...oh they get to know you and*
182 *you get to know them”* [30]. Patients believed it was important to have ‘a conversation’ with the clinician, where
183 the options are discussed to ensure the clinician understands the impact of treatment options on the patient’s life.
184 The speed and momentum of diagnosis and treatment can result in patients feeling ill prepared, in particular for
185 the side effects of treatment [28]. They wanted treatment plans to be clear, provided in a timely fashion, and
186 consistent from professional to professional [23].

187

188 *Patients experience of acute care & treatment*

189 This theme captures patients' experiences of preparing for treatment and their acute care.

190

191 *Preparing for surgery*

192 The psychological preparation for surgery can start weeks before admission [24, 31]. One patient described it as
193 worse than the diagnosis; for her, the thought of the impending surgical procedure (vaginal reconstruction) was
194 devastating, terrifying and she felt uncertain whether she would ever be the same again [24]. Hilton and Henderson
195 [24] described this experience of an impending bodily change as 'metamorphosis'. Physical pre-surgical
196 procedures were also captured in detail. For example, patients recalled the onerous procedures of bowel
197 preparation prior to surgery [21], and neobladder reconstruction patients recalled being measured and 'tattooed'
198 for stoma placement prior to their surgery, even though they were not expecting a stoma. This was described as
199 unsettling and for some the fear of the change to self following surgery felt worse than the diagnosis [21, 24].

200

201 *Waking up after surgery*

202 Waking after surgery is described as a feeling of 'alienation from the body' [32]. This encapsulates the shock and
203 disgust some patients experience in response to their stoma, and numerous abdominal drains [21]. Simple acts of
204 kindness are important "what a nice woman that was [nurse] when I woke up after my first operation when I
205 opened my eyes she was sitting at my bed holding my hand now what do you think of that...that's a good one"
206 [30].

207

208 *Post-operative care*

209 Hands-on training on patient' stoma appliances and catheters begins in the acute recovery phase. This was a
210 positive experience, but many felt it should have continued after discharge [27]. Although aftercare was generally
211 good, for some, post-operative pain was not well managed, with pain management regimes leaving patients feeling
212 "knocked out" or "mentally in the left field" [21], and disorientated to time and place [21].

213

214 *Patient's experience of non-radical surgical treatment*

215 Two studies captured non-radical surgical treatment experiences. Patients commonly reported short lived related
216 symptoms [22, 26]. Patients receiving BCG treatment reported abdominal pain, painful, urgent and more frequent
217 urination [22]. Some also reported passing blood clots, blood in the urine, flu like symptoms, fatigue and soreness
218 at the catheter site [22]. Clark [22] interviewed patients who had undergone TURBT and those patients described
219 painful and urgent urination, knife like stinging and passing blood clots – *“it was just the initial shock when you*
220 *put that thing in, and the first time you go to the potty and urinate that hurt. That hurt like hell”*. However,
221 symptoms were generally temporary.

222

223 *Patients experience post treatment*

224 This theme mostly captures the period shortly after treatment, during which patients experience immense change
225 and details the ways in which people learn to adapt to new, often distressing experiences.

226 Post-surgery recuperation was long and something patients felt they needed support with [21]. It was described
227 by one patient as *“the point I became a cancer survivor”* [24]. Hilton and Henderson [24] referred to this
228 experience as ‘an unfolding path’ – recuperation was a time of immense change; encompassing new experiences,
229 new learning and adaptation both physically and psychologically [21, 23, 24]. Weight loss following surgery was
230 common, and patients felt exhausted and weak on their return home. Although they felt unhappy about lost vitality
231 there was a sense of acceptance that they needed to pace their activities and some employed coping strategies,
232 such as starting walking routines to regain strength [21].

233

234 Support of family and friends was especially valuable at this time, though paradoxically this was a time when
235 some experienced disappointment and difficulty with close relationships; a few patients reported feeling
236 disappointed by the lack of support and felt as though they were being treated differently [23].

237

238 Patients' experience of homecare was variable and it was a lottery in terms of how much aftercare they might
239 receive [23]. Knowledge and expertise to deliver homecare to patients following a radical cystectomy varied –
240 *“the homecare, nobody, not one person knew or had any experience with this. They had experience with bowels*
241 *but not bladder”* [23].

242

243 New experiences were often unexpected and distressing. For example, patients reported not being told how they
244 could deal with incontinence. Many reported initiating their own strategies such as wearing pads at night, changing
245 underwear style, only wearing black trousers so leakage wouldn't show, and establishing bladder schedules; for
246 example, setting alarms to go off through the night to ensure regular voiding[23, 21], in the absence of education
247 from healthcare services [23]. Some neobladder patients had to learn to self-catheterise this felt easier than
248 learning to void their neobladder. Mechanics of voiding the neobladder very different to their original bladder and
249 more redolent of defecation in that they needed to "force it out" and "strain" [21]. Self-catheterising for some
250 however felt disgusting and was avoided [21].

251

252 *The New Normal*

253 Having experienced a period of immense change, this theme captures the next phase, referred to as the 'new
254 normal' [21]. Here patients describe their quality of life post treatment i.e. their experience of adapting (or not) to
255 new toileting characteristics; new ways of being sexual; and living with the lifelong threat of cancer.

256

257 Quality of life (QoL) following treatment for BC was mixed for both surgical and non-surgical patients. Patients'
258 reported both negative and positive aspects, but it was also something fluid and it fluctuated over time [15, 29].
259 For example, Cerruto and colleagues [15] explored the quality of life of a cross section of patients (one-year post
260 surgery up to 30 years) who had an ileal conduit following a radical cystectomy . They presented patient profiles
261 at one, three, five, seven, and plus seven years post-surgery. One year post surgery, QoL was reported to be good
262 / unchanged for some, but for others it was worse, with poor sleep and being dependent on others to manage their
263 ostomy notable areas of concern. By three years, most reported having poor QoL; main areas of difficulty were
264 continued dependence on partners to manage their ostomy, concern about leakage and smell of urine, and
265 subsequent decline of social activities. Worsening of QoL over time was reported for surgical and non-surgical
266 populations and attributed to a decreasing optimism about recovery [15, 29] and for surgical patients, the
267 overwhelming feeling of not being the same [15]. Loss of friendships and the detrimental impact on social life
268 was also reported by Persson and Hellstrom [32] but they noted that these occurred quite soon after surgery when
269 patients were faced with who, and how to tell, and how people would react.

270

271 By five years post treatment, quality of life had improved and patients reported feeling in a better state of health
272 compared to pre-surgery. Cerruto and colleagues [15] attributed this improvement to adaptation. Patients reported
273 feeling less dependent on partners, problems such as urinary leakage remained but these were managed; *“I don’t*
274 *have anxiety about my condition, there are some precautions that should be observed, I must be careful that there*
275 *are no leaks but it happens rarely in my case and I can live almost normally”* [15]. By seven years post- surgery
276 social relations had recovered and activities of daily living felt less restricted. This finding was also supported by
277 Foley et al [33] who explored the cancer experience of long term survivors and found over time survivors had
278 acquired a greater appreciation for life.

279 However, some concerns persisted over time; for surgical patients this included lack of sexual activity and physical
280 complications such as hernias, urinary tract infections and peristomal skin lesions etc. which affect ostomy
281 management and risk leakage [15]. Long-term effects of cancer were described by survivors as ‘a constant’ in
282 their lives and as a reminder of their cancer [34, 21].

283

284 *Accepting incontinence*

285 Incontinence following surgery was generally permanent and learning not to be embarrassed about leakage was
286 key to successful management [21]. New routines to respond to new toileting characteristics were commonplace
287 [21, 27]. Some patients described difficulties and subsequent adaptations related to returning to work. For
288 example, finding a clean place to self-catheterise away from home was described as difficult, particularly for men.
289 Male public toilets were often perceived as dirty, and sitting on the toilet seat was unfamiliar and frustrating. For
290 some men this resulted in a reluctance to travel, or where necessary holding large volumes of urine to avoid using
291 public toilets. For some, a change in toilet characteristics also extended to their bowels; some experienced chronic
292 diarrhoea and unpredictable flatulence [21, 32]. Patients described locating toilets ahead of time as a protective
293 strategy and planning their toilet use became a major priority [21, 27]: *“If you go to some function probably the*
294 *first thing you seek out is the toilet”*; *“Life is normal. It’s almost as if it didn’t happen except for the inconvenience*
295 *of having to sit and plan where I go based on having to go to the bathroom”* [21].

296

297 Despite understanding the importance of hydration, many surgical participants reported not drinking enough. For
298 some this was because of the need to subsequently empty their bladder which meant staying closer to a toilet,
299 which increased isolation as patients remained at home; for others it was about managing continence, with some
300 patients avoiding beer as this often resulted in night time leakage [21].

301 Ongoing fears included leakage of gas and odour, and visibility of the stoma [32]. Patients often selected different
302 clothes to minimise visibility and damage to the stoma (e.g. wearing loose dresses, supporting the stoma with
303 suspenders [32]). Concerns about visibility also resulted in changes to social activities, for example avoidance of
304 swimming pools [32].

305

306 *Changing sexuality*

307 Changes in sexuality were reported by men and women [27] who had undergone non-surgical [35, 26] and radical
308 surgical treatment [35, 21, 23]. Non-radically treated patients usually reported a short period of abstinence due to
309 fear of contamination of their partner with the treating agents [35, 26], but for some abstinence seemed more
310 permanent “*we don't have sex because of that stuff they were putting in me. I still get an erection and masturbate*
311 *and I don't tell her about that but I do and when I come it doesn't come out like it used to because of that irritation*
312 *in there*“ [35]. For radical surgical patients, despite having prior knowledge about the impact on sexual function,
313 i.e. impotence for men, vaginal shortening / dryness for women, the reality was still a shock. Men in particular
314 had been certain that it would not be the case for them and described impotence as a loss of their manhood which
315 led to other ways of achieving an erection [35, 27], but this was often met with disappointment [21]; “*no more*
316 *sex life, I feel destroyed physically, emotionally. Once I was a master of myself, now I depend on my wife. The*
317 *surgery carried away all that I had*“ [15]. For others, sexual relationships were re-established but in a different
318 way; “*BC has changed our sex life a bit, we still have sex but it's different now, well obviously it's different for*
319 *me. Since I can't have normal intercourse it's a lot of foreplay but I enjoy that too. It's not as good as it was*
320 *before but it's still pretty good, I bought a vibrator so she can still have orgasms – it changed the dynamic of sex,*
321 *you know it's more to make sure she has an orgasm*“ [35].

322

323 Post-surgery, women reported physical and psychological concerns about sex [35, 23, 27], with the loss of
324 physical intimacy commonly reported “*sometimes it's almost a platonic relationship*“ [35]. The appearance of

325 the stoma and the bag were of concern for some as they perceived it to be off-putting sexually [35, 23, 27, 32],
326 with some fearing leakage from the stoma during sex [23]; *“not in a million years would I let anybody close to*
327 *me with this stoma and bag and all that, I’m disgusting. How it looks, I mean I have a bag of pee hanging in front*
328 *of me, I find it revolting I’m sure anyone else would”* [23].

329

330 The degree of acceptance about loss of sexual function was reported to be influenced by age, stage of life, and
331 how much importance a couple placed on sex [23]. In contrast, re-establishing a sexual relationship after BC was
332 influenced by good communication between partners [35]. Interestingly, despite how common sexual problems
333 seem to be amongst BC survivors, very few sought professional assistance [27], with Mohamed and colleagues
334 positing that this was perhaps due to the fact that many were grateful to be alive [27].

335

336 *Living with the lifelong threat of cancer*

337 A *‘deal with it’* and *‘just take it as it comes’* attitude were commonplace [21, 33, 29, 34]. Survivors reported being
338 very aware that many people die from BC and so a stoical and optimistic attitude to new experiences soon
339 developed [21, 23, 33]. Similarly, living each day and having a new found sense of appreciation for their life was
340 also apparent and may be partly attributed to the perception of cancer as a lifelong threat [21, 27, 34]. Follow up
341 schedules proved to be a constant reminder of how fragile life can be [21, 34] and many survivors reported that
342 support from family and friends had been vital throughout their journey with cancer [34, 29].

343 See online resource 3 for a preliminary conceptual framework of the patients’ experience of being diagnosed with
344 bladder cancer through to survivorship.

345

346 **Discussion**

347 This is the first systematic review of qualitative evidence focusing upon first-hand accounts of the lived experience
348 of BC. The review identified the significant impact of this disease upon the patient and their next of kin, and that
349 currently there is little attention paid to this by BC care practitioners. Most of the data reported events at the
350 beginning (at diagnosis) and end (life after treatment) of the patients’ pathway and there was an over-
351 representation of patients undergoing radical surgery, when the majority of patients receive non-radical
352 (conservative) treatments. As the concerns of those undergoing conservative treatments cannot be assumed to be

353 the same as those of the RC population the review highlights the need for more qualitative research to inform
354 understanding of the experiences of this population.

355

356 Sexual concerns were especially common with an unmet need for information and support [35, 21, 23, 27, 32,
357 26], which support the findings of a recent PROM pilot report [36]. The fact that very few patients reported
358 receiving help for sexual distress is a concern [27] and suggests perhaps the shift toward exploring the patients'
359 holistic experience, in particular their sexual experience, as set out by the National Cancer Survivorship vision
360 has not yet been reached [5]. The findings of the review suggest that health professionals need to be more
361 proactive in eliciting areas of distress and, given the gender specific concerns highlighted in this review tailored
362 interventions would be more appropriate [27].

363

364 Body image was an important concern for those undergoing surgery. Patients' reported experiencing significant
365 alteration to their body [32] and women in particular reported feeling unsexual [35, 23, 27, 32]. Visibility of the
366 stoma was problematic and resulted in patients' altering clothing and social activities [32]. Concerns about body
367 image were also reported in the PROM pilot report and the findings of this review evidence that conclusion [36].
368 Only one (excluded) study found body image not to be important[37], but this may be due to those authors asking
369 patients to consider a future event (impact of surgery) on body image; it is not clear whether patients were
370 specifically asked about appearance post-surgery, and given the duration of the interviews (16 minutes on average)
371 it seems unlikely that any discussion would have been in-depth. Encouraging patients to reflect on their
372 experiences in some depth enables a more valid disclosure of concerns [32], which might account for the disparate
373 findings.

374

375 Less frequently described but nonetheless explored were patients' experience of acute care and discharge and this
376 review highlights how some of the most basic acts of kindness, such as holding a patients hand on waking from
377 surgery can make such a difference to their experience.

378

379 This review identifies a relatively neglected area of cancer and the poor level of evidence in this field. It offers an
380 understanding of the patient experience pre-diagnosis through to survivorship, complementing a recent BC PROM
381 pilot [36] and ongoing work in BC QoL development to develop ways to comprehensively assess sexual [8] and

382 body image issues in particular [38]. It also serves as a useful starting point for developing teaching / training
383 materials. Knowledge of the patient experience from diagnosis through to survivorship and highlighting the
384 challenges in reporting concerns is valuable to new and existing health professionals tasked with shifting the focus
385 from clinical activity to patient experience. Finally, it's a response to patients' hopes for professionals to better
386 understand their experience and in particular the impact of bodily and sexual changes [23].

387

388 ***Limitations***

389 The review only included articles in English language and most of the included studies were carried out in North
390 America (within a specific healthcare system). As such it may limited understanding of a more global picture of
391 patients' experience with BC. The review applied a date limitation from 2000 to present. Although this will have
392 restricted our search and subsequently missed articles of relevance, it was an attempt to capture patients'
393 contemporary experiences of clinical services and treatments. In synthesising the data from all the studies,
394 irrespective of their cancer stage and treatment, subtleties in relation to quality of life, need etc. associated with
395 certain treatments or extent of illness will have been missed. Nevertheless, several themes identified in the review
396 are expected to be common throughout the illness trajectory and helpful in addressing future care irrespective of
397 stage / treatment.

398

399 ***Recommendations***

400 The findings of this review are relevant and important to the field but reflect a paucity of relevant literature. Prior
401 to the development of any new measure a clear conceptual framework is needed [39-41] and this review suggests
402 that there are gaps in our understanding that need to be filled before high quality, sensitive measure of quality of
403 life can be developed for this population. This article offers the beginnings of a conceptual framework (see online
404 resource 3); however to develop a robust framework more research is needed. Future research should aim to
405 improve reporting of qualitative findings relating to BC, should include larger numbers of patients (and caregivers)
406 receiving non-radical treatments, and should include longitudinal studies to capture change over time. With this
407 in mind, authors are now undertaking longitudinal surveys into the quality of life in patients being treated for and
408 after a diagnosis of BC, e.g. the OTIS study
409 [<http://www.abdn.ac.uk/hsru/research/assessment/interventional/otis/>].

410

411 ***Implications for practice***

412 The review highlights that a better understanding of the patients experience throughout each stage of their pathway
413 could be gleaned. It is clear patients' experience varies and some require more or less support than others at
414 different points along the patient pathway. Support and informational needs may be gender specific and may differ
415 in intensity for example for those who may not have support from family and / or friends.

416

417 **Conclusion**

418 The findings contribute, through a qualitative synthesis, to a greater understanding of the lived experience of BC.
419 The review has pooled the evidence making it more accessible to individual centres where numbers of patients
420 with BC may be small, thus restricting knowledge of the full effects of cancer for this group of patients. This
421 might also explain why the patient experience for this group of patients has received less attention, compared to
422 other cancer types (e.g. breast). It is noteworthy that these experiences are identified from self-reports, which
423 suggests that discussion of them might be incorporated into the clinical pathway when appropriate. The findings
424 identify the impact of BC upon the lived experience and suggest a need to embed PROMs within care pathways
425 and to encourage care providers to understand their importance.

426

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429

430

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