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Toward an Understanding of Patients’ and Their Partners’ Experiences of Bladder Cancer

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Abstract

Background:
Bladder cancer is often characterised by recurrence and progression, on-going surveillance and treatment, side effects and complications, and is associated with chronic ill health that may compromise relationships, social activities, and employment.

Objective:
The aim of this study was to gain an understanding of the quality of life disruptions among both those diagnosed with bladder cancer, and their supportive partners (spouses, other family members of friends).

Interventions/Methods:
Couples were identified from a tertiary care public hospital database. Nine heterosexual couples (married/defacto) and another couple comprising a clinical participant and her daughter-in-law were interviewed for approximately 60 minutes. Interviews were then audio recorded and transcribed with Qualitative Description used to gain an in-depth understanding of participants’ experiences without previous agenda or knowledge, allowing their viewpoints to be summarised in everyday terms.

Results:
Thematic analysis highlighted four themes: Physical Responses, Cognitive and Emotional Reactions, Survival Techniques and the importance of partner support and its assistance for clinical participants’ acceptance of, and adaptation to their bladder cancer surveillance and treatment protocols.
Conclusion:

A key finding was the value of a supportive partner in dealing with the effects of bladder cancer daily. From a health service perspective, the need for clear information provision and counselling/support to assist patient management was also evident.

Implications for Future Practice:

Health professionals need to appreciate the quality of life implications for patients and partners, thus understanding the needs of couples. Greater collaboration with and by health professionals who assist in care may allow couples to move more confidently towards adaptation to bladder cancer.

Keywords

Australia, Bladder Cancer, Cystectomy, Cystoscopy, Incontinence, Intravesical Therapy, Partner Support, Quality of Life, Sexual Dysfunction, Thematic Analysis, Transurethral Resection of Bladder Tumour (TURBT)
Introduction and Background

Bladder cancer (BlCa) manifests when epithelial cells lining the bladder become malignant. Approximately 90% of BlCa diagnoses in developed countries are transitional cell carcinomas which may also involve cells of the renal pelvis and ureter.\(^1\) Approximately 70% of diagnoses are non-muscle invasive (NMIBlCa), with recurrence rates of 50-70%, and progression to muscle invasive BlCa (MIBlCa) occurring in 10-30% of cases.\(^2\) A primary diagnosis of MIBlCa is often associated with a poor outcome despite aggressive treatment.\(^3,4\) In Australia the male:female prevalence ratio is 3:1, with the five-year survival rate lower among women.\(^1\) Women are also more likely to have MIBlCa.\(^5,6\) Other common risk factors include racial background, advanced age (50-70 years), and occupational exposure to carcinogens including aromatic amines and benzene derivatives.\(^2\) However, the most common risk factor is smoking.\(^1\)

Diagnosis involves history, physical examination, urinary markers, and flexible cystoscopy.\(^7\) Painless, gross or microscopic haematuria is commonly the first sign of BlCa.\(^1\) Transurethral resection of bladder tumour (TURBT) provides histopathology for a definitive diagnosis, staging, grading, and treatment.\(^8\) Adjuvant intravesical chemotherapy or immunotherapy using Bacillus Calmette-Guérin (BCG) are often recommended post-TURBT to reduce microscopic tumours circulating.\(^2\) For recurring and aggressive NMIBlCa, and MIBlCa, a radical cystectomy (RC) is considered.\(^9\) However, this potentially lifesaving surgery has both physical and psychological complications including urinary, bowel and sexual dysfunction, body image, dependence, and social and relationship issues which affect quality of life (QoL).\(^10,11\)

QoL acknowledges both the medical and non-medical ramifications of a chronic disease. Although there remains little agreement about a precise definition of QoL, common dimensions include physical, psychological, social, functional, and spiritual wellbeing.\(^9,12-15\) Studies of other cancers have outlined that client/physician communication at the time of diagnosis can lead to
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misinterpretation due to stress and the amount of information imparted, leaving the perception of an unfavourable interaction with the healthcare system.\textsuperscript{16-18} Furthermore, as many as 50\% of patients have been noted to complain about the use of jargon at diagnosis,\textsuperscript{19} an observation also made when a new treatment plan is introduced,\textsuperscript{20} and at the time of pre-surgical education.\textsuperscript{21}

In the BlCa context, poorer QoL has been associated with reduced role function, diminished body image and self-esteem, anxiety and depression, perceived burden, financial problems, loneliness, embarrassment, and stigma.\textsuperscript{22-25} Despite this understanding, further qualitative research into the experiences of BlCa patients has been encouraged.\textsuperscript{26} The current research acknowledges this need, but also extends previous research in two ways. First, both patients with MIBICa and NMIBICa were included as there is currently a particular paucity of data regarding the experiences of those with NMIBICa. Second, the perspectives of supportive partners (spouses, other family members or friends) have rarely been acknowledged, and they too are included in this in-depth inquiry into the nature of QoL disruptions occasioned by BlCa.

Methods

Sample and Setting

Clinical participants were recruited by searching medical files from the database of a 300-bed tertiary acute care public hospital. Participants who met the inclusion criteria were identified as being older than 18 years, with a diagnosis of BlCa, being able to give consent in English, having no evidence of cognitive impairment, being able to discuss their BlCa experiences, and having a partner also willing to participate. Qualitative Description (QD) recommends a purposive, maximum variation recruitment strategy enabling all relevant components of the phenomenon (gender, age, type of treatment, and time since diagnosis) to be represented.\textsuperscript{27,28} In this instance, recruitment ceased after 10 clinical participants and their 10 partners had agreed to participate. Potential participants were sent relevant information for themselves and their partner. A verbal
explanation was also given at interview before providing consent. Each participant was assigned a pseudonym and reference number to maintain confidentiality and anonymity.\(^{29,30}\)

**Data Collection and Analysis**

Nine married or defacto couples, and one couple comprising clinical participant and her daughter-in-law were recruited. Median ages at interview were 67 years (range 41-86) for clinical participants (61 years, range 53-75) for partners. Clinical participants had had BlCa for a median of 9 years (range 3-24). Table 1 summarises further characteristics of both clinical participants and their partners.

Data collection was guided by a set of in-depth, semi-structured, open-ended questions (Table 2) informed by a review of the literature.\(^{31}\) Interviews were conducted predominantly in participants’ homes or a private room in the hospital, lasting approximately one hour, and were audio-recorded for later transcription. Verbatim transcription aims to preserve participants’ experiences by using their own words without interpretation.\(^{28}\)

**Trustworthiness**

This study incorporated trustworthiness using the criteria of credibility, auditability, fittingness, and confirmability.\(^{29}\) These criteria promoted transparent believability, demonstrated by using detailed documentation, vivid description, visible decision-making and an audit trail.\(^{32,33}\) Participant’s transcripts were checked by the senior author and participants, with the latter assisting with the verification of accuracy through member’s checking.\(^{34}\) Approval for this study was granted by the authors’ institutional ethics committee.

Thematic analysis is appropriate when little information exists, or for a comprehensive description.\(^{34}\) A six-step model assisted in interpreting participants’ meaning.\(^{35}\) After re-reading transcripts and sorting data, four key themes were identified from among the twenty interviews:
Physical Responses to treatment and side effects, Cognitive Reactions and Emotional Reactions to living and coping with BlCa, and the Survival Techniques used to deal with BlCa (Table 3).

**Findings**

After a thematic analysis, the key themes to emerge were Physical Responses, Cognitive Reactions, Emotional Reactions, and Survival Techniques.

**Physical Responses**

Treatment and surveillance of BICa varied for participants but nearly all experienced side effects, such as discomfort and incontinence.

Treatment and Adverse Side Effects

The discomfort of cystoscopy, TURBT, intravesical chemotherapy, or BCG, radiotherapy and RC, and their subsequent side effects (e.g., urinary and sexual dysfunction) impacted on both clinical participants and partners. After 14 years of 3-monthly cystoscopies, Eddie said:

“… the bleeding, the pain, the anaesthetics … it does get you down and … you get a bit sick of it … (L73-74) … just get over one lot and you’ve got to go in and start all over again … after a few years it does wear you down …” (L41-42).

For clinical participants who underwent RC, their lives were inevitably altered physically. Barry was horrified by the thought of losing his bladder “… the prospect of a … bag … was awful but the alternatives … an internal bladder construction were worse” (L145-147). Post RC Barry realised how much his life had altered: “…the way I run it [life] now, that is … the biggest difference and it has been somewhat difficult to cope with” (L871-874).

Continence Matters

Incontinence concerned most clinical participants with a bladder intact, whereas leakage was an issue for those who underwent a RC. The latter needed to have access to spare clothing, stoma products, and catheterisation equipment at all times. Josie wore black pants to hide leakages and always carried spare clothing and appliances. Charles learnt to self-catheterise his neobladder, but
Barry was resistant to change, refusing to carry any clothing or equipment to alleviate stress and embarrassment. When he first experienced leakage Barry was “… horrified that … this is the future … I thought I don’t … want to live like that” (L744-746).

Five clinical participants with a bladder intact suffered urinary frequency and urgency causing them to urinate every 10-60 minutes around the clock with little notice. They often had to run to relieve themselves and were always aware of toilet locations. Frank’s incontinence through the night meant that he woke with blood and urine in the bed which his partner Flo had to clean up. She was happy to assist but struggled to cope with the washing demands. Their circumstances improved after Frank purchased continence pads and learnt self-catheterisation from the nurse. Heather also had a lack of bladder control and urgency:

“… coming home … on the bus … I just sat there, and I couldn’t do anything I just wet myself … it’s … embarrassing … but what can you do about it, you can’t, there’s nothing you can do, you can’t control it …” (L327-330).

Despite the constant need to urinate, and the pain, some participants held on as long as possible before emptying their bladder to gain control. Eddie continued this practice at night, not getting up at the first urge because “… you are giving in to it as it dominates” (L930).

On-Going Needs

Participants had on-going needs relating to care and support. However, when these were lacking, and needs were unmet, participants felt disrespected. No counselling or community supports were available, yet they wanted somebody to take notice that they had fallen:

“… through the loop … as far as … having a support network … there’s a lot … of support … out there for … breast cancer … I don’t find that with bladder cancer …” (Debbie L1624-1627).

For many, the physical constraints of BlCa had resulted in unemployment or general financial hardship. Barry received financial assistance, Eddie had a disability pension and three other clinical participants had been forced to retire to deal with their physical issues.
Cognitive Reactions

Clinical participants’ thoughts about their lives and bodies were indicative of how BlCa affected their QoL, such as reflections on the inability to engage in a productive life, including family, social, and work roles, and to uphold their previous persona.

Diagnosis and Information

Diagnosis and information provision were marked by poor communication from urologists, highlighted by three clinical participants who had not understood they had cancer because terms such as tumour, carcinoma, or polyp were used. They were devastated upon finally discovering their true diagnosis. One almost deliberately drove off the road because he thought he was dying anyway. The clear use of the word ‘cancer’ was preferred, including its likely severity. As Alicia noted:

“… my last cystoscopy the doctor said that you have bladder cancer … well no one has ever … said that to me before … it just said stage one carcinoma … they never ever anywhere mentioned the word cancer … it was just a kick in the face almost … that that’s what it is but no one’s talked about it that way before …” (Alicia L17-26).

After Gareth underwent a TURBT he heard nothing from the hospital and believed that the problem was rectified. He had been diagnosed with bowel cancer four years before, so when he attended a regular bowel check-up, Gareth mentioned his TURBT. On looking up the results the surgeon informed Gareth that he had BlCa. “I never really found out what it was, they just said … they removed tumour or a growth … the information was a bit vague …” (Gareth L35-37). Back pain 18 months after Eddie commenced 3-monthly cystoscopies and TURBTs led his general practitioner to send him for an x-ray. When he asked about the results Eddie was told not to worry, as all cancer patients had that x-ray. Eddie did not know he was a cancer patient and it horrified him:
“… knocked the stuffing out of me (L475-477). … I first got told … in recovery … he told me they found one the size of a 50-cent piece plus quite a few smaller ones … plus, some polyps. … he never mentioned cancer…” (L463-467).

Despite having haematuria, a BlCa diagnosis still caught participants unaware and they failed to take in all of the information. Barbara said “… if you don’t … ask, you’re not going to get” (L170). “People are going to think everything’s okay … so if you’ve got problems you need to let them know” (L1295-6). Partners attended meetings to record information or listen to the advice given, to maximise retention. However, couples felt they could not ask questions as visits were too brief, leaving them feeling rushed, with questions often unanswered. For example, “… you don’t absorb it till you come out … it don’t all sink in, you just hear the cancer” (Flo L328-30). Even when they wrote a list “… you forget things or you’re just there to hear what they have to say and … don’t state … things that are … on your mind” (Debbie L1366-1368). Partners also wanted to know about the effects of BlCa on other families, sensing that firsthand experience was better than a medical leaflet. They sensed a lack of inclusion in the care process, so it was left up to them to seek support and attend appointments because “they’re certainly not going to seek you out. You’ve still got to keep everything going” (Grace L375).

A Life Overshadowed

Treatment and adverse effects left participants believing their life was overshadowed by BlCa. ‘Cancer’ equated to death for participants, family, and friends who were often too scared to visit. When Charles’ BlCa metastasised to his kidney his doctor warned him to get his “… affairs in order [laughter] and well I’m still here” (L92-93) after eight years. Frank’s situation was so dire that he arranged his funeral, legal papers, a cemetery plot, and a box of instructions for Flo. Most clinical participants’ lives were dominated by the urinary side effects of BlCa treatment which affected their thinking about sexuality, employment, and social events. For Eddie, “it dominates your life … it does wear you down…” (L41). The hardest part was “… revolving
your life around going into hospital…every three months.” (L179-180). Two clinical participants revealed their vigilance in checking for blood when they urinated:

“… you’re always checking … I check to make sure there’s no blood anywhere … and I’ll probably continue to do that until I die. … it’s always there in the back of your mind or if you get an ache or a pain …” (Heather L593-604).

Couples were threatened by the disruptive nature of BlCa. They were displeased by the time taken for treatment as their lives turned into a ticking clock of treatment slots and intervals, while incontinence, urinary frequency and urgency socially isolated them. BlCa affected clinical participants’ employment and social activities, culminating in the cessation of long-enjoyed sports. Jose no longer felt confident swinging a golf club, and believed her bowling ball was too heavy after having a post-RC hernia. Although Jose still enjoyed swimming, she pictured her stoma pouch floating past her eyes so gave that up too. Dennis kept his BlCa a secret at work in case he appeared weak or had his diagnosis held against him. “I felt an obligation to be at work doing what I was paid to do and being sick wasn’t … part of the mantra” (L701-703). BlCa absolutely dominated Eddie’s life, leaving little time for other activities. Edith said “he’d had enough … I can understand that … invasion of your body, we lived around that …” (L355-356).

Talking it Over

Talking it over allowed communication about progress or problems. Poor communication resulted in marital disharmony for one couple and five partners agreed that there should be counselling available because they had no one with whom to discuss their concerns about the consequences of living with a person with BlCa. For some intimate couples, this extended to the discussion of sexual issues and love in their relationship. For example, Debbie said “I don’t think I’ve ever really had anybody that I could discuss it with … there’s not been anybody to turn to” (L138-44), nor had anybody asked “What are you coping with … here?” (L142-3).
Clinical participants also required a discussion with someone after their diagnosis to give guidance. Partners worried about being the only person to whom the clinical participant could confide fears and anxieties, as the intimate nature of BlCa, and lack of understanding by others, prevented open discussions. Barbara’s nurse friend would visit just for Barry to ‘whinge’ at her:

“… Just having someone to complain to and who knew what … he was talking about … that’s useful… because he’s not always wanted to talk to me about it, … that’s fine as long as he’s talking … to somebody” (L228-236).

On hearing of Eddie’s suicidal ideation, his partner Enid telephoned Lifeline and gave him the phone to talk to a counsellor. Enid said he “… slowly came to terms with it” (L89-90) “… we were a long time before we … talked to one another about it” (L90-91).

**Emotional Reactions**

This theme concerned the emotional reactions expressed by participants toward BlCa.

Anxiety and Shock

Anxiety and shock were commonly reported. There was fear of having future surgery, collecting urine in a plastic bag, experiencing treatment that was worse than they had already undergone, about BlCa returning, and death. Four participants were particularly confronted by the prospect of bladder removal. “… not that, I don’t want that … if I have to die I have to die” (Frank L405). Barry said “… they didn’t give me any option but to remove it which was scary …” and he was “… absolutely horrified” (L94-95) and very emotional while preparing for it.

Some clinical participants became anxious when their next surveillance cystoscopy appointment card arrived. For Heather and Alicia, this card was a reminder of cancer, frailty, embarrassment, the intrusion to their bodies, and the fear of test result. In contrast, Dennis and Eddie became anxious when their appointment card did not arrive, because they felt they may have fallen off the list. Participants concluded that it was up to them to keep track of
appointments, and partners also took on that responsibility. However, comments indicated that the process of, for example, confirming appointment times, was frustrating and inconvenient.

Partners discussed the effects of the changing moods and emotions experienced by clinical participants and the need to give them space and time to recover after treatments. Dennis became tired, depressed and angry “… because you can’t cope and … you become antisocial because you don’t want to go out … because you’re saying, ‘where’s the toilet?’” (L119-120). Debbie was devastated that “somebody … you love has got what feels like a death sentence” (L6). When Heather was diagnosed she said “I don’t want to die, I’m too young” (L82-3), but while having regular TURBTs, and experiencing side effects she said “I just want to die, I don’t care if I die” (L870-2). Having BICa made Ian realise he was not “… the person that gets away with everything … that’s what I thought all my life” (L196-197).

Life Supports

Clinical participants reported their partners, family, and friends to be important sources of support. They were effusive about the assistance they received, expressing gratitude and amazement, although partners themselves downplayed their role. Barry appreciated his weekly visits from a friend as “… most people who knew … stayed away … I think they were … scared that they’d turn up and I’d … be dead [laughter]” (L570-571).

Sexuality, and Loving Relationships

Sexual dysfunction was a disheartening side effect for male clinical participants who still desired a satisfying sexual relationship, with erectile dysfunction (ED) and the inability to ejaculate causing great distress. Conversely, female partners focused on the closeness of their relationships, and the family they had built together, rather than the sexual act. For them, the demise of sex was not as important as having their clinical participant alive. The inability to perform was felt particularly by three men who voiced frustration with various pills and painful
injections that nevertheless failed to facilitate sexual arousal or ejaculation. Even more of the male participants had a long-lasting painful burning sensation on ejaculation that made sexual encounters unpleasant. Charles recalled a discussion he had had with a specialist at age 64:

“… the specialist … said … some people at 60 don’t … practise sex anymore [laughter] … so maybe I … shouldn’t worry too much [laughter]” (L753-757). “Well my opinion, I wish I could … put me back to normal but … I can’t …” (L770).

Dennis said “I can understand if you don’t want to be with me anymore” (L761). This made Debbie sad as “… we’ve been through so much and sex is only a part of that” (L766-767) “… you learn to adapt … it makes you realise the important things in life … [crying]” (L1614-16). However, the day before Barry’s RC, he and Barbara “made the most of the last … opportunity” (L442). Since then sex was either lacking or unfulfilling. Barry said “… the thing I miss most is having a proper sexual relationship … that’s … undoubtedly the biggest thing” (L432-433). Barbara did not require sex but said “…if it’s going to bother one of us, then it’s a problem” (L622-4). She thought the ‘macho’ element played a part in Barry’s struggle with ED.

Some men were eager for sex as soon as possible after their TURBT to ensure their masculinity was intact. Their partners viewed this as typically macho. Eddie and Enid always had sex before he went to hospital because afterwards they abstained due to painful ejaculation but “… being a bloke you want to know it still works” [laughter] (L833-834). Frank abstained because he thought he could give Flo BiCa, but Flo knew “… you can’t catch it …” (L220) and believed that “… an erection is hard for him and he feels embarrassed … not a man …” (L251-252). Frank told friends not to visit him in hospital and sent family away after five minutes. Flo thought he did not want people to see him frail and ill. When Ian started losing blood it was three weeks before he told Ida, and she had to force him to visit his doctor. Mimicking her husband Ida said “… can’t be anything wrong with me, I’m a perfect man …” (L11-12).

Embarrassment and Intrusiveness
Surveillance and treatment caused embarrassment owing to their intrusiveness, particularly as they were conducted in front of what was described as a room full of strangers. Having a nurse teach them how to catheterise, or care for a wound caused by the catheter, was equally embarrassing. Alicia found the cystoscopies horrible and humiliating:

“… you’re lying there with a big sheet and all that’s open is this little gap with your private bits and you’ve got your legs in the air … it’s just like, oh … kill me now because … I was so embarrassed …” (L196-198).

Dennis found cystoscopies “… painful and … disconcerting …” (L313). “… the embarrassment of having your legs up in stirrups as if you’re giving birth … I didn’t want to know … so I switched off …” (L323-325). The idea that a “stranger was handling him” (Debbie L86) caused Dennis to opt for an anaesthetic so he was oblivious to it.

The Nature of Care

Most participants discussed the nature of the care they required and its delivery. The hospital system was frustrating as were staff shortages, the perception of being on a processing line, not being listened to, and dealing with embarrassment and discomfort. Clinical participants’ stories began with their introduction to the healthcare system that assisted a few but missed the needs of many. They discussed tests, times, misdiagnoses, care providers’ skills, delays, and disorganisation, all of which were part of the build-up to receiving their diagnosis. They mentioned rough and painful cystoscopies. Even inserting anaesthetic gel was excruciating.

Four male clinical participants were outspoken about appointment waiting times:

Barry: “… for a two-minute examination that takes me … half a day … you get in the list … wait …, one thing about medical treatment in the hospital system … is you learn patience. You get to do a lot of waiting …” (L510-512). “… I was in at … eight in the morning … and … taken into surgery about 3 …” (L517-119).

Dennis: “You have an appointment for 1 o’clock and when at 10 past 4 you go up to the counter and say I’ve been up here twice already can you tell me what’s going on? ‘We forgot you’” (L390-392).
Ian: “… I’m havin’ that done at one o’clock … it’s ten past one, what am I doing sat here… why don’t they … hurry up so’s I can get out of here …” (L480-483). “… it’s … the nuisance … wasting my … time …” [laughter] (L605-607).

Gareth: “… you can wait for well over an hour up to … two hours last time … they were running late. It’s quite tedious sitting there” (L186-188).

Partners were concerned that clinical participants were given information after procedures when they were still effected by drugs. Grace thought this was the case for Gareth as he did not remember what he was told. Partners also mentioned that they were often not consulted before the clinical participant was discharged. Two partners with young children were not asked if they were ready to care for their husbands or were adequately equipped to do so. Grace said that “Everything’s still got to keep functioning” (L377), “… you find out what you can cope with. I’ve realised I’m much stronger than I … thought …” (L696-7). Clinical participants noted that the urology clinic was busy, and the nursing staff were doing their best, but they did not appreciate having their needs ignored, disorganisation, lengthy waits, delays, or being forgotten.

Some participants found staff, particularly nurses, to be “… just magnificent” (Barbara L899) because “… they’d bend over backward … no complaints there … and the doctors were really good” (Barbara L1539-43). Yet others were concerned about the discontinuity of medical care, including how unnerving it was to have a different urologist every time. There were communication issues with staff who telephoned a partner of a clinical participant ready for discharge, only to find him still in recovery on arrival. This was considered a poor use of his partners’ time which was frustrating. Participants felt they were not being adequately informed. Dennis, for example, was telephoned and told that he was starting BCG without a discussion of side effects. Later when he suffered from incontinence, he felt that he not heard, having to argue to see a continence nurse. Charles was not aware that ED was associated with the formation of a neobladder and said that he did not feel fully informed about that impact prior to surgery.
Survival Techniques

Participants dealt with BlCa in numerous ways, often contradicting themselves with other behaviours or views on BlCa. Partners faced some similar challenges in daily coping with BlCa.

Acceptance

Multiple participants accepted the diagnosis stoically with statements such as “there’s nothing you can do, these things happen, can’t do much about it”, and “what else can you do”. Regarding treatment, “if it has to be done, it’s got to be done”, “we just accepted it”, and “I accepted it had to be done”. Comments about incontinence included “that’s what happens, you have to accept it”, “it’s one of those things, part of living with it”, “this is the way it is”, and “you just have to get on with it”. Despite such acceptance, six participants were very emotional and cried during their interviews. Heather questioned ‘why me?’, yet Alicia said she “got over it … I accepted it very quickly” (L138). When Alicia’s BlCa returned she said “I’m not worried about it … I know that I’m gunna win this” (L330). Eddie had slowly come to terms with his BlCa as “it becomes part of … life we just accept” (Enid L652-3). Frank said “I accept … I had it, I accept that … they cured it … I am convinced … that everything’s okay” (L503-506). Four partners commented about putting on a brave face for their spouse, particularly by downplaying issues.

Having Faith

Some participants had faith in alternative treatments (e.g., herbs, apricot kernels, cranberry juice) or placed implicit trust in their specialist, or their faith. Eddie perceived a link between taking apricot kernels and his increased time between cystoscopies. Despite the awful taste they control it but “… doesn’t fix it” (Eddie L423). He said:

“… you hope that … you’ve got … rid of it …” (L442-443) “… you’ve just gotta have faith” (L977). “… the most important thing is to … be there for your treatments and to trust the people that are treating you …” (L1157-1158)

Others relied on faith, which assisted them to get through their ordeal and survive.
“… I’m… glad that it’s clear and hope it stays that way …” (L747). “I’m … thankful … it’s like a weight lifts off you …” (L752-753). “… it could come back, and I just hope and pray that it doesn’t …” (Heather L923-924).

Dennis had faith in a previous urologist who had moved his practice to another hospital. When Dennis came across him again he called it a God incident. A corridor consultation led to transfer of care back to this urologist and Dennis felt much better. Dennis also had faith in Prostate-Eze which his physician said “…might work for one in five … if it’s working for you keep taking it” (L71-72). Dennis and his partner Debbie drew on their “inner strength … we’ve relied heavily on our faith … we’ve prayed a lot together …” (L1604-1606).

Avoidance, Denial and Distancing

Some clinical participants also used avoidance and denial, while distancing was used by partners to continue the smooth running of their family and creating time to attend to their own needs. Five clinical participants denied the severity of their BlC or its cause. For example, Ian did not believe his diagnosis “…they’re wrong” (L352), “I can’t have it, can’t be me [laughter]” (L188), Dennis avoided acknowledging his treatment as he “… switched off…” (Dennis L325) and Debbie distanced herself to maintain control of their children and home.

Despite 26 years of smoking Eddie denied that it caused his BlCa because he did not inhale. He enjoyed his pipe and cigars like “old friends”. In fact, all clinical participants had been smokers, and denial that it might have caused BlCa was common. Ian was the strongest example:

“… why do you say smokin’ because almost everyone that has bladder cancer smokes?” (L834) “I been smokin’ since I was ten, [62 years] and when I retire … when I’m getting bored … we decided to take up [occupation] the cancer came four years after I started … so it could be the chemicals …” (L861-865).

Ian and Ida were so sure that smoking was not a cause of BlCa that they still smoked. After 47 years of smoking Frank also denied it to be a cause of BlCa. He was diagnosed after phototherapy for a skin condition. His physician denied that phototherapy caused his BlCa, but
Frank was adamant: “I couldn’t prove it. Because otherwise what could all of a sudden cause bladder cancer” (L295-29). Alicia and Ian thought their BlCa to be an insignificant, small, slow growing spot they had removed every three months. This positive belief helped convince them that BlCa was not a concern. At times, participants seemed at war, fighting a deadly enemy. Common comments were “… this isn’t the end”, “… not giving in to it”, “I’m gunna win this” and “you … take control … otherwise it dominates”. Heather denied her family involvement in her BlCa care and appointments, yet her moods adversely affected her entire family. Barry refused to prepare adequately for leakages and had not changed anything related to his stoma.

Discussion

Few BlCa studies have focused on patients’ experiences, and even less on the perspective of supportive partners, or the impact of BlCa on the couple. However, although there is a lack of research in this area, some of the themes identified could reflect similar issues noted in other cancer patients, such as negative post-treatment experiences, diminished family/friend support, post-surgical body image, sexuality, lack of education and information, and the threat of cancer recurrence.22, 23, 26

This study found that clinical participants and their partners repeatedly acknowledged the importance of the healthcare system in the lives and some of the undesirable interactions they experienced. These included a general lack of information and support both at the time of diagnosis and on return for further treatment. Other comments alluded to the clinical participant not being listened to, not having questions answered, and being told, rather than asked, about treatment options. This was particularly pertinent when there were doubts or uncertainties about outcomes concerning urinary and sexual dysfunction. Clinical participants were misdiagnosed, and experienced long waits for an appointment, and procedural delays. There was anxiety around
regular surveillance cystoscopy appointments, and the lack of support and assistance with symptoms such as incontinence and sexual dysfunction, and the related embarrassment and humiliation of these invasive procedures.

QoL was marred by the associated treatment that inevitably had uncomfortable adverse effects (e.g. urinary and sexual dysfunction). These include the need to deal with new toileting practices, changing stomas, catheterisation, urinary leakage, and incontinence which were problematic when participants had not been sufficiently educated. The study also found that incontinence, self-catheterisation, having a stoma, pain, and leakage greatly affected QoL.

Clinical participants’ reactions comprised responses to dealing with the anxiety associated with having BlCa and feeling confronted by mortality. They were less able to enjoy everyday activities such as participating in sports, socialising or other recreational activities with family and friends, and encountered employment difficulties, which led to financial hardship for some couples. Yet the overwhelming support offered by partners, and the importance of communication and patience, demonstrated that a loving relationship was what enabled couples to manage the required changes to their daily lives. In their study, Fitch et al. 22 also recommended that couples communicate about sexual dysfunction as this may positively assist couples’ relationships. Understanding these important roles played by partners will enable healthcare professionals to be more open to their involvement in care, preventing partners from feeling ‘on the outside.’

Perhaps the most poignant finding from the interviews was a glimpse into the Survival Techniques participants used in their attempt to adapt to BlCa. According to Fife,35 adaptation to a life-threatening illness can only occur when the individual has trusted coping methods, a well-developed sense of self, a continued social standing, and mastery over the disease threat. Both
clinical participants and partners were often compromised in their endeavour to adapt due to the significant adverse effects that negated their mastery over BlCa. Findings suggest that adaptation to BlCa occurs in a variety of ways, including adjustment to the procedures and requirements of the healthcare system, which were often annoying and frustrating. Whereas some participants simply accepted BlCa and the associated processes and procedures, others attempted to deny its existence in their lives, played down its significance, or placed an emphasis on their faith (e.g. faith in a higher being, the abilities of their urologist, or in foods and supplements).

**Clinical Implications**

There are simple strategies that could be used to address the information needs of couples that may lead to a fuller understanding of the disease. For example, participants wanted the urologist to sit with them after their initial procedure to explain what happened and articulate a care plan. Importantly, at diagnosis 30% of clinical participants did not clearly understand that they had cancer due to urologists’ use of medical jargon. As a result, participants emphasised that the word ‘cancer’ must be used, rather than synonyms such as ‘carcinoma’. If there is a recurrence at a later time, this too needs to be explained, along with the new treatment plan.  

Appropriate information assists in the understanding of the disease process and treatment requirements, and should be explained using simple terms, or through pamphlets with relevant diagrams. Clear information at diagnosis, and along the BlCa trajectory as medical circumstances change, is a key requirement of the healthcare system. This telling and re-telling of patients’ BlCa diagnosis is required to ensure its severity is understood, enabling couples to become involved in treatment decision making. Benner et al. found that even when participants reported positive healthcare system interactions many continued to have significant unmet needs. Fitch et al. noted similar reactions from participants who felt that healthcare professionals did
not meet their informational needs, making it imperative for a partner to attend during appointments. Further, a pre-surgery dialogue explaining the positives and negatives of the procedure might also encourage participation in treatment decision making, which may be reflected in positive QoL outcomes.\textsuperscript{21}

Participants desired genuine support, and the chance to meet others with BlCa. This was to enable a glance at how others dealt with adverse effects and the very personal issues related to BlCa. Participants also asked why no counselling was offered given the adverse psychosocial concomitants of the disease and the severity of adverse effects. They questioned the lack of public awareness and fund raising for BlCa and asked why there is no information about BlCa risk factors and symptoms in the media, as many had never heard of BlCa until their diagnosis.

Understanding these latter factors and the important roles played by partners will enable healthcare professionals to be more open to their involvement in care and prevent partners from feeling ‘on the outside.’ This understanding by healthcare professionals is crucial to assist individuals in their adaptation to their illness, particularly when treatment is traumatic, and when it may be difficult to find meaning in the situation.\textsuperscript{35,36}

\textit{Conclusion}

This study is believed to be the first to seek the perspectives of both patients with MIBlCa and NMIBlCa, allowing the description of two unique experiences. First, the changes in body image and function associated with surgery and second, the ongoing surveillance, treatment and associated adverse effects of those who did not undergo surgery. The additional inclusion of supportive partners permitted the nature of these experiences to be further understood as they are lived by the couple rather than just the patients. This study has contributed to the topic of BlCa
Experiences of bladder cancer

and its effects on the lives of patients and their partners by describing their daily experiences and the difficulties faced in attempting to adapt their lives to the unique needs of BlCa.

Nevertheless, the findings and recommendations come with caveats. First, participants were recruited from the one facility. Perhaps participants from other public institutions, the community, or private practices may have had different experiences. Further, participants were required to speak English, negating the ability to capture a multicultural perspective on the experiences of BlCa. Finally, the dyads were mostly heterosexual couples. Broader findings, particularly in terms of support and acceptance, could have emerged if the insights of lesbian, bisexual, and gay couples, for example, were available. Additionally, it should be noted that although bowel dysfunction is a common issue among those with BlCa,¹,¹⁰,¹¹ this topic did not arise among current participants. Although it can be argued that bowel dysfunction is aversive and embarrassing, it nevertheless represents a gap in the full understanding of BlCa experiences.

This study has drawn attention to key aspects that the healthcare system plays in this context, in particular, the need for information including a clear diagnosis using the word ‘cancer’, continuing updates on the trajectory of the disease and information in various forms as well as the inclusion of partners in medical appointments. Psychosocial implications require attention with counselling and contacts for professional support for patients and for partners. Facilitation of contact with others who are on the same BlCa trajectory could assist couples and become a source of support and information. The research has shown the benefits of partner support in assisting clinical participants to accept and adapt to BlCa. The current study has allowed an appreciation of the QoL of participants, and understanding of the needs of couples, and the importance of positive collaborations with health professionals that might allow them to more confidently and comfortably move towards adaptation to BlCa.
References


Table 1. Descriptive Information for Clinical Participants and Partners

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<tr>
<th>Participant</th>
<th>Pseudonym</th>
<th>Age</th>
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<th>Years together</th>
<th>Education</th>
<th>Employment</th>
<th>Nationality</th>
<th>Outcome</th>
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Abbreviations: CP, clinical participant; P, partners.
Table 2. Semi-structured open-ended interview guide for clinical participants.

**Pre-diagnosis questions**

- How long have you had BlCa?
- Can you tell me about the first signs and symptoms that you had or what made you go to see your doctor?
- What did you know about BlCa and its risk factors?

**Questions about diagnosis**

- Can you describe what happened and how it felt when you were diagnosed with BlCa?
- What exactly was your diagnosis?
- What were your immediate thoughts and concerns?
- What type of tests did you have as part of the diagnosis process?
- Who did you discuss your BlCa with?

**Ongoing treatments and tests**

- Please tell me about the tests and ongoing treatment that you have had or are having.
- How did you cope with the tests and treatment?
- Who did you have to support you at home?
- What needs did you have during the tests and treatment and how were those needs met?
- Were there any needs you were unable to have met?
- What types of external support services do you use or need?
- How has your BlCa affected your social and work life?
- What affect has BlCa had on your intimate relationships and sexuality?
- How do you manage to cope with your BlCa?
- What symptoms are you living with now?
- What would you say is the worst part of having BlCa?
How would you describe your journey with BlCa so far?

What advice would you give to someone else who asked you about BlCa?

If you could, what would you change about the things you have been through and the decisions you have made in regard to your BlCa?

Can you describe your experiences with medical staff and services?

Do you have any questions for me?

Note. Identical questions were used to interview partners, with obvious changes such as ‘How long has your partner had BlCa?’

Table 3. Final Themes and Sub-Themes Derived by Thematic Analysis.

<table>
<thead>
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<td>Cognitive Reactions</td>
<td>Diagnosis and information</td>
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### A life overshadowed
- Public persona
- Talking it over (P)

### Emotional Reactions
- Anxiety and shock
- Supports for daily life
- Sexuality and loving relationships (Being macho (P))
- Embarrassment and intrusiveness
- The nature of care

### Survival techniques
- Acceptance
- Having faith
- Avoidance, denial and distancing

Abbreviations: P, partners’ only responses.