

Section 11

Discussion

Introduction

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

This PEEK study in bladder cancer includes 44 people diagnosed with bladder cancer throughout Australia. In addition, 5 carers or family members to people with bladder cancer took part.

Incidence, prevalence and mortality

Bladder cancer occurs more frequently in men and those over 60 years of age¹. In 2021 there were and estimated 3,066 new cases of bladder cancer in Australia, approximately 2,400 of these were men; the median age was 76.3 years^{2,3}. There were an estimated 653 deaths from bladder cancer in Australia in 2021, it is the 9th most common cause of death from cancer². The five year survival during the period 2011 to 2017 was 55%³. In Australia, at the end of 2016, there were 8165 people living with bladder cancer³.

There was a decrease in 5 year survival from 68% in 1982 – 1987, to 53% in 2009-2013, the reasons for this are not clear and cannot be explained by an increase in age at diagnosis which has only modestly increased in this time period^{1,4}. However, there was a decrease in age-standardised mortality rate from 5.4 per 100,000 in 1982 to 3.8 per 100,000 in 2017¹, this is due to a reduction of overall incidence.

Demographics

The demographic data we collect in the PEEK study helps us to understand how our PEEK participants compares to people in Australia, and with people that have bladder cancer.

In this PEEK study, the proportions of participants that lived in major cities and had non-school qualifications (certificate, diploma or degree), were all similar to that of the Australian population. There were higher proportions that lived in areas with higher

socioeconomic status.⁵⁻⁷ There were no participants from the Northern Territory, and there were a lower proportion of participants from Queensland, and Western Australia while a greater proportion from NSW, and Canberra compared to the proportion that live in each state⁸.

Table 12.1: Demographics

| Demographic | Australia % | Bladder cancer PEEK % |
|---|-------------|-----------------------|
| Live in major cities | 71 | 69 |
| Non-school qualification | 65 | 63 |
| Higher socioeconomic status (7 to 10 deciles) | 40 | 58 |
| New South Wales | 32 | 46 |
| Victoria | 26 | 27 |
| Queensland | 20 | 4 |
| South Australia | 7 | 10 |
| Western Australia | 10 | 4 |
| Tasmania | 2 | 2 |
| Northern Territory | 1 | 0 |
| Australian Capital Territory | 2 | 6 |

Health status

In PEEK studies we collect information about other health conditions that participants manage, as well as health-related quality of life (with the SF36 questionnaire). The purpose of this is to have an idea of the general health of the participants in the study. We can also compare this data with the Australian population, and with other studies with bladder cancer participants.

Other health conditions

The majority of participants in this PEEK study had at least one other condition that they had to manage, and on average 2 other conditions. The most commonly reported health conditions were sleep problems and anxiety, followed by arthritis or scoliosis, and depression.

The National Health Survey was conducted in 2017 to 2018, it is an Australia wide survey conducted by the Australian Bureau of statistics. Almost half of the Australian population have one chronic condition⁹. Common chronic health conditions experienced in Australia in 2017-18 were: mental and behavioural conditions (20%), back problems (16%), arthritis (15%), asthma (11%), diabetes mellitus (5%), heart, stroke and vascular disease (5%), osteoporosis (4%), chronic obstructive pulmonary disease (COPD) (3%), cancer (2%), and kidney disease (1%)⁹. The Australian Bureau of statistics reports that 10% of Australians have depression or feelings of depression and 13.1% have an anxiety-related condition⁹.

In this PEEK study, participants had higher levels of anxiety (40% compared to 13%), depression (26% compared to 10%), arthritis (38% compared to 15%),

diabetes (10% compared to 5%), and asthma (17% compared to 5%) compared to the Australian population. High rates of anxiety in depression have been reported in other studies¹⁰

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual¹¹. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function¹¹.

Population norms for the SF36 dimensions in Australia were assessed in the 1995 National health survey, while this was conducted 25 years ago, it can give an indication of how the bladder cancer community in this PEEK study compares with the Australian population¹². The bladder cancer PEEK participants on average had considerably lower scores for the SF36 Energy/Fatigue, SF36 Social functioning, and SF36 General health SF36 domains.

Participants in this PEEK study had scores within the moderate to very good range. In other studies, people with bladder cancer have displayed worse health-related quality of life compared to people with prostate cancer or colorectal cancer¹³, and often reported problems with conducting usual activities.¹⁰ However, following surgery, bladder cancer did not affect health-related quality of life for those without symptoms¹⁴.

In this PEEK study, Participants with advanced bladder cancer and males had worse physical function, participants with trade or high school qualifications had worse pain, males and those living in areas with mid to low socioeconomic status had worse social functioning, and males had worse general health.

Similar to this PEEK study, other studies have reported that people with advanced stage have poorer health related quality of life, and in contrast that males have better health related quality of life¹⁵. Other factors associated with poorer quality of life include old age, comorbidities, anxiety, poor emotional function, poor cognitive function, poor social support and poor self efficacy^{10,13,15,16}

Key points

- PEEK bladder cancer participants had high rates of depression and anxiety
- PEEK bladder cancer had an average of 2 other health conditions they needed to manage, most often sleep problems and arthritis or scoliosis

Symptoms and risk factors

I'd never heard of it and never heard of bladder cancers, never heard of bladder cancer in my life. My wife is a registered nurse and has been in aged care for 25 years. Goes, what the hell are you doing with bladder cancer? Cause that's an old man's disease. And, you know, everybody said, you know, everyone queried me along the way. Were you a smoker and did you work in heavy industry or with chemicals or toxins and that kind of stuff? I said, No, no, no, no, no. I sit behind a desk all day and have and have for 30 years. I'm a pen pusher or keyboard person. So that was a bit bizarre that I didn't fit the archetype for that thing, being 52 and non-smoker and an office worker. I don't sort of fit the demographic for this.

Participant 017_2022AUBLC

Risk factors for bladder cancer include smoking, workplace exposure in the textile dyeing, petrochemical and rubber industries, diabetes, the chemotherapy drug cyclophosphamide, family history, and chronic inflammation of the bladder¹⁷. The most common symptom is haematuria, other less common symptoms include problems emptying bladder, dysuria, polyuria and abdominal or back pain¹⁷.

There are higher age standardised mortality rates from bladder cancer for in those living in very remote areas of Australia compared with those that live in major cities, likewise, those in the most disadvantaged areas have higher age standardised incidence and mortality compared with those living in the most advantaged areas¹. Migrants have a higher risk than Australian born¹⁸, and Indigenous Australians have the same risk as other Australians¹⁹.

In the PEEK study, information about symptoms and quality of life from symptoms before diagnosis are collected in the online questionnaire, and in the interview, participants talk about the symptoms that actually lead them to get a diagnosis. Taken together, we can get an insight into the number and type of symptoms participants get, the symptoms that impact quality of life, and the symptoms that prompt medical attention.

In this PEEK study, the most common symptoms before diagnosis were urine related such as blood in urine, needing to pass urine often and having a burning feeling when passing urine. Over 70% of participants went to sought medical advice after seeing blood in their urine. Pain in the abdomen or lower back was also a common symptom.

Mine was so simple. There's only one day in the whole of my pre diagnosis prior to me seeing a doctor. It's a matter of hours from first noticing. I had never noticed any pain, any sensation, anything whatsoever. I woke up one morning to help a friend in a business to drive a truck for them. And I'm a PROFESSION, but I have a heavy vehicle licence, and I want to do a pee when I woke up in the morning. And I went to urinate and I thought, Oh, it feels like I'm passing a lot of water, like a lot of fluids. And I looked down and I just saw a stream of what looked like pure blood flowing out of my body. And I absolutely freaked out.
Participant 001_2022AUBLC

Histological types

The most common type of bladder cancers are transitional cell carcinomas, accounting for more than 90% of cases. The remainder of bladder cancers are squamous cell carcinomas, adenocarcinomas and small cell carcinomas^{20,21}.

Stages of bladder cancer

Stage 0 bladder cancer is confined to the bladder lining, stage I has spread into the connective tissue, stage II is in the muscle of the bladder. Stage III has spread through the bladder and into the surrounding fat and may have spread to nearby organs and stage IV has spread throughout the body⁹.

There are conflicting reports about the differences in the stage of presentation of the disease between men and women, some report no differences between men and women²², while others report that women present with more advanced disease²³. Women are more likely to die from the disease than men²⁴⁻²⁶, one study reports that this only occurs in those older than 70, the younger patients have the same disease specific survival²².

Recurrence and progression

So I had another cystoscopy a few weeks back and that was the second one. So I was diagnosed about June last year. And so this was the second cystoscopy that I'd had. And it came back all clear. And in fact, the

oncologist remarked that it was odd that they didn't even take a biopsy of just some tissue that might have looked a bit suspect. He said if I didn't even do a biopsy, it means you're very, very clear. So that was good to hear and, oh look, it's once it's happened, it can happen any time. So it's just a matter of having to live with the knowledge that it could happen again because it happened the first time. So it's not like I'm cured.
Participant 030_2022AUBLC

Bladder cancer recurrence typically occurs within a year of definitive treatment²⁷. Depending on type and stage of disease, recurrence occurs in approximately 50 to 70% cases, and will progress in 7-40% of cases²⁸.

In this PEEK study, almost half noted that they had a recurrence, and a quarter of participants described prognosis in relation to probable recurrence/cycle of recurrence

Diagnosis

There are inconsistencies in diagnostic pathways with many patients experiencing delays in diagnosis, and there are no Australian evidence-based guidelines for haematuria presentation^{29,30}. The UK National Institute for Health and Care Excellence recommend investigating suspected bladder cancer in patients aged 45 and over with unexplained visible haematuria and in patients aged 60 and over who have unexplained non visible haematuria and either dysuria and raised white cell count³¹. The American Urology Association recommend cystoscopic evaluation for all patients with visible haematuria and aged 35 or older, and high risk patients over the age of 40 presenting with microscopic haematuria³². A patient cohort in an Australian hospital reported that the probability of bladder cancer in patients presenting with haematuria was less than 1% for patients under 45 years, 13% at age 65 and 26% at age 80, based on this the authors recommended an approach similar to the UK guidelines²⁹.

In this PEEK study, participants were asked to describe the symptoms that actually led to their diagnosis, as opposed to all the symptoms that they could recall. The most common symptom leading to a diagnosis of bladder cancer was blood in the urine followed by pain in the bladder region and 60% of the participants were diagnosed within 3 months of noticing symptoms. Early detection for bladder cancer is important, delayed diagnosis is associated with poor outcomes, investigations for patients with suspected bladder cancer include blood and urine tests, imaging studies and referral for urology review, and cystoscopy^{27,32-34}.

A worldwide systematic review of the haematuria assessment described that women compared with men had a longer wait for urology review, were referred to urology less often, had fewer imaging studies and fewer cystoscopy²⁹. In addition, despite greater risk of disease, smokers had less comprehensive assessments compared to non-smokers³⁰. Delays in diagnosis and treatment of bladder cancer are associated with poorer outcomes^{35,36}. Patients with macroscopic haematuria are more likely to be referred to urology sooner than those with microscopic haematuria³⁷, and are diagnosed sooner³⁸. However, between 15 and 20% of patients presenting with haematuria will have bladder cancer^{29,39}, general practitioners may not want to over-investigate the cause of haematuria for an unlikely cancer diagnosis, this may be a factor in the delays that patients have in referral to urology.³⁰

A hundred participants that had visual hematuria and had subsequently been diagnosed with bladder cancer in Western Australia described the waiting times to diagnosis and treatment⁴⁰. The median time from haematuria to surgery in this cohort was 69.5 days⁴⁰. Delays commonly occurred due to lack of public awareness of symptoms of bladder cancer, patient fear and anxiety, delayed and non-referral from primary care, administrative delays and resource limitations⁴⁰.

Another study described that the delay between cystoscopy and getting results universally caused anxiety and stress⁴¹. In this PEEK study, the majority of participants did not have enough emotional support during the diagnostic period, and almost half of the participants waited more than two weeks to get their diagnosis following diagnostic tests.

Biomarkers

Biomarkers may be used to detect bladder cancer or recurrences⁴². The protein nuclear matrix protein 22 (NMP22) has lower specificity to detect bladder cancer compared to cytology, however, the presence of NMP22 was associated with recurrence^{43,44}. UroVysion uses fluorescence in situ hybridisation (FISH) to detect chromosomal abnormalities, it is approved in USA to aid diagnosis and to monitor tumour recurrence⁴². Other methods of detection under investigation include analysis of microRNA, epigenetic changes and next generation sequencing⁴². There are some mutations that may be of prognostic value, FGFR3 in non muscle invasive bladder cancer (NMIBC) was shown to be associated with recurrence in a large study⁴⁵, however, two other studies found no association^{46,47}. Next generation sequencing techniques have highlighted that TP53 mutations and CDKN2A mutations may have worse

outcomes and PIK3CA and or PI3k/Akt mutations may be associated with better disease specific outcomes^{48,49}. PD-L1 may be used to select patients for atezolizumab or pembrolizumab, and FGFR2 or FGFR3 mutations for FGFR-targeted therapy (erdafitinib)⁵⁰

There are no routine biomarker tests currently recommended by the Royal College of Pathologists of Australasia, most bladder cancers can be identified by histological examination, immunohistochemistry may be useful in distinguishing between tumour types⁵¹.

Almost all of participants in this PEEK study did not recall having discussions about biomarkers and the majority were interested in having this test. No participants could name a biomarker test result.

Understanding and knowledge

Knowledge about chronic disease before diagnosis varies between individuals. Some will gain information from family and friends with the condition, though it can result in misconceptions and misunderstandings^{52,53}. Some people will seek out information about a possible diagnosis, or explore the reasons for symptoms, before receiving a final diagnosis^{54,55} others, especially those who have symptoms for long periods before diagnosis, will gain information in terms of how to live with or adapt to symptoms they experience⁵⁶. For some people, the first time they have heard of their chronic condition is when they are diagnosed⁵⁵. At the time of diagnosis, it may be useful for the healthcare professional to talk about how much a patient knows about a condition so that appropriate information can be given, and correct misconceptions⁵⁵.

Participants in this PEEK study noted that they did not have enough emotional support when they were diagnosed. Almost all participants had limited or no knowledge or understanding of bladder cancer when they were diagnosed. In another study, the majority people with bladder cancer (68%) reported that they did not receive enough information at diagnosis⁵⁷. A common theme throughout this PEEK study was a lack of awareness of the condition in the community, in addition to wanting more information about their condition, in particular, treatment options.

In another study, people with bladder cancer described poor communication from their doctors at the time of diagnosis, where unclear language (such as “tumour”, “carcinoma”, or “polyp”) were used leading to misunderstanding about diagnosis⁵⁸. The use of more direct terms such as “cancer” was preferred⁵⁸

Key points

- The majority of participants had symptoms before diagnosis, these were mostly blood in urine or changes to urination habits.
- Lack of emotional support in a sometimes lengthy period from diagnostic tests to diagnosis
- Almost all had limited or no knowledge about bladder cancer when diagnosed.

Decision making

So I don't have one doctor. I mean, I have a GP who sent me to the hospital for a cystoscopy. And the hospital told me that I have cancer. And they said that the treatment for me is surgery to remove the bladder. And I said, well, is there more other options for me? And they said, you can try radiation, but we do not recommend it for your age because you're not very old and you can handle the surgery. And with surgery that it cannot come back because you don't have a bladder, but with radiation that can come back and also with radiation, maybe not now, but maybe in few years, the radiation itself can cause cancer. So I said, okay, then I go for surgery, but I can I still talk to them, I still get some more information for radiation. So I was not given very clear information that in my case, radiation, radiation was equally successful. So then I told them, do you need more me to continue? ... So I just wanted to be aware that, you know, the main difference was radiation versus surgery and both have pros and cons. And I really wanted to be completely, very clearly informed. But because both treatments have got risk, it's not that one is right or wrong. It's what you are prepared to pay, what risk you want to take. Participant 028_2022AUBLC

The decision-making process in healthcare is an important component in care of chronic or serious illness⁵⁹. Knowledge of prognosis, treatment options, symptom management, and how treatments are administered are important aspects of a person's ability to make decisions about their healthcare^{60,61}, highlighting the importance of healthcare professional communication. In addition, the role of family members in decision making is important, with many making decisions following consultation with family⁶².

Most participants in this PEEK study were presented with multiple treatments or multiple options, however in some cases there was only one viable option. Participants described the most important considerations in decision making as taking the advice of

their doctor, being cancer free or avoiding recurrence, side effects, ease of administration, and quality of life.

The majority of participants in this PEEK study described that they did not take an active role in decision making about their treatment. In some cases, it was because they felt there was only one treatment option available to them, and in others, that they were told what to do without discussion. It is noteworthy that the most common theme when asked about what they would like to see in future treatments was more information about their treatment options, and it was the second most common theme for what they wanted to see in future information. In addition, the most common theme for future communication was that it should be more transparent and forthcoming.

In other studies, people with bladder cancer described being overwhelmed by the amount of information given when discussing treatment options, while others felt they did not get enough information, in addition, some advice was inconsistent between healthcare professionals⁶³. Those that were more informed about their options were more satisfied with their treatment.^{64,65} One study described women including family in decision making whereas male participants were more likely to describe family in a non-supportive role⁶⁶. In this PEEK study, approximately 10% took the impact on their family into account when making treatment decisions, and fewer took advice from family and friends when making treatment decisions.

In other studies, people with bladder cancer described both wanting to play an active role in decision making and others did not^{41,63}. Those that wanted a more active role in decision making described seeking a second opinion, finding more information online, or talking to other people⁶³, in addition, they described feeling uncertain about their doctor's recommendation and whether it satisfied their own treatment goals⁴¹. Those that did not want to take an active role in decision making described a preference to defer decisions to their doctor, as their doctor knows best⁴¹. Almost half of the participants in this PEEK study took the advice of their clinician into account when making treatment decisions, a total of 26% only took the advice of their clinician when making decisions, while the remaining considered other factors.

Goals of treatment and decision-making

Confidence to take part in decision-making is increased by knowledge, being prepared with relevant questions for their consultation, and summaries of previous

consultations and results^{67,68}. Participants in this PEEK study had limited to no understanding of bladder cancer at the time of diagnosis, making initial decision making difficult. However, a quarter of participants noted that they had changed decision making over time as they had become more informed or assertive.

Participants in this PEEK study described their treatment goals as taking the advice of their doctor, being cancer free or avoiding recurrence, minimising side effects, ease of administration, and quality of life. In other studies, people considered disease recurrence, prolonging life, avoiding cystectomy, family, return to normality or work, convenience of treatment, recovery time from treatment, and quality of life when making decisions about treatment for bladder cancer^{69,70}

Key points

- Many participants did not feel that they took part in their treatment decision making
- Participation in treatment decision making may be increased with more transparent and forthcoming information about treatment options

Treatment and healthcare provision

In this PEEK study, to get an insight healthcare access, information about access to healthcare professionals, health insurance, health system, and financial consequences from having bladder cancer are collected.

Access to health professionals

In this PEEK study, more than 76% of the participants were given their diagnosis by a urologist, and 19% were given their diagnosis by a general practitioner. Almost all participants had access to a urologist, and to a general practitioner, and 63% had access to a nurse.

A focus group of 20 people with bladder cancer in America described difficulties in finding a urologist, lack of continuity of care, difficulty in getting timely medical appointments as barriers to bladder cancer treatment, and having a single point of contact with either a nurse or patient navigator as a facilitator to care⁶⁹. In addition, they described wanting treatment closer to home rather than traveling to major cities⁶⁹. In this PEEK study, participants noted the difficulty in communicating with healthcare professionals between appointments and the difficulty in getting appointments with their specialist.

Affordability of healthcare

I've thought at times. Wow. This is expensive, Like, some of the out-of-pocket expenses. Yeah. Um, and, ah, you. Yeah. I thought, wow, that's really, really expensive. And I've had other people saying to me, they're having cystoscopy, they've gotten out of pocket and, and there's lots of things and, but I've had several operations of like more than seven and a half hours. Robotic surgeries and complicated things like that, which I've been I've paid out 5000 out of pocket for anaesthetist yeah. For one operation and stuff like that for a really high profile anaesthetist that did an awake intubation on me, you know what sort of stuff. So, um, it's been expensive and I've just thought I could have bought a Harley [Laughs], you know, the cost of these couple of operations. I could have done this or that with the money rather having surgery. Damn.
Participant 001_2022AUBLC

Almost half of the Australian population have private health insurance with hospital cover⁶⁵. This can be used to partially or completely fund stays in public or private hospitals. Between 2006 and 2016, the proportion of private health care funded hospitalisations in public hospitals rose from about 8% to 14%⁶⁵. In this PEEK study, a higher proportion had private health insurance compared to the Australian population.

Participants in this PEEK study described the costs and loss of income they experienced due to having bladder cancer. In this PEEK study, approximately a two-thirds had private health insurance and participants were most commonly treated as private patients in private hospitals. Work status did not change for approximately 60% of participants, this was mostly because they were already retired at the time of diagnosis. Where work status did change, it was primarily having to take leave from work or reducing hours worked.

The majority of participants in this PEEK study had monthly out of pocket expenses, with 50% spending up to \$250 a month. the costs were from paying for treatments, gap payments, and cost of specialist appointments. Over half of the participants described having at least some cost burdens, but for those without a cost burden this was primarily due to having everything paid for through the health system.

In other studies, people with bladder cancer described having financial difficulties as a result of their diagnosis. Reasons for financial difficulties included being unable to work, having a low income, or a lack of insurance^{10,58}. People aged under 65, those on lower income, or without insurance reported more financial difficulties^{10,13}.⁷¹, and financial difficulties resulted in treatment delays in lower health related quality of life⁷¹

Treatment

Treatment decisions are based on tumour grade and stage. Treatment may include surgery, chemotherapy, radiotherapy or a combination of these²⁷, a multidisciplinary approach improves the use of multimodal treatment⁷². Tumour recurrence frequently occurs within the first year of definitive treatment, and more than half of high grade tumours recur^{73,74}. The majority of participants had surgery to treat bladder cancer, and more than half the participants had Bacillus Calmetter-Guérin (BCG) treatment, 20 participants (48%) had chemotherapy, and three participants (7%) had radiotherapy.

The first specialist I saw only talked about the gold standard is that we should rip everything out. And he wouldn't, he was immovable, but I'm also immovable, so I refused. ... I will, I refused to cooperate with the surgery and insisted on a referral to an oncologist. So at that point they offered me what they call the trimodal option. So bladder salvage, which is what my main focus was on bladder salvage. So I didn't want to go down the road to surgery. ... Okay. Well, once I got to the oncologists, they said that they felt that they could preserve my bladder and so they recommended it. And how does the chemotherapy dose dense? In fact, it was called. And I also saw a radio and oncology radiologist as well. And so the treatment that was recommended was the track to weekly for four sessions, followed by, I think it was 30 sessions of radiotherapy.

Participant 020_2022AUBLC

Surgery

Early bladder cancer are treated by Trans Urethral Removal of Bladder Tumour (TURBT). High risk early bladder cancer, invasive bladder cancer and locally advanced bladder cancer, the tumours are treated by cystectomy, urinary function is restored by procedures such as an ileal conduit, continent urinary diversion, or bladder reconstruction (neobladder)⁷⁵.

There is growing evidence of better outcomes for patients who undergo radical cystectomies in high volume hospitals. Following implementation of volume guidelines in the UK, there was a decrease in 30 and 90 day mortality⁷⁶. In Australia, a review of radical cystectomy in Victoria reports of increased in-hospital mortality and prolonged intensive care unit admission in patients who had a radical cystectomy in a low volume hospital (less than 4 radical cystectomies per year) compared with those in a high volume hospital (more than 10 radical cystectomies per year)⁷⁷. A review of

NSW RCs reported that high volume centres (more than 6 radical cystectomies per year) had better disease specific survival than low volume centres (less than 3 radical cystectomies per year)⁷⁸. A registry of radical cystectomies performed could be beneficial, it could detect quality improvements⁷⁷. In addition, the number of RC performed by surgeon and hospital to ensure that bladder cancer patients are treated in medium to high volume centres. In Sweden a prospective database of radical cystectomies identified risk factors for complications⁷⁹.

Elderly patients experience higher complication rates, higher hospital readmissions and higher perioperative rates following radical cystectomy⁸⁰. Alternatives need to be considered and more data is needed to determine which elderly patients will benefit from radical cystectomy in terms of complications, quality of life and survival⁸⁰.

Other treatments

Following the surgical removal of the tumour, non-invasive high grade tumours can be treated with BCG immunotherapy for prevention or delaying of recurrence⁸¹⁻⁸³. This is given weekly for six weeks once the bladder has healed from surgery, maintenance schedules with BCG are not well defined^{82,84}. Non-invasive low-grade tumours have a poor response to BCG⁸⁴.

Muscle invasive tumours and BCG failures should be treated with cystectomy with urinary diversion. Neoadjuvant chemotherapy may be used with large tumours to assist with resection, there is a 5% advantage at five years, however, those that do not respond have a worse outcome due to delaying surgery. Adjuvant chemotherapy should be administered for lymph node positive tumours and or for tumours that invade muscle or surrounding organs⁸⁴.

Post surgical follow up of bladder cancer patients usually consists of urine cytology, repeat CT and regular check cystoscopies. Recurrence usually occurs within 12 months and over 50% of high grade tumours recur²⁷.

Pembrolizumab can be used for locally advanced or metastatic disease in patients that have received platinum-based chemotherapy⁸⁵. Avelumab as maintenance therapy for locally advanced or metastatic disease in patients that did not progress on first line platinum based chemotherapy⁸⁵.

Urinary diversions

Three systematic reviews of quality of life following neobladder or ileal conduct diversion suggests that those with a neobladder had a quality of life advantage over other methods of urinary diversions⁸⁶⁻⁸⁸

A meta-analysis of post-operative quality of life following continent and incontinent diversion showed no overall difference in overall quality of life, mental health and social health⁸⁹. However, those that had incontinent diversion displayed improvements in physical health compared to continent diversions. Those that had a neobladder had better emotional function and body image compared to incontinent diversion. The long-term quality of life following continent or incontinent diversion was not clear.

A mixed methods study of cancer and non-cancer ostomy patients described the most common symptoms that influenced daily life, these were fatigue and/or sleep problems, leakages, pain, bladder or bowel complaints, physical activity, usual daily activities such as work, clothing, diet and relationships/sexual intimacy.⁹⁰

A qualitative study of people that had undergone urinary diversion described that resumption of normal daily activities with no or limited restrictions on social and personal life, older age, and lower complications were associated with a better quality of life⁹¹. Those that had difficulty in the management of the ostomy, and those that had only a partial resumption of normal activities were more likely to have poorer quality of life⁹¹.

In this PEEK study participants described a negative impact on quality of life from having a stoma or problems with incontinence, and they described information about stoma management or from their stoma nurse as helpful. Some participants described that bladder preservation was an important treatment goals, while others described a hope that in the future there will be treatments that either prevent bladder loss or that bladder replacements will be improved.

Allied health

And the occupational therapist was really good too. She said to me, Are you just expecting to go back four days a week? I said, Oh, well, that was a plan. And she said, Well, that's really stupid, but you know, you're your own worst enemy. You need to go back one day a week and see how you go, and then two days a week,

maybe for a couple of weeks and then build up slowly and just see how you are. And, and I also, because I'd had 23 lymph nodes taken out, I went to see a lymphedema physio because I just wanted to get a baseline and make sure that if I got any leg swelling that she'd already seen me and to give me some exercises to make sure I didn't get lymphedema. And she said the same thing. She said, you're stupid, just going back straight away and, and you need to just grade it. So that was really helpful. And then it built up over a couple of months back to four days a week again. And so my goals were just getting back to work and managing to get through the day here was, you know, learning how to manage the bag and when to empty that sort of stuff and not have a leak. And, and then at home also done swimming and playing tennis this not that often but and walk the dogs all the time so and it's a bit scary start doing lifting, because the literature says you can get a hernia quite easily so I've done that slowly but now I come back to pretty much full strength again. I'm just a bit more careful now.
Participant 018_2022AUBLC

Allied health is important to manage the physical, emotional, practical and financial consequences of bladder cancer. The most common allied health professionals accessed by participants in this PEEK study were physiotherapists, counsellors or psychologists, and dieticians. In addition, a recurring theme throughout the study was the need for easier access or direct referral to emotional and mental support, however, only a third reported accessing counsellors or psychologists.

Lifestyle changes

Diet and exercise needs of people with cancer change throughout the course of their treatment and survivorship⁹², and lifestyle changes may be made by individuals to improve treatment outcomes, improve quality of life and reduce recurrence risk factors⁹³. In this PEEK study, participants described using physical exercise for both maintaining mental and physical health, as well as maintaining a healthy diet to manage their general health.

Other studies noted that people with bladder cancer making lifestyle changes such as diet and exercise, describing benefits to health-related quality of life^{14,41,94}. People with bladder cancer were motivated to exercise to have better outcomes following surgery, to improve health, return to normality, resume playing sports, however, side effects, worry about leakage and comorbidities were a barrier to exercise.^{95,96}

Complementary therapies

Complementary therapies include taking supplements, mindfulness and relaxation techniques, massage therapy and acupuncture and many others. Complementary therapies have been reported to be used by between 40% and 80% of people with cancer, with reports of improvements in stress or side effects of treatments⁹⁷⁻¹⁰⁰.

Key point

- Participants were in need of mental and emotional support, better access or information about how to access counsellors or psychologists may fill this unmet need.

Clinical Trials

And goodness me, it would be nice to see more actually more research into bladder transplants for those people that haven't got them any more. It would be nice if there was a less confusing amount of information about immunotherapy and about trials, because looking for trials is is very complicated. So some an easier access to that. I still see an oncologist. I'm sure that they would be very helpful, but without actually going and taking their time up just for questions, it would be good to have something that I could get clear, information that I could trust. To find potential trials, look at new research coming out. Participant 020_2022AUBLC

Clinical trials are essential for development of new treatments. The benefits to participants include access to new treatments, an active role in healthcare, and closer monitoring of health condition. The risks to participants include new treatment may not be as effective, and side effects.

A search of the Australian New Zealand Clinical Trials Registry was conducted on 20 June 2022. The search included any study that included participants with bladder cancer, was conducted in Australia, and was open to recruitment in the last five years. A total of 23 studies were identified that had a target recruitment of between 12 and 1292 participants (average=395), there were 16 studies that were international, and 7 studies that were conducted exclusively with in Australia. There were 17 studies that included only bladder cancer participants, and 6 studies that listed bladder cancer in the inclusion criteria among other types of cancer. The most common types of studies were investigating drugs (n=19), other studies were investigating surgery (n=1),

allied health (n=1), surveillance (n=1), and patient reported outcome questionnaires (n=1).

There were 18 studies conducted in New South Wales, 18 studies in Victoria, 12 in Queensland, 10 in Western Australia, and 6 in South Australia. There were no studies conducted in Tasmania, the Australian Capital Territory, or the Northern Territory.

In this PEEK study, 76% of participants had not discussed clinical trials, 12% had participated, however, and 50% were willing to participant in a clinical trial if there was one available to them.



Figure 12.1: Distribution of clinical trials for bladder cancer in Australia 2017-2022

Patient treatment preferences

Clinical guidelines that are aligned to patient preferences are more likely to be used and lead to higher rates of patient compliance.¹⁰¹⁻¹⁰³ Patient preferences and priorities vary across different health issues, preferences are associated with health care service satisfaction, they refer to the perspectives, values or priorities related to health and health care, including opinions on risks and benefits, the impact on their health and lifestyle^{101,104}.

To help inform patient preferences in the bladder cancer community, participants in this PEEK study discussed side effects, treatment administration, adherence to treatment. Participants in this PEEK study used examples to describe both mild and severe side effects. Examples of mild side effects included Fatigue, pain and nausea. Aches and pain were also used as an example

of severe side effects, as was the emotional impact. Mild side effects were also described as those that can be self-managed, and don't interfere with life, and severe side effects as those that do interfere with everyday life.

In other studies, people with bladder cancer have described side effects and symptoms they experienced as a result of their bladder cancer or treatment for bladder cancer. The types of symptoms reported include; urinary symptoms (frequency, incontinence, urgency, leakage, blood, and pain), pain and discomfort (in particular pain in bladder, pelvic and abdominal area), gastrointestinal symptoms (dry mouth, reduced appetite, nausea, vomiting, diarrhoea, and constipation), general malaise and fatigue (in particular disrupted sleep from changes to bladder function), sexual problems (sexual function, interest in sex), and emotional and mental health problems (depression, embarrassment from changes to bladder function)^{9,10,13,41,58,63,70,105}.

People with bladder cancer have noted the overall burden of side effects and rated the most troublesome side effects as blood in urine, frequent urination, sting or burning during urination, urgency to urinate, restricted movement due to pain or stiffness, worry about leaking (especially during sex, bed wetting, unable to hold it in), blood following cystoscopy, pain or discomfort during urination, and reduced interest in sex⁷⁰. In addition, people with bladder cancer have described the impact that changes to bladder function has on their daily lives, including disrupted sleep and always needing to know toilet locations^{58,63}. In this PEEK study, the symptoms that participants most wanted to control were pain, nausea and vomiting, and diarrhoea.

Self-management

Self-management of chronic disease encompasses the tasks that an individual must do to live with their condition. Self-management is supported by education, support, and healthcare interventions. It includes regular review of problems and progress, setting goals, and providing support for problem solving¹⁰⁶. Components of self-management include information, activation and collaboration¹⁰⁶.

Information

Um, I've just found just the booklets from the Cancer Council. I've just found that they have been excellent information sources. Um, but because it just depends

like every, night, like I have random thought and they kind of answer my questions like, you know what I mean? Like there's always an answer somewhere on the Cancer Council website.
Participant 009_2022AUBLC

Information is a key component of health self-management^{107,108}. The types of information that help with self-management includes information about the condition, prognosis, what to expect, information about how to conduct activities of daily living with the condition, and information about lifestyle factors that can help with disease management^{107,108}.

Participants in this PEEK study were most commonly open to information after they had gotten over the shock of their diagnosis, or right from the beginning. Others were receptive to information following treatment, continuously, or after they had a chance to learn about their condition so that they are able to ask questions. In another study, people with bladder cancer described a lack of appropriate information at diagnosis, for example their doctor not giving them a clear diagnosis that they could understand, or were given important information after procedures while still effected by drugs⁵⁸

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options, disease management, disease cause, and physical activity were most frequently given to participants by healthcare professionals, and, information about complementary therapies, how to interpret test results and, hereditary considerations were given least often. The topics participants most often searched for were treatment options, disease cause, disease management and, how interpret test results were most frequently searched for independently and, information about physical activity, clinical trials, and hereditary considerations were searched for least often.

In other studies, people with bladder cancer described the topics of information that were useful, this included; general information about cancer, side effects of treatment, managing side effects, treatment advantages and disadvantage, follow up schedule and tests, financial concerns, and what to expect^{63,65,109}. In some studies, people with bladder cancer described situations where they did not receive enough information to be able to cope, this included information about complications after surgery and chemotherapy, self-care after surgery, what to expect from chemotherapy, and the amount of maintenance

required following continent and incontinent diversions^{63,65}

Participants in this PEEK study described preferences for talking to someone plus online information as main preference. The internet was described as accessible, and a source of data they could digest at their own pace. Talking to someone was valued as it allowed them to ask questions, and it was described as more personalised and relevant. Written information was a preferred source for some, as this was a resource that they could refer back to. In other studies, people with bladder cancer described getting information from the internet, other people with bladder cancer and support groups, bladder cancer charities, social media, videos, printed material, indicating that a wide range of formats are useful information sources^{63,65}

Participants in this PEEK study described information that they found helpful, most often this was information from health charities. Others described information about what to expect, treatment options, and side effects, and other people's experiences as helpful. Information about treatment options, talking to their doctor, information specific to their stage, and information about stoma management was also described as helpful. Participants most commonly described that no information was not helpful, they also described being able to decide for themselves if information was credible or not. Information from their doctor, worse case scenarios, and a lack of information were all described as not helpful.

In this PEEK study, gaps in information provision were also identified. Information about treatment options, disease cause, and disease management were most frequently given to participants by healthcare professionals. Information about complementary therapies, hereditary, genes and biomarkers and interpreting test results were given least often. The largest gaps in information, where information was neither given to patients nor searched for independently were hereditary, genes and biomarkers, clinical trials and complementary therapies.

Participants in this PEEK study described what they would like to see in future information about bladder cancer. Topics included that information was more accessible and easy to find, that it includes all the treatment options available to them, and that information will include were to get emotional and mental support. In addition, participants wanted information about bladder cancer to reach the wider community, to increase awareness of their condition.

Activation (skills and knowledge)

Oh, yes. Um, I, I had BCG, um, basically for the last couple of years, and then I got to the point where I just couldn't handle the BCG any longer. The side effects seem to be getting worse and worse. And my urologist was obviously checking, doing, cystoscopy every three months and every six months. And in the end, his recommendation was that I'd done well to stick it out as long as I had and basically to stop the BCG, which is what I did.

Participant 036_2022AUBLG

Patient activation is the skills, knowledge, and confidence that a person has to manage their health and care; and is a key component to health self-management. Components of patient activation are support for treatment adherence and attendance at medical appointments, action plans to respond to signs and symptoms, monitoring and recording physiological measures to share with healthcare professionals, and psychological strategies such as problem solving and goal setting.

Patient activation is measured in the PEEK study using the Partners in Health questionnaire. The Partners in Health questionnaire measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease.¹¹⁰ Participants in this PEEK study had very good knowledge about their condition, were good at coping with their condition, were good at recognizing and managing symptoms, and were very good at adhering to treatment.

In other studies, people with bladder cancer described their motivations for adhering to treatment, therapy or surveillance schedules. Some described being motivated by feeling that they were taking care of themselves, support from family, support from healthcare professionals, and adhering to what their doctor prescribed for them^{41 95,111}. People with bladder cancer described reasons for not adhering to treatment, therapy or surveillance because of side effects, and not seeing positive changes^{70,95}. In this PEEK study, participants described adhering to treatment as per the advice of their clinician, as long as treatment is working, as long of side effects are tolerable, and for a specific amount of time (usually 2 to 3 weeks).

Communication and collaboration

Dead set nothing. Didn't know. Didn't even know you could get bladder cancer. And, and even, even then the word, the word cancer in any form whatsoever didn't exist. It was, it was not talked about. Um. The wording was possible carcinoma and that was it.
Participant 040_2022AUBLC

Dutch participants with Non Muscle Invasive Bladder Cancer (NMIBC) expressed that verbal and non-verbal communication was important to them, participants were less likely to ask questions if the medical professionals appeared to be busy, they preferred information that was clear and concise otherwise they worried¹¹². An organised hospital implied to the participants professionalism and was confidence building¹¹². In a number of other studies, people with bladder cancer described the importance of continuity of care with the same healthcare professionals, the importance of communication between healthcare professionals, convenient ways to make and keep track of medical appointments, and knowing who contact to get their needs met^{41,58,63, 70}.

In this PEEK study, participants also described wanting to have more time with their healthcare providers, and the importance communication between healthcare professionals for continuity of care.

Collaboration is an important part of health self-management, the components of collaboration include healthcare communication, details for available information, psychosocial and financial support^{107,108}. Communication between healthcare professionals and patients can impact the treatment adherence, self-management, health outcomes, and patient satisfaction¹¹³⁻¹¹⁶.

An expert panel identified the fundamental elements of healthcare communication that encourages a caring, trusting relationship for patient and healthcare professional that enables communication, information sharing, and decision-making¹¹⁷.

Building a relationship with patient, families and support networks is fundamental to establishing good communication¹¹⁷. Healthcare professionals should encourage discussion with patients to understand their concerns, actively listen to patients to gather information using questions then summarising to ensure understanding¹¹⁷. It is important for healthcare professionals to understand the patient's perspective and to be sympathetic to their race, culture, beliefs, and

concerns. It is important to share information using language that the patient can understand, encourage questions and make sure that the patient understands¹¹⁷. The healthcare professional should encourage patient participation in decision-making, agree on problems, check for willingness to comply with treatment and inform patient about any available support and resources¹¹⁷. Finally, the healthcare professional should provide closure, this is to summarise and confirm agreement with treatment plan and discuss follow up.

Communication and collaboration with healthcare professionals was measured in this PEEK study by the Care Coordination questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome¹¹⁸. The participants in this study experienced good quality of care, and good coordination of care. They had a good ability to navigate the healthcare system, and experienced average communication from healthcare professionals.

Participants that noted having good communication with their healthcare professionals noted that this was because of two-way, holistic, supportive and comprehensive conversations. In other studies, people with bladder cancer described characteristics of good communication with healthcare professionals, these included; thorough explanations, transparent and direct, supportive, reassuring, appearing interested, and responding to needs^{69,70}. In addition, good communication resulted in greater satisfaction with treatment choices, and adherence to therapy^{64,65}.

Negative communication was described as dismissive or one way conversations, information that was withheld or was not forthcoming. In other studies, people with bladder cancer described characteristics of poor communication with healthcare professionals, these included; being insensitive to intrusive procedures leading to embarrassment of patient, insensitive ways of delivering diagnosis or test results (for example via email), lack of time to discuss issues important to the patient^{58,69}. Participants in this PEEK study described wanting future communication to be more transparent and forthcoming, delivered with more empathy, and to have more time to discuss issues important to them.

Well, basically he just said that, well, get in and check it on a regular, you know, semi-regular basis sort of thing. And COVID was a disruptive force, I've got to say that, it didn't quite go to plan because of that. Pretty good. I've got to say that I didn't have too many issues with it did delay things at times but not to any great extent put it that way. It was only weeks, not months. And so, yeah, and I think that the discussion side of it probably. He spoke to me more as I, at the hospital rather than go back and see him. Whether I was 100% clear on everything. I would not say that I was. Normally when I go and see a specialist, I do take my wife with me, I mean she worked in the hospital system, which she can generally interpret something that I haven't quite picked up on as clearly. So I sort of yeah, I wouldn't say I was 100% clear of what was going to happen initially, but he spoke to me about the BCG and what should happen with that. And I didn't have any well, basically when I got down to that, that was another issue. But. Yeah. That's, that's basically what we spoke about.

Participant 011_2022AUBLC

Care and support

Yeah, I've found that they've been awesome. When I had a problem there maybe six months ago, I was having problems with where around the stoma. it was pretty red. And yeah, when seen the nurse and she told me to change the bag like daily instead of, you know, it was doing two or three days and things like that. So I've found that if I have any problems, I can ring her up, you know. And she's been great to ring up. I actually should, I save having to go into the hospital. I was taking pictures of me stoma and I'll send it to her and she was sending messages back and try this or try that. So didn't actually have to come to the hospital. So I was having like telephone consults with her. And I found it really good support.

Participant 044_2022AUBLC

In the USA, a study that included thirty participants with Muscle Invasive Bladder Cancer discussed their unmet needs, medical needs were lacking during the post-operative period, pain, bowel dysfunction and support for stoma and catheters were most frequent unmet. During the survivorship period (6 to 72 months post operatively) participants most frequently needed ongoing support to adjust to functions of daily living¹¹⁹.

In this PEEK study, participants were asked what care and support they had received since their diagnosis. This gives an insight into what services patients consider to be support and care services. Most commonly, participants described not receiving any support. In Volume 5 (2022), Issue 2: PEEK Study in Bladder Cancer

other studies, people with bladder cancer described the types of support they would have liked but did not have access to. People with bladder cancer described wanting more peer support, counselling, support to address problems with sexual function, information about services available, financial support, relationship support, and support to get to medical appointments.^{58,65,109} Participants in this PEEK also described they type of support that they wanted in the future, this included access to support and care in general, that they would like peer support, and that their will be more awareness of bladder cancer and what it is like to live with the condition.

Participants in this PEEK study that did receive support, described it in terms of support from organisations such as charities, from the hospital or clinic they were treated in, and peer support, both online and in person. In other studies, people with bladder cancer described the type of support they received and from whom they received the support. The types of support included support to make lifestyle changes, managing treatments and appointments, household duties, emotional comfort, providing information, providing support when coming recovering from treatments, information about services, and managing side effects and symptoms^{63,69,109}. They received support from nurses and healthcare professionals, other people with bladder cancer, partners, family, and friends^{58,63,69}

Well, the main support of that is basically from via Facebook and ZOOM some some of the bladder cancer groups. BEAT's been a big help they had an open forum, I was on a Zoom meeting I was on that last night they had a chap on, and I'm glad I didn't do it prior to the operation to be honest, he showed a few gory pictures. One of the urologist or gentleman's he's been in the field for quite a few years 40 years or something urology. There was a few, but answered questions and describing operations for various people. So I thought it was fairly good, I went down to a bladder cancer walk on Sunday and a walk in CITY, in Memory of The young lass that died with bladder cancer died from bladder cancer. And people there, it's a registered charity, BEAT they were very supportive. And, you know, all of the family members plus members of the medical association are medical, they were there. So, you know, just general chit chat and no one got too personal about anything, but it was a yes. Good supportive environment.

Participant 011_2022AUBLC

Anxiety associated with condition

I think the delay time between the procedure and saying getting results is the only one because it can be very stressful. You know, between having the procedure, the cystoscopy and then getting the results. Sometimes, you know, it's sort of I know it's hard because you can't get an appointment with the urologist sometimes, but, you know, it's a three or four weeks or something like, you know, sitting around wondering.

Participant 007_2022AUBLC

The rates of depression and anxiety are higher in people with chronic conditions compared to the general population. In a meta-analysis of 20 qualitative studies, it was reported that people with chronic conditions experienced anxiety or depression as either as independent of their chronic condition or as a result of, or inter-related with the chronic disease, usually however, anxiety and depression develops as a consequence of being diagnosed with a chronic disease¹²⁰.

In this PEEK study, anxiety associated with bladder cancer was measured by the fear of progression questionnaire. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety¹²¹. On average fear of progression score for participants in this study indicated moderate levels of anxiety. In addition, there were high rates of depression and anxiety in the PEEK bladder cancer participants.

In other studies, people with bladder cancer described having anxiety about their condition. Specific times when anxiety about condition noted were before treatment, before surveillance tests, and during the diagnostic period, however, once diagnosis is confirmed, some reported a reduction in anxiety^{14,41,58}. People with bladder cancer described being anxious about disease progression or returning, death, continence, and dealing with a urostomy^{41,58,70}. People with progressive disease had higher stress levels⁷. Younger people with bladder cancer have described more fear compared to older people⁶⁹.

Quality of life

Because it affected us being diagnosed with it as well. And because it was in the middle of COVID, like right at the start of COVID. When I was first diagnosed then. Every you know. The last two years. It's like shit for everyone. We didn't want to go out anywhere. We didn't want to socialise with our other family members.

We were invited to birthday parties. I didn't want to go. I didn't want to mix with anyone because of the fear of catching something and then missing out on an operation or missing out on a check-up and things like that. So yeah, it affected our quality of life.

Participant 033_2022AUBLC

In relation to quality of life, participants in this PEEK study described a mix of positive and negative impacts on quality of life, with more participants describing the negative impacts. Negative impacts were due to the management of side effects of treatment, the mental and emotional impact, the emotional strain on partners and family, and due to intimacy problems.

In other studies, people with bladder cancer have described the impact of their condition on quality of life. The impact of side effects, such as pain, cognitive function, urinary function, sexual function^{58,69}. Changes to sexual function has been described as impacting quality of life in other studies. This is from loss of sexual function, loss of sexual interest, anxiety about leaks, and pain^{58,63,70}. Changes to urinary function had an impact on day to day life, worry about incontinence or leakage, making some activities more difficult since access to toilets is essential,^{9,10,58,63,70}. People with bladder cancer described difficulty in travel or taking holidays, unable to act spontaneously as they need to know that a toilet is nearby, and needing to urinate at night leading to disrupted sleep and fatigue^{63,69}.

People with bladder cancer have described the impact on their mental or emotional health, especially with respect to depression, embarrassment from change in urinary and bowel function, body image, and worry that they will die from bladder cancer.^{9,10,14,63,69} Others described regret in not taking better care of their health⁹. People with bladder cancer have described the negative impact on their ability to work, role in their family, social life, ability to enjoy physical activities, and their independence^{9,10,58,63}.

In terms of positive impacts of bladder cancer, participants in this PEEK study described a positive impact from bringing people together, and to make them realise what is important. Similarly, in another study, people with bladder cancer described a positive impact of bladder cancer on their quality of life. This was from a change in their outlook, and strength from surviving a major illness⁶³.

People with bladder cancer have described the impact of bladder cancer on relationships. Many have described losing friends, that family and friends equate cancer with death and are too afraid to visit^{58,63}. Partners of

people with bladder cancer have described changes to their relationships, the effects of the changing moods and emotions of their partners, and the disruption of medical appointments and treatment and problems with urinary function was socially isolating.⁵⁸

In this PEEK study, a common theme was that a relationships suffered because family and friends withdrew, not knowing what to do or say, and from family dynamics changing from the stress and emotional impact of bladder cancer. Others reported that relationships were strengthened by people who were well-meaning and supportive, and that it had strengthened relationships.

Coping with bladder cancer

I'm just I think having a couple of close friends that I could talk to about it in my life and helped and I did a bit of exercise, I think helps you just, you know, working full time always distraction are good to, so it just keeps you busy and, you're not, dwelling on on negative things, which is there. But as I think at times, I definitely, and especially early on was very concerned and it would affect me sometimes when I'd think about it well, I'd often think about it, but again, didn't want to talk about it too much.

024_2022AUBL

In other studies, people with bladder cancer described how they coped with bladder cancer, or activities that they did to maintain their mental or physical health. People with bladder cancer described accepting or adapting to their condition being positive, and acknowledging that their health was better compared to others^{9,58,65}. In addition, people with bladder described the importance of support from family and friends, and support from healthcare professionals^{69 14, 9,58}. Others described being prepared when leaving home by knowing the location and accessibility of toilets, eating a healthy diet, bot smoking, and regular exercise^{9,58,70,95,122}

Participants in this PEEK study described maintaining their mental health, and noted the importance of family and friends, the importance of exercise, using mindfulness or meditation techniques. Almost a quarter noted that they did not do anything to maintain mental health. Participants in this PEEK study described maintaining their general health by being physically active, keeping busy, managing their stoma or incontinence, and complying with treatment.

Oh, I just feel that it was definitely a burden on my husband and I don't know what I would have done without him, to be honest, because he was the one that

would come and pick me up after my BCG and he'd have the hot water bottle there and he'd fill it up and then he'd drive me home and be so concerned that he could see how uncomfortable I was. And I just don't know what I would have done without him. I felt quite reliant upon him and he found it very frustrating because he couldn't do anything to help. He wanted to try and take it away from me, but he couldn't. So it was quite stressful for him as well.

Participant 036_2022AUBL

Characterisation

There were 44 participants with bladder cancer, and 5 carers to people with bladder cancer in the study from across Australia. The majority of participants lived in major cities, they lived in all levels of economic advantage. Most of the participants identified as Caucasian/white. Most of the participants had trade or high school qualifications, and most were employed either full time or part time, or were retired. Approximately a quarter of the participants were carers to family members or spouses.

Physical activities were not limited for participants in this study, and emotional problems rarely interfered with work or other activities.

Participants in this study had an average of two symptoms before diagnosis, and the most common symptoms were blood in urine and needing to pass urine often.

This is a group that had health conditions other than bladder cancer to deal with, most often sleep problems, arthritis or scoliosis, and anxiety,

This is a patient population that had blood in their urine leading to diagnosis which they recalled clearly. Most participants sought medical attention after noticing symptoms and were diagnosed after their general practitioner referred them to a specialist.

This is a cohort that were mostly diagnosed with bladder cancer following experiencing symptoms. On average, this group had four diagnostic tests for bladder cancer, they were diagnosed by a urologist in a specialist clinic. The cost of diagnosis was not a burden to them and their families. They were mostly diagnosed with urothelial carcinoma, and stage I. This is a group that had no emotional support at the time of diagnosis. This is a cohort that did not have any conversations about biomarker/genomic/gene testing, and had no knowledge of their biomarker status.

This is a study cohort that had no knowledge of bladder cancer before they were diagnosed. This patient population described prognosis in terms of no evidence of disease or in remission, or in relation to monitoring their condition with tests, scans, or regular follow up appointments.

This is a patient population that had discussions about multiple treatment options.

This is a study cohort that took into account the advice of their clinician as part of many considerations when making decisions about treatment.

Within this patient population, participants had not changed decision making over time, this was because they had always taken the advice of their clinician.

When asked about their personal goals of treatment or care participants most commonly described wanting to be cancer free, avoid recurrence or increase longevity

This is a group that were cared for by a urologist, and had access to a general practitioner to treat their condition.

Almost two-thirds of this cohort had private health insurance, mostly treated as private patients treated in the private hospital system. This is a group that did not have trouble paying for healthcare appointments, prescriptions, and paying for basic essentials. Their monthly expenses due to bladder cancer were not a burden.

The work status of participants in this study did not change due to bladder cancer. Carers and family did not have to change employment status.

Participants had surgery, and drug treatments for bladder cancer. The most common treatments were transurethral resection of bladder tumour and Bacillus Calmette-Guérin.

This is a group that did not have discussion about clinical trials, though would consider taking part if there was a suitable one for them.

This is a patient population that described mild side effects as symptoms such as fatigue or lethargy. This is a study cohort that described severe side effects as symptoms such as pain.

This is a patient population which described adhering to treatment as per the advice of their specialist, as long as prescribed, or as long as treatment is working. This is a study cohort that needed to see evidence of stable disease or no disease progression. If treatment worked, it would mean that they could do everyday activities and return to normal life.

Participants in this study had very good knowledge about their condition, were good at coping with their condition, were very good at recognizing and managing symptoms, and were very good at adhering to treatment.

Participants were given information about treatment options, disease management, and disease cause from health care professionals, and searched for treatment options, disease causes, and disease management, most often. This is a group who accessed information from non-profit, charity or patient organisations most often.

This is a patient population that access information primarily through the internet, a health charity, or from other patient's experiences.

This is a study cohort that found information from health charities, other people's experiences, and what to expect from the disease, side effects and treatments as being most helpful.

Participants commonly found no information unhelpful, and information from their GP as unhelpful.

This is a group that preferred talking to someone plus online information. This is a study cohort that generally felt most receptive to information after the shock of diagnosis.

Most participants described receiving an overall positive experience with health professional communication, which was holistic, two way and comprehensive. For those that had a negative experience it was mostly communication was dismissive, a one way conversation.

The participants in this study experienced good quality of care, and good coordination of care. They had a good ability to navigate the healthcare system, and experienced moderate communication from healthcare professionals.

This is a patient population described not receiving and care or support. For those that did have support, it was from charities, their hospital or clinic, or from online support groups.

This is a patient population that experienced a negative impact on quality of life largely due to the side effects of treatment or symptoms of conditions that they need to manage

This is a study cohort that experienced at least some impact on their mental health and to maintain their mental health they noted the importance of family and friends, the importance of exercise, and mindfulness or meditation in maintaining their mental health.

Within this patient population, participants described being physically active, and the importance keeping a normal routine, and managing their stoma or incontinence in order to maintain their general health.

Participants in this study had felt vulnerable especially during or after treatments, and when first diagnosed and the first few months after diagnosis. To manage vulnerability, they practised self-help (resilience, acceptance, staying positive) to manage the feeling of vulnerability

This cohort most commonly felt there was a positive impact on their relationships, with relationships strengthened, and that people were well-meaning and supportive.

Participants felt they were a burden on their family, due to the mental or emotional strain.

Most participants felt there was some cost burden which was from the costs of treatments, and gap payments for public or private health.

The participants in this PEEK study had moderate levels of anxiety in relation to their condition.

Participants would like future treatments to be more accessible particularly equitable, timely and includes access in rural locations, and for there to be more open and informed discussions about treatments.

This is a study cohort that would like information to be more accessible and easy to find, and also to include all treatment options available to them. Many participants were happy with the information they had about their condition.

Participants in this study would like future communication to be more transparent and forthcoming, and delivered with more empathy.

Participants would like future treatments to include access to appropriate real-world support services. Many participants were happy with the care and support they received.

This patient population was grateful for healthcare staff, and for low cost or free medical treatments through the government.

It was important for this cohort to control, pain, nausea and vomiting, and diarrhoea. Participants in this study would consider taking a treatment for more than ten years if quality of life is improved with no cure.

Participants' message to decision-makers was to raise community awareness, and that they were grateful for the healthcare system and the treatment they had received.

This is a patient population that wished they had known what to expect from their condition especially the symptoms, and side effects of medication. They also wished they had been more assertive in relation to understanding treatment options and discussions about treatment

The aspect of care or treatment that participants in this study would most like to change is to have is they would have like more time and personalised attention with specialists.

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