UNDERSTANDING PATIENT EXPERIENCE WITH BLADDER CANCER IN ALBERTA

SUSAN NGUYEN, MARLYN GILL

PRINCIPAL INVESTIGATOR: DR. NIMIRA ALIMOHAMED

PACER ACADEMIC SUPERVISORS: NANCY MARLETT, SVETLANA SHKLAROV

SPONSOR: ALBERTA HEALTH SERVICES CANCER STRATEGIC CLINICAL NETWORK

Ethics ID: HREBA.CC-17-0197

Table of Contents

PaCER REPORT

"You have to beg, borrow and steal to get information": Understanding Patient Experience With Bladder Cancer In Alberta

Susan Nguyen and Marlyn Gill

March 25th, 2018

Executive Summary

This qualitative research study informs the Cancer Strategic Clinical Network (CSCN) of patient experience with the current Alberta Health Services (AHS) Bladder Cancer Pathway in Alberta. The study included patients with both muscle invasive and non-muscle invasive bladder cancer.

PaCER Methods

Patient and Community Engagement Research (PaCER) enables specially trained patient researchers to engage in peer-to-peer qualitative research. There were three phases in the research; Set or Co-design, Collect, and Reflect. The research was iterative, following the directions indicated by the patient participants. The data were analyzed using participatory grounded theory method (Teram, Schacter & Stalker,2005), a variation of Glazer & Strauss' (1967) grounded theory especially appropriate for patient-to-patient qualitative research.

Results

Our results indicated that participants perceived service gaps, especially with respect to ongoing contact with providers and information between the various diagnostic and treatment stages along the current Bladder Cancer Pathway. Follow up after surgery was sporadic with incomplete information. Patients believed that waiting in isolation for test results and surgery negatively impacted their overall health and wellbeing.

We identified seven main categories within the bladder cancer patient's journey:

Table 1

Theme	Sub Theme
1) Blood in Urine – Go to GP	a) Recognition of possibility of bladder cancer b) Delay in bladder cancer diagnosis over a continuum of just over a year
2) Meeting With Specialist(s)	a) Patient perception of meeting with specialist(s) b) What and how patient was told about diagnosis of bladder cancer c) Delay in receiving diagnosis from specialist(s) d) Patient ability to hear diagnosis

3) Non-Muscle Invasive Patient Experience	3i) Non-muscle invasive treatment experience a) Patient's perception of knowledge of treatment b) Views on early discharge 3ii) On-going surveillance for recurrence a) Respect for patient dignity b) Provider care and competence c) Recurrences
4) Muscle Invasive Treatment Experience	a) Perception of choice of diversion and/or stoma b) Post-surgical support c) Early discharge from hospital and follow-up d) Adjusting to life with a "new" bladder post cystectomy
5) Patient Experience of Waiting Throughout The Bladder Cancer Journey	a) Experience of waiting b) Perceived isolation c) Speedy access
6) Rural Patients' Experience	a) Availability of informed emergency treatment b)Travel considerations
7) Psychological and Emotional Sequelae	a) Effect of the word "cancer" b) Trauma of bladder cancer surgery/treatment c) Stress of being own advocate

Discussion

The participants in this study believed that the two main areas for concern in their patient journey with bladder cancer in Alberta are: a) connectedness with their health care providers throughout all stages of their journey, especially while waiting for the next stage and b) the ease of ability to get the necessary information from either their provider or another reliable source when they needed it. They perceived that their overall medical care from their various providers was really good. It was the feeling of not knowing "What is the next step?" that created a lot of frustration, anxiety and stress for the participants. They needed ongoing connection and information between the various tests and treatments.

Recommendations:

1) The aid of a nurse or navigator, a "go to person" would be a valuable resource for patients especially when they are first diagnosed and learning about the disease and what their journey may entail.

2) A centralized clinic for the different specialists was seen as a real benefit in terms of speed of diagnosis and treatment and convenience.

3) Centralized records were seen as a benefit especially when dealing with emergencies.

4) Provider system organized support groups were viewed as an improvement to the patient led support groups that currently exist. Patients expressed the need for a combination of medical and peer support.

5) Participants expressed the need for the cystoscopy exam to be replaced with some other type of diagnostic procedure like a urine test similar to the FIT stool test for colorectal cancer. They believe that a less invasive but accurate screening test that could be done regularly possibly as part of an annual screening after a certain age could potentially catch bladder cancer sooner.

6) A desire was expressed for classes for each stage of their journey with bladder cancer. Many felt that it was necessary to have time to partialize the information that they had received, and the availability of classes would allow the opportunity to learn about each step of the journey in more detail and the chance to ask questions and review what they have learned.

7) A compilation of Tips/Resources from “expert” patients, those that had gone through the journey before them. This was thought to be an excellent backup for those that may not have access to a support group.

8) The participants expressed the need for increased awareness of bladder cancer both amongst medical professionals, especially primary physicians, and the greater community.

9) The provision by medical providers of a list of reliable websites.

PaCER REPORT

“You have to beg, borrow and steal to get information”: Understanding Bladder Cancer Patient Care Experience In Alberta

Susan Nguyen and Marlyn Gill

March 25th, 2018

Introduction

This Patient and Community Engagement Research (PaCER) qualitative research study is the patient perspective of the current Alberta Health Services (AHS) Bladder Cancer Pathway undertaken to inform proposed further research to improve the Bladder Cancer Pathway in Alberta.

Bladder cancer is the fifth most common cancer in Canada, accounting for 5% of all new cancers (approximately 738 patients in Alberta in 2012) and is 19th in national funding (Canadian Cancer Society’s Advisory Committee on Cancer Statistics, 2016). Understanding the patient perspective of their journey with bladder cancer is a crucial first step in improving the overall care for patients with this disease.

This study, using PaCER qualitative research methods, will ensure that any changes in the bladder cancer pathway are designed with the consideration of the patients’ collective experiences, perspectives and goals. All of the researchers in this study are specially trained patients with chronic diseases and one of the researchers is a bladder cancer survivor.

Background and Context

A brief literature review of studies investigating bladder cancer patients’ experience with diagnosis and treatment revealed that most patients believed they have not been given enough information about bladder cancer in their conversations with doctors and nurses (Arora et al., 2011; Fitch et al.,2010; Heyes et al.,2014; Leydon et al., 2000; Mossanen et al., 2016; Mohammed et al., 2014; Skea et al., 2014). Lack of information included awareness of options, information about the next steps and details about their condition. Arora et al. (2011), Beitz & Zuzelo (2003); Mohammed et al., (2014); McMullen et al., (2016) noted that patients wanted improved follow up after cystectomy surgery especially with regards to information, help with medical supplies and support adjusting to their new lives. Psychological support was often needed for these patients as such patients often struggled with new body images as well as sexuality (Fitch et al, 2010 and Heyes et al., 2014).

The need for recognition of psychological distress was noted since many patients experienced shock and fear at diagnosis and suffered from ongoing anxiety with respect to repeated surveillance cystoscopies (Heyes et al. 2014 and Koo et al., 2017). Several articles note the need for patient centred care and patients’ wish to be treated with dignity and respect as a whole person (Arora et al., 2011; Koo et al., 2017; Skea et al., 2014; Garg

& McMullen, 2016). One article, investigating the usefulness of employing a multidisciplinary team when treating patients with bladder cancer, concluded that multi-disciplinary teams could possibly be beneficial for patients (Prades et al., 2015).

Methods

PaCER uses several qualitative research methods set within the patient engagement research framework outlined in *Grey Matters* (Marlett & Emes, 2010). For this study we chose participatory grounded theory (Taram, Schacter & Stalker, 2005) as we wanted to understand the patient experiences and beliefs in the hope of developing some theory around how bladder cancer patients perceive their care pathway within the province of Alberta.

Recruitment and Inclusion Criteria

We used purposive sampling of patients who had been diagnosed with bladder cancer within the last ten years, were over age 18 and were able to speak English well enough to participate in focus groups or interviews. All of our participants were members of Bladder Cancer Support Groups. Each prospective participant was interviewed by telephone by a research team member to ensure that they fitted the criteria and understood the parameters of the study.

Participants

We recruited 13 participants (7 males, 6 females). We facilitated one SET or Co-design focus group (3 participants), one Collect focus group (5 participants), one Reflect group (7 returning participants), and conducted narrative interviews with 5 patients.

Demographic Information

Table 1

PARTICIPANT	SITE	GENDER	AGE	STAGE/GRADE	TREATMENT
C1	Canmore/ Calgary	M	76	1	TURBTs, Epirubicin, BCG
C2	Calgary	M	58	3?	TURBTs, BCG
C3	Calgary	M	64	MIBC	TURBT, RC-IC (ostomy)
S2	Red Deer/Calgary	F	72	1 & secondary primary cancer left kidney/ureter	TURBTs, BCG, RC-IC (ostomy); left kidney/ureter

				4/17	removal 4/17
CIL1	Ft. McMurray/ Calgary	F	66	0 (Low Grade)	TURBT
S1	Calgary	M	81	NMIBC-MIBC	TURBT, BCG, RC-IC (ostomy)
E4	Edmonton	M	66	Unclear at time of FG	Back to back TURBTs
E1	Tofield/ Edmonton	F	55	2 MIBC	TURBT, chemo, RC-neo
E2	Edmonton	F	79	3 MIBC	TURBT, RC-IC (ostomy)
E3	Edmonton	F	78	MIBC	TURBT, RC-RC (ostomy)
E5	Edmonton	F	64	NMIBC – low grade	TURBT
S3	Edmonton	M	61	MIBC	TURBT, RC-neo
E6	Edmonton	M	?	MIBC	TURBT, RC-neo, chemo

Data Collection and Analysis

We collected data using the PaCER framework, which consists of three phases: SET or Co-design, COLLECT and REFLECT

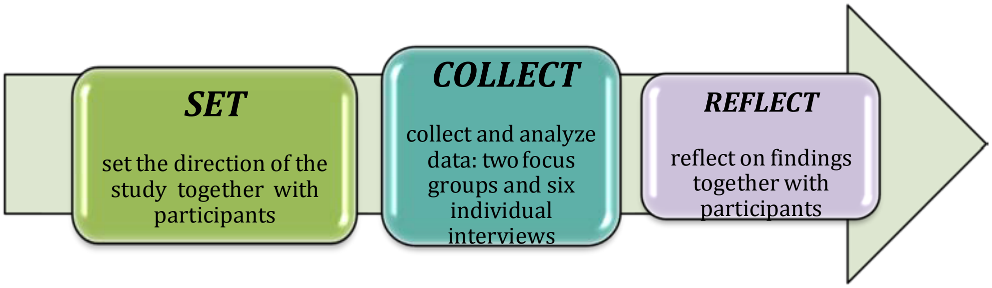


Figure 1. PaCER Research Method

Our patient engagement research process is iterative and amenable to changes in direction depending on the information received from any group or interviewee (Marlett, Shklarov et al., 2014). Participants are involved in all stages of the research (Gill, Bagshaw et al., 2016; Gillis, Gill et al., 2017; Miller, Teare et al., 2016). The Set group is used to indicate what topics are of the highest importance to the patient participants and directs the guiding questions for the Collect focus group and narrative interviews. Information from each subsequent Collect group or interview is used to inform the guiding questions for the next group or interview. However, each group or interview participant was asked the same initial question: *Please tell us about your patient care experience with bladder cancer.* This opened the door for participants to describe their experiences. We encouraged discussion among the participants and used short prompt questions to deepen the information being given. In focus groups, we used two PaCER facilitators; one to facilitate the discussion, one to take flip chart notes. All groups and interviews were audio recorded and later transcribed. Both recording methods (audio recording and flip charts) were used in the analysis.

Set Group

Our Set group had three participants. Despite the small number, the group lasted for the full five hours as all three participants discussed their experiences in detail. The flip chart notes were posted on the walls and the three participants were asked to check the veracity of the notes and were invited to give additional comments on all of the noted topics as well as identifying any omissions. In keeping with PaCER protocol we used the flip chart notes to develop the guiding questions for the first Collect group.

Topics of major importance to our participants used to formulate guiding question for the first Collect group were:

- We are “people” not a case or disease. Please see us holistically.
- Being An Informed Patient
- Perceived Glitches In The Journey

- Stress and Ramifications of Patient Perception of Cancer = Death
- Living The Rest of My Life
- Good Communication Between All Caregivers

Collect Groups and Narrative Interviews
We held one Collect focus group (n=5) lasting for the full five hours, and interviewed five participants using narrative interview techniques. We analyzed the data iteratively. We reached saturation of themes and sub themes after the Collect focus group and two narrative interviews, but went forward with three already planned interviews to be sure that we had rich and thick data to inform the subsequent phases of the overall project.

Reflect Group
We had seven returning participants for the Reflect groups. We ran two simultaneous Reflect Groups – one in Calgary and the second in Edmonton. The decision to do the two groups was partially due to the inability of participants to travel and that it was more economically feasible to send one researcher to Edmonton to facilitate the second group rather than cover the travel expenses of several participants.

In the morning session participants of both groups reviewed the themes and subthemes the PaCER researchers had identified emerging from the data gained during the Set and Collect focus groups and narrative interviews. Posters outlining seven major themes and twenty-seven subthemes analyzed from the data using participatory grounded theory (Gillard & Simons, 2012; Taram, Schacter & Stalker, 2005) were displayed on the walls. Each poster named the theme/subtheme, an explanation of the theme or subtheme and several verbatim quotes to illustrate the theme or subtheme. We also posted the recommendations from the participants. Participants were asked to go round all of the posters making notes on as many as they liked. They could disagree, agree with the information as well as add comments and experiences within any given theme or subtheme. They were asked to fix a coloured sticky note to the poster if they had made a comment, allowing us to see which themes and sub themes were most popular and therefore most important to our participants. This allowed participants to check our analysis, challenge or add to it, and allowed for the emergence of theory based on the data during the afternoon discussion. For the afternoon discussion we connected the two groups by speaker phone to give completeness to the group analysis.

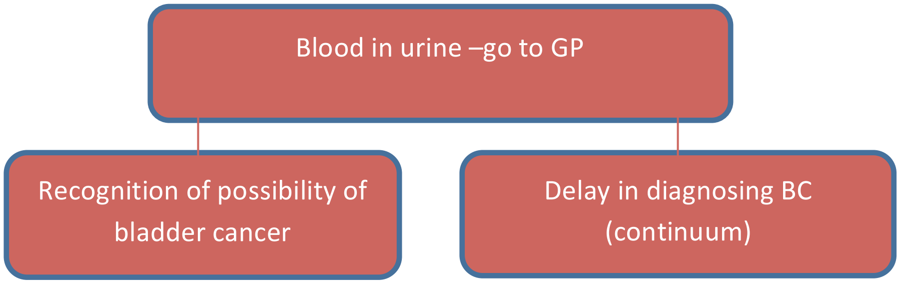
Research Credibility and Trustworthiness We used several strategies to raise the credibility and trustworthiness of the research: (1) The patient researchers facilitating the groups, interviewing patients and analyzing the data had to understand, reflect on, and state his/her biases (Bogdan & Taylor, 1975; Kirk & Muller, 1975; Patton, 1990) (2) As surgical patients we had a familiarity with the experiences of the participants (Shenton, 2004). (3) We used research colleagues, academic supervisors from PaCER, and peers to review and discuss the emerging data, coding, and themes (Lincoln & Guba, 1986, Shenton, 2004). (4) We employed iterative questioning, triangulation (e.g., grounded theory and participatory grounded theory (Taram, Schacter & Stalker, 2007 and two different data collection techniques), and thick description of bladder cancer patient experiences (Lincoln & Guba, 1986, Patton, 1990). (6) We completed a literature review to assess the congruence of our findings with previous research (Berg, 1989; Lincoln & Guba, 1986; Morse et al., 2002; Shenton, 2004). (7) Patient to patient research tends to lessen the reflexivity present when traditional healthcare providers are used (Berger, 2015).

Results

The results section is divided into seven themes: 1) Blood in The Urine – Go to GP; 2) Meeting the Specialist; 3) i) Non-Muscle Invasive Treatment Experience; 3ii) Ongoing Surveillance for Recurrence; 4) Muscle Invasive Treatment Experience; 5) Patient Experience of Waiting Throughout the Bladder Cancer Journey; 6) Rural Patient Experience and 7) Psychological and Emotional Sequelae.

1) Blood in the Urine – Go To GP

Figure 2



Blood in urine –go to GP

Recognition of possibility of bladder cancer

Delay in diagnosing BC (continuum)

The most common symptom of the possible presence of bladder cancer is blood in the urine. The majority of our participants experienced this symptom to varying degrees and this prompted them to get checked out for the potential cause. We found that our participants experienced two different scenarios; a) recognition by the primary physician of the possibility of bladder cancer and b) delay in a bladder cancer diagnosis over a continuum of just over a year. Several were fortunate that their general practitioner suspected something more serious that a UTI and ordered further tests referring them to a urology specialist quickly. Other participants experienced a delay in getting additional investigation and referral to a specialist. Some believed that their family practitioner wasn't as aware of bladder cancer as they perceived he/she should be or test results showed an alternative possible cause for blood in the urine such as kidney issues, potentially masking the ability for bladder cancer to be diagnosed right away.

Table 2

<u>Theme</u>	<u>Exemplar Quotes</u>
Blood in Urine - Go To GP	***SN202*** *I never noticed anything until a day later. I went to the bathroom at home. My bladder was working fine but I peed a chunk of blood. That's when I went to the doctor.* ***S395*** *Well, it (blood in the urine) happened on a Friday night. I got on a plane Saturday. I was at Walmart going through the*

	aisles to find the biggest and best padding. I had to get home. I got home. I saw the doctor the next day. ***SN322*** *I had gross hematuria on a Friday night. I called my husband and said that I'm in trouble. He said that we would go see the doctor on Monday but it was a public holiday in February so I went on Tuesday.* ***S001*** *…I stepped down off the stool, missed the stool and hit the floor. The next morning I woke up and went to the washroom and I was peeing blood. It was a bit scary.*

a) Recognition of the Possibility of Bladder Cancer

Many of our participants believed they were fortunate that their GP was either already familiar with bladder cancer and suspected it right away as a potential cause for the blood in their urine or at the very least realized that it was more than a UTI and further investigation was warranted.

Table 3

Subtheme	**Exemplar Quotes**
Recognition of Possibility of Bladder Cancer	***S065*** *I was fortunate that I had a GP that was more proactive. He realized that I had something a bit more serious than a bladder infection because he has come across bladder cancer before.* ***S066*** *When I had blood in my urine I went to him (GP) right away. He got me in within 48 hours for an x-ray and ultrasound. The results came back within the hour and he got me in to see an urologist the same day. I went and saw the urologist.* ***S093*** *The doctor I went to initially, who wasn't my family doctor, was interested enough in sending me for the ultrasound.* ***S365*** *I had blood in the urine. He (GP) sent me for a cystoscopy and the urologist said that I had bladder canc*er.

b) Delay In Diagnosing Bladder Cancer- Continuum of just over a year

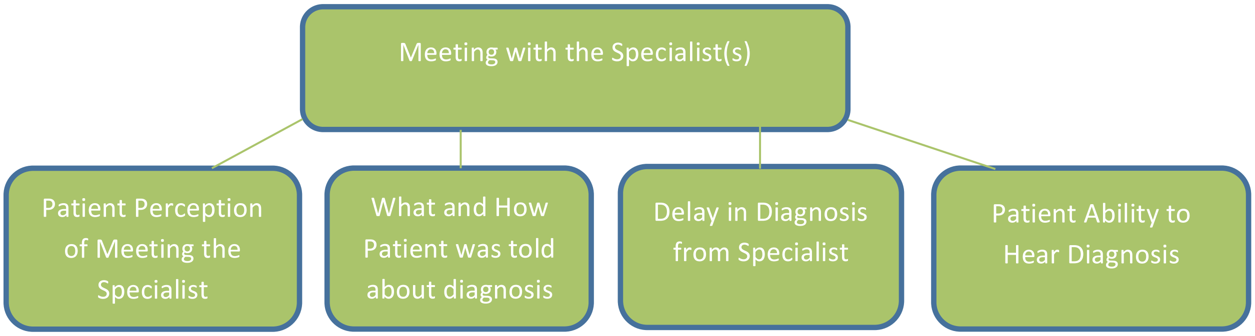
Several of our participants experienced a delay in being diagnosed with bladder cancer. The delay varied from several weeks to just over a year. There appeared to be two main reasons for this. A few of the participants believed that their GP wasn't as aware of bladder cancer as they perceived that he/she should/could be and they were treated for a period of time as having a UTI before finally having further investigative testing and referral. Fast diagnosis of a UTI was believed to be more prevalent in women. A second reason for delay with some participants is that they had a pre-existing condition causing blood in the urine. They knew what they were experiencing was different but their physician disregarded their experience. This highlights the need for physicians to trust that patients know their own bodies. In a few cases participants believed that faster referral to testing and a specialist could have possibly meant an earlier diagnosis, potentially saving their bladder.

Table 4

Subtheme	**Exemplar Quotes**
Delay in Diagnosing Bladder Cancer (Continuum)	***S028*** *That is what is frustrating for me is that the medical community isn't aware of how predominate bladder cancer can be.* ***S029*** *I don't think that my GP is aware of bladder cancer. It never got investigated as bladder cancer.* ***S037*** *I have heard from a number of people that don't have their bladders anymore. Their GP had been treating their issues as an infection and had them on antibiotics and all sorts of stuff.* ***S311*** *I think that is a gender issue as well. I think men get more attention with blood in the urine because women have more issues "down there" with blood.* ***S384*** *I had over a year of preamble. With bladder cancer, as a female, what was the risk?* ***R018*** *…My GP tried to attribute my issue to the kidney stones that I'd had earlier. My presenting symptoms were excruciating back pain a month before the blood appeared in my urine. I knew it was different than the kidney stone pain.* ***R021*** *There were several presenting symptoms. You have to be totally blind to the understanding of bladder cancer not to pick up on one of them. There was weight loss, blood in the urine – not droplets, but gushing blood. There was a pulmonary embolism. All that happened in a period of about a couple of weeks.* ***S019*** *For about 20 years I have dealt with a kidney disorder. I have nephritis and it doesn't process the blood properly. That had sometimes caused some blood in my urine. I was given an antibiotic because they thought it was a bladder infection.*

2) Meeting With The Specialist(s)

Figure 3



Our theme of Meeting with The Specialist(s) has four subthemes a) Patient Perception of Meeting The Specialist b) What and How Patient Was Told About Diagnosis of Bladder Cancer c) Delay In Knowing Diagnosis From Specialist and d) Patient Ability To Hear Diagnosis

a) Patient Perception of Meeting With Specialist

Our participants had mixed reviews about their meetings with specialists. Several saw more than one kind of specialist. In addition to an urologist, some saw an oncologist and a urological surgeon, depending on their diagnosis and treatment plan. The biggest concern amongst the participants was difficulty with communication either with the specialist and/or office staff and getting the necessary information about upcoming surgeries and/or treatments. Some participants were fortunate and received the much needed information and were given the necessary time to ask questions, while others felt like they were in the dark and did not know where to turn to get what they felt they needed. A few patients felt that they experienced a benefit of ease of access and possibly a speedier appointment process due to having more than one specialist located in the same medical facility.

Table 5

Subtheme	Exemplar Quote
Patient perception of meeting with specialist	***R030*** *When I met the urologist I was ready to give up and when I met with the surgeon I was motivated and encouraged and felt I had an opportunity to beat this disease.* ***S484*** *Well, they (urologists) need to learn to communicate better in my opinion, or have someone do it for them. I do know that they are busy.* ***S522*** *I had the luxury of having Dr. _____. He was amazing…I had an hour and a half to question everything.*

	We had the white board and I used Google. ***S502*** *The surgeon took time to talk to me about what was going to happen (before my cysto) and I thought that was wonderful.* ***S451*** *I don't know about the nurses but at the front desk whoever is answering the phone, the phone system needs to be blown up because you can't talk to a real human being…* ***S468*** *I was dealing with what was a possible recurrence. He (urologist) scheduled me for a biopsy. I get a phone call from his office and was told that I was scheduled for another cysto. I asked why I was going for a cysto and they couldn't give me an answer.* ***R032*** *That is the benefit of having our Institute here. At the time I went through all this, the cystoscopies were done at the Grey Nun. They also did the TURBTs and if the pathology comes back negative life goes on except for a recurrence. There was no need to go back to the urology office at what was then the Hyde ? centre.* ***R033*** *In my case I had to go to the Hyde centre to meet with the urologist who did the TURBT to get the diagnosis of muscle invasive. Because I was there and because the surgeons were also there, (now they are at the Kaye clinic) that facilitated my being able to see the surgeon so soon after getting the diagnosis of muscle invasive. That was so positive. As E3 said it is more positive that even the cystoscopies are done at the same facility.*

b) What and How a Patient Was Told About Diagnosis of Bladder Cancer

One of the biggest participant concerns was their ability or inability to get the information they needed about their exact diagnosis and the information they needed about any surgery or treatment plan. Participant experiences varied along a continuum with some getting what they needed and others feeling alone and stressed as they tried to get information from providers or other sources. Some patients believed they had been told about their diagnosis in a caring manner while other felt the news was abrupt and offhand.

Table 6

Subtheme	Exemplar Quotes
What and how a patient was told about diagnosis of bladder cancer	***S057*** *My urologist was really good about explaining the process and what was going to happen to me and all that it entailed.* ***S068*** *I had the same problem. I had difficulty getting*

	information. There was no connection to get information from anyone. We didn't have Bladder Cancer Canada back then. ***S070*** *What happened for me with the surgery, I wasn't told that it was a scope surgery. I didn't even know about the existence of scope surgery.* ***R035*** *I had the same experience as ___. I was fortunate to have the surgeon available to me and my family who were able to ask the questions that they had.* ***S024*** *I went to my GP (who is a really great doctor but doesn't have any bedside manner) because I couldn't get into see my urologist right away. He said "Hello, how are you? By the way you have bladder cancer." So there you go.* ***S482*** *Because that speciality is so special, you have to beg, borrow and steal to get bits of information. If you are not capable of that, then what?* ***S505*** *I tried to do some research on how to read these things (pathology reports) but that doesn't match up and I am still struggling to understand them. I'm confused.*

c) Delay in Knowing Diagnosis From Specialist

Most participants received their biopsy results within a couple of weeks from the initial TURBT surgery. Some however due to circumstances or protocol were waiting for extended periods of time to know for sure what they were dealing with. This caused anxiety and extreme stress.

Table 7

Subtheme	**Exemplar Quotes**
Delay in knowing diagnosis from Specialist	***R009*** *…During my treatment twice I did have polps removed. They were sent off to Toronto to find out if they were cancerous or not. You are waiting 4 weeks for results.* ***S095*** *Maybe it (pathology results) came back in two weeks but you don't know until you see your doctor in 6 weeks. You're sitting waiting for six weeks and wondering.* ***S099*** *I've got a good doctor that is good for that as well but it took 4-6 weeks to get the results back. He was able to look up the results in NETCARE..* ***S417*** *For me when I bled in September, I wasn't diagnosed until Christmas Eve. That was challenging.* ***S443*** *Well, I phoned because he (urologist) told me after the surgery in the recovery room that I would hear (about the pathology results). I didn't hear so I phoned his office.* ***S444*** *His (urologist's) receptionist said that if it was cancer I would hear. So, I believed that I didn't have cancer .I do have*

	a friend who is a physician. He got the report for me and then I saw my family doctor. ***S446*** *I did (talk to my urologist about not getting the pathology results) and then gave him hell. He put it down about people being on holidays. Well, I still believed that I didn't have cancer.*

d) Patient Ability to Hear Diagnosis

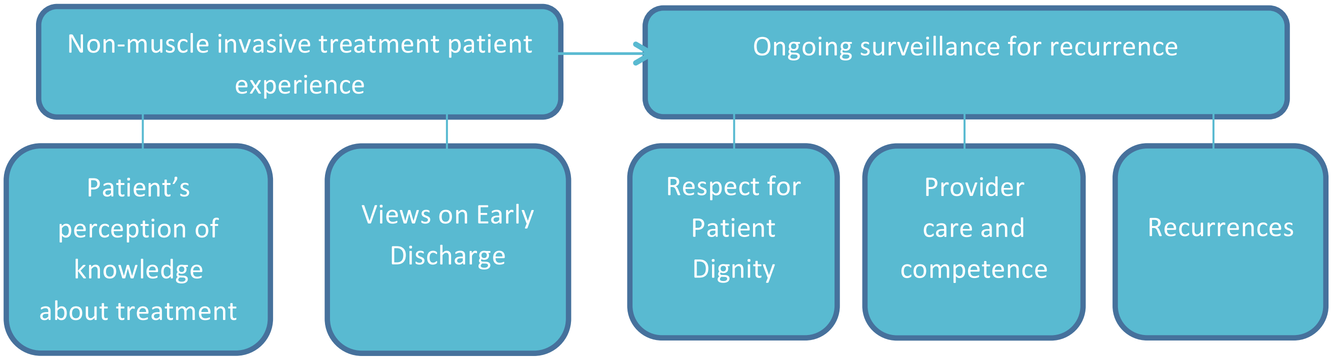
Participants had varying ability to hear their official diagnosis of bladder cancer. Many expressed the feeling of being shocked to hear the word "cancer" and described a "shutting down" of their capacity to hear or understand what they were being told about the details of their condition. This underlines the need for some kind of access to a provider who can explain treatment details once the cancer diagnosis has been assimilated. It also speaks to the advisability of patients being accompanied by a family member.

Table 8

Subtheme	Exemplar Quotes
Patient ability to hear diagnosis	***S732*** *After an hour and a half (of consultation with my doctor) my memory is gone.* ***S128*** *When you go into the doctor's office you have so many things going on in your mind and there is that cloud when you have a diagnosis and you will forget.* ***S228*** *He (urologist) showed me pictures and I remember going "I've got cancer. I don't have a bladder. How am I going to live through this?"* ***S197*** *It's the whole cancer thing. When you first hear the word "cancer" you think it equals death.* ***S198*** *Most people link cancer to death so when you hear the "c" word your mind goes in all kinds of places. You look at your life and all those things.* ***S206*** *I was told that I had the "best" kind of cancer. It was self-contained and could be dealt with the immunotherapy.*

3) Non-Muscle Invasive (NMIBC) Treatment Experience

Figure 4



Even though the Trans Urethral Resection of Bladder Tumour (TURBT) surgery is usually performed as the initial step for biopsy for the majority of bladder cancer patients, no matter whether they are NMIBC (non-muscle invasive) or MIBC (muscle invasive) patients, we chose to put the data of the TURBT experience in with the NMIBC treatment experience (3i) because NMIBC patients often have multiple TURBTs due to recurrences. The third theme of NMIBC has been divided into two sections; the overall patient treatment experience and then ongoing surveillance for recurrences with two and three subthemes respectively.

3i) NMIBC Treatment Experience

a) Patient's perception of knowledge about treatment

Most participants believed that they had a minimal amount of knowledge and information with regards to what to expect pre and post TURBT and follow up BCG immunotherapy treatment. All participants expressed a need to know what to expect pre and post any treatment in a manner that was easily assimilated and understood. They wanted the right information at the right time.

Table 9

Subtheme	**Exemplar Quotes**
Patient perception of knowledge about treatment	***S053*** *All through the treatment (BCG) there was no information.* ***S296*** *If you are going to have a treatment plan a restatement of information will avoid that information dump which means nothing to you because it is too much too soon.* ***S609*** *There wasn't any information to get from the hospital. So I did Google. The best information was from Vancouver*

	Health. Here is the TURBT, your discharge information, your three pages. Great, you're good to go. Okay, now I know what to do. ***S727*** *After the TURBT they gave me little handout and it had a phone number on it which is important.* ***S052:*** *With me, after that first operation and going to see the urologist that was really the only time that I got a little bit of information about what BCG is and what I had and what the treatment would be.* ***S713*** *I didn't know that the biopsy is harder than the TURBT because there is more pulling at the skin and there is more damage. I didn't know that. I thought that something was really wrong.* ***S714*** *I did discuss that (biopsy procedure) with my urologist. He said that it wasn't surprising that I had that (bladder spasms). It would have been nice to have been forewarned to know what to expect.*

b) Views on Early Discharge

Several participants perceived that they were discharged early post TURBT surgery and experienced complications once they were home. Not only did they question if their discharge was premature, but described returning to the Emergency Department of the hospital where they had their surgery and having to start the process all over again because of a lack of available patient records.

Table 10

Subtheme	**Exemplar Quotes**
Views on Early Discharge	***S338*** *When I came back to the hospital after surgery with a bladder infection it was an emergency then because I couldn't go and needed antibiotics.* ***S340*** *This was my third surgery so I thought it was no big deal. They sent me home. You have to be able to pee before you can go home. I felt fine and got home and I'm home and then had to go back to the Emergency.* ***S341*** *You can't get back in. Once you are discharged then you have to go through the whole process again. There is no record of you. I started screaming because I was in so much pain.* ***S342*** *My issue (post-op) wasn't infection. It was clotting.* ***S343*** *I was in the Rockyview for five days and finally was able to pass (urine) and then I went back to Canmore and was in their hospital for five days after having to go to emergency.*

3ii) Ongoing Surveillance for Recurrences

The treatment path for a non-muscle invasive patient can be long and involves repeated surveillance cystoscopies. The main concerns with this area of the treatment journey were in regards to respect for patient dignity, provider care and competence and dealing with the challenge of possible recurrences.

a) Patient Dignity – this proved to be an area of concern for patients in relation to how they were treated both before and during a cystoscopy exam. Men and women in most locations have to wait in a mixed waiting area and only the women have to change into gowns. Other perceptions of lack of dignity were where and when exchanges happened between a physician/staff and the patient. Most patients found it difficult to ask questions and have a conversation with their physicians while dressed in a gown lying on a gurney.

Table 11

Subtheme	Exemplar Quotes
Patient Dignity	***S137*** *Males now, it is easier. You don’t have to get stripped down. Only women have to strip down and change into a gown. Men just have to drop their drawers and lie down on the table.* ***S139*** *The men can keep their clothes on but the women have undress and sit there in these short little gowns. They give you a housecoat but it isn’t much longer. I bring my own housecoat to keep warm and for privacy issues.* ***S144*** *There is this belief with the hospital administration that women take too long to undress (for a cystoscopy exam) and therefore we have to be “prepared” and stripped down.* ***S460*** *…When I said that I’d like to talk to him; it was when I’m in a gown and I’m lying on the gurney. I said no, I don’t find that I’m very comfortable with that.* ***SN350*** *When I went in for the scope it didn’t take me any more time to get ready with the fact that I had pants on.* ***SN402*** *I would appreciate it if you called me Mrs. ______ and then I would say “Hi, my name is ____.” These young girls are twenty and I’m sixty-six. Where I come from calling you Mrs. _______ is a sign of respect.* ***SN338*** *I’m tall. I’m 5 foot nine. Canadians are not that tall. So the little dresses that they give you to wear at the hospital are clearly short for me. I have this little problem.* ***SN371*** *I’m a nurse so I know that it is easy to say, “The appendix in bed 3.” Behind the appendix is a human being with emotions and the fears and the concerns and the family who is emotionally involved and has concerns.*

b) Provider Care and Competence – Several participants had concerns about how they were treated by staff and questioned staff caring and competency at various times during their journey. There was also an element of fear of having no recourse if they perceived that they were not being treated appropriately.

Table 12

Subtheme	**Exemplar Quotes**
Provider Care and Competence	***S133*** *Scope can be a longer wait. I have waited 45 minutes or an hour for my scope. They are always running late. It doesn't allow for questions.* ***S147*** *When I go for BCG 90% of the nurses there are awesome but there are that 10%, one lady in particular. Every time I have her, she just rams it (catheter) up there (the urethra). I'm always sore and bleeding after I get her doing the (BCG) treatment. I dread it when I find out I'm getting her.* ***S151*** *There should be some kind of rating or review process as well from the patient's point of view. I'm sure that lady's been there forever. Has anyone rechecked them?* ***S153*** *You don't know who to complain to because you don't want it to backfire on you. You don't know if the next time you come in and get that person…* ***S348*** *That was my other issue that I ended up on the wrong ward. I had the blood clotting and they had to put the three way (catheter) in again to flush and they didn't know which hole to put it in* ***SN398*** *For one of my scopes I had a sweet little nurse. She was gentle and kind and stayed with me until the doctor came. She didn't just stick you on the bed and do the swabbing and walk out. That was cool.* ***S502*** *The surgeon took time to talk to me about what was going to happen (before my cysto) and I thought that was wonderful.*

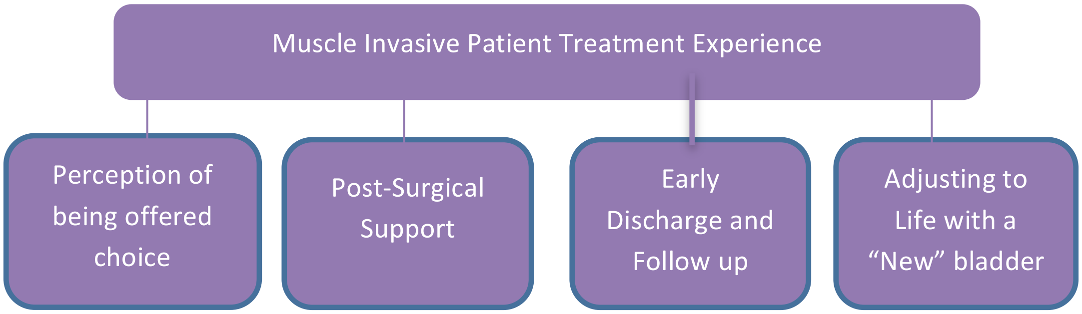
c) Recurrences – One of the main concerns that a non-muscle invasive bladder cancer patient deals with is the risk of recurrence. Bladder cancer has a recurrence rate of up to 80% so regular follow up is a priority and the main defence for patients to help prevent the progression of the disease. Recurrences and /or the fear of recurrences can also greatly extend the treatment time period for a patient, increasing anxiety and stress.

Table 13

Subtheme	***Exemplar Quotes***
Recurrences	***S007*** *I had another recurrence and went on to do the infamous BCG treatment.* ***S046*** *After it came back, it was more aggressive and they found some weird cancer cells and referred me to Dr. ______. They sent it to the Cancer Review Board.* ***S048*** *My BCG (treatment) took three years instead of two because of the infection in the prostate. I had to have polps removed too. So that just extended everything a lot.* ***S276*** *If I remember correctly I was told by Dr. _______ that bladder cancer was high recurring and I would have to have regular check-ups all the time.* _***S406*** *I had the cystoscopies every 3 months. I made it once to six months. I never made it to a year before I needed a TURBT.* ***S638*** *You guys (with bladders) are in a scenario where the cancer has an 80% recurrence.* ***S643*** *I'm five years out. I only get anxious the day before my (cysto) procedure.* ***S644*** *This is different from the cancers where they consider you cured after 5 years. This is one that will follow you and there is always the possibility of it coming back.*

4. Muscle Invasive Treatment Experience

Figure 5



Patients who are diagnosed with muscle invasive bladder cancer have a much more complex treatment journey because the disease has progressed to at least stage 2; the muscle wall of the bladder and the disease has the potential to become life threatening. Some patients are advised to have chemotherapy pre-surgery while others may have it post radical cystectomy. Some patients may not need chemotherapy or not be candidates to receive it due to other co-morbidities. This theme has four subthemes: a) perception of being offered choice of diversion and/or stoma site b) post-surgical support c) early discharge from hospital and follow up and d) adjusting to life with a "new" bladder

a) Perception of Being Offered Choice of Diversion and/or Stoma Site

Some participants reported that they had a good experience with their providers who gave them the information they needed and spent time with them to help them make the right decision for their treatment. Other participants perceived that they were either not provided with enough information to make the choice or not offered a choice. Still others assumed that they did not have a choice for various reasons.

Table 14

Subtheme	**Exemplar Quotes**
Perception of Being Offered Choice of Diversion/Stoma site	***S796*** *One thing I'd like to ask is about the time spent selecting the diversion because I've heard that some people don't get enough time.* ***S798*** *I assumed because of my age that a neo wasn't an option but we didn't talk about it.* ***S035*** *They mark where the stoma is going to be but there isn't as much information given that could have been given at that point.* ***S253*** *For me, I pretty much live in elastic band pants now. So when I was being talked to by the stoma nurse and they do the big felt pen and mark where they think the stoma should go…I was thinking that is where the stoma has to be. Now I find out later that I could have had the stoma placed lower so that I could wear a belt. I didn't know that at the time.* ***S187*** *They (bladder diversion options) were presented to me but I didn't get much information. I would want to talk to someone with experience.* ***S255*** *The difficulty of putting it lower would have affected my ability to shave the area. That would have been a nice thing to have been able to make a decision about. I might have said that I would have preferred that to not being able to wear a belt.* ***S524*** *At the _______, they know their stuff. The other thing is that they give you choice. They need to allow you some level of decision making. They need to explain that.* ***S530*** *My surgeon talked me out of it (ileal conduit) and said, "What about a neo?" I had totally written off the neo. But that is a whole conversation.* ***S532*** *They are taking out a whole lot of bladders and with women they are taking out reproductive organs with the bladders. There is a whole conversation around that that I had with my surgeon.*

a) Post-Surgical Support

The complex nature of a radical cystectomy surgery requires a whole host of post-surgical supports. Patients need training in how to manage their “new” bladder in the form of an internal neobladder or the ileal conduit with external ostomy pouch. Home care is often a necessary requirement to help with post-surgical recovery after release from the hospital. Participants in our study revealed that the majority of care they received was excellent but there were/are some information and service gaps. They stressed the need for ongoing support until they believed they were confident in their ability to cope. The gaining of confidence varied along a time continuum and continued support was vital for their re-entry into a social life.

Table 15

Subtheme	Exemplar Quotes
Post-surgical support	***S589*** *The home care that I had was excellent. Those ladies knew what they were doing. They kept coming for about a month until I was really confident.* ***S590*** *That is an important concept. They (home care) kept coming until you were confident (changing appliance). It could be a month, three months, or six months. It is a major body function. You have to be able to manage it.* ***S592*** *I don’t know if they (home care) will give you a month (of home care) now. That is the concern. For someone to do well in the community they need to be confident.* ***S604*** *It (post bladder removal) is an overwhelming period of time. You don’t have the hospital call bell. There is a lot in that transition (back home into the community).* ***S032*** *I really do thank the nurses with dealing with the stoma, they were wonderful. I think that we need more interaction with the nurses as opposed to dealing with the medical doctor. Maybe that would help. I think that helped me a lot after the surgery.*

b) Early Discharge From Hospital and Follow up

Several participants were discharged from the hospital earlier than they expected. A few of them perceived it was about getting more patients through the system quicker. In some cases they perceived early discharge resulted in a return to the Emergency Department or being admitted back into hospital. Some participants experienced good follow up from home care once discharged but others experienced gaps in service and had difficulties obtaining the post operative care that they felt they needed. The first few weeks at home were stressful for these radical cystectomy patients. In addition to the physical recovery from the surgery many found the transition back into the community very challenging. They were no longer in a hospital setting with medical staff at the ready to assist. Several participants in our study experienced some post-surgery complications that were not bladder related but were a direct result of their radical cystectomies. Some of these cases have resulted in more surgery and thereby extending the patient's total recovery time. Some patients reported outstanding issues and had not been able to get clarification as to the implications on their overall health. There were also concerns about the five year follow up limit for cystectomy patients

Table 16

Subtheme	***Exemplar Quotes***
Early Discharge From Hospital and Follow up (Short and Long term)	***S081*** *When you have a stoma and you have to be aware. Other than me phoning up the stoma nurses because I have a concern about something…there is little else.* ***S085*** *If I had some previous information and some follow up I would have definitely paid more attention to something that seemed trivial at the time* ***S166*** *Maybe I may not have anything to go there for but it wouldn't be a bad idea to see somebody that is a caregiver and be able to hear about some things that you could expect. (in future)* ***SN270*** *When I came out of the hospital, there is a good thing and a bad thing. I guess they want more patients to get through the system.* ***SN271*** *They asked if I was good to go and I thought I was but I ended up back in (hospital) three weeks after I left and ended up staying longer because I didn't have any official training on how to use my neobladder and the issues that could go on with it later.* ***SN273*** *They should do a little more education when it comes to when you leave and make sure that you are ready to go out of the hospital.* ***SN275*** *They got to know me by the first name in emergency because I went back a bunch of times and after they flushed my bladder a few times and got it working they said that I should come back in have a bit of time to be able to get to do it myself.* ***SN277*** *Home care was set up but I think I jumped the gun leaving the hospital a bit early because I thought that the catheter and the flushing wouldn't be a big issue but there were things I didn't know about.* ***S755*** *I was told if I had an emergency to go to the University. They have the resident urologist so that is*

	where I would go if I had a need. – follow up? ***SN211*** *I was in and out of there (hospital) for the better part of a month learning how to work my bladder properly.* ***SN143*** *So I had my CT in April 2017 which was the 5.5 year mark and it showed a recurrence of the cancer. So if we had decided not to do a CT scan at that point, I wouldn't have known that I had a recurrence and wouldn't have had very good outcome.* ***SN170*** *Yeah, my issue was for everybody that has a cystectomy they need to have a CT scan follow up for more than five years, maybe at least ten. I don't know but certainly more than five.* ***SN293*** *Do they after 2 or 3 years, do an ultrasound on your bladder to see how it's formed? Once it's working, it seems to be good to go, right?* ***S168*** *I have a hernia right now, what kind of problems could that cause? It may be related to bladder cancer and maybe it isn't. It would be good to know.* ***SN294*** *I had the issue with the leak in my bowel and kept coming to him and telling him and he said "No, you have infection in there" and not saying that I have a leak in my bowel.* ***SN310*** *I was told to drink a lot of water but no one told me how much water. I drank way too much water and flushed my system of all my calcium.* ***SN312*** *It comes with experience…With some of my issues down the road…I have to wear protection at night and I get a rash and it is itchy all the time and sweaty. I learned that I have to make sure that there is powder there and it is all clean before I go to bed.* ***S594*** *Major abdominal surgery. I was wired for sound. Then I got C diff. I was in the hospital for over 3 weeks. Totally depleted, totally malnourished.* ***S595*** *How many people have we heard of recently with bowel obstruction or problems moving their bowels? It is a major surgery.* ***S601*** *My diet, how do I get my strength (post op)?*

d) Adjusting To Life With A "New" Bladder

We were told adjusting to living with a "new" bladder took time. Several participants reported that it took the better part of a year to get fully recovered from the radical cystectomy surgery and comfortable with their lifestyle adjustments. Lack of information available to help with transitioning back into the community and daily living once they were discharged from the hospital with time limited home care were the main concerns. They also discussed the need for more information about the products they would need to use, especially those with an ileal conduit pouch.

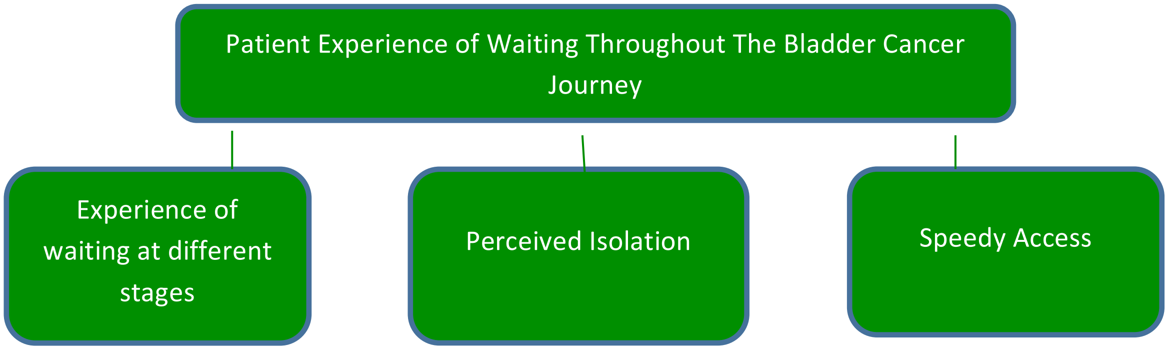
Table 17

<u>**Subtheme**</u>	<u>**Exemplar Quotes**</u>
Adjusting to Life With a "New" Bladder	***S675*** *I had to make some dietary adjustments with managing what I have. It was bowel surgery and my neo gets cranky if my bowel gets cranky.* ***S677*** *Someone brought this up at our support group who was having a real issue with incontinence. That is another thing was a surprise. She is beyond what ADL will cover in terms of incontinence supplies. She can't get her incontinence under control.* ***S597*** *Now again, you're home and glad that you are home, but now what? You have so much to deal with. You guys are at home learning about your appliance and I was learning about mine (neobladder).* ***S601*** *My diet, how do I get my strength (post op)?* ***S602*** *What about the products? Whether you have an IC or a neo, you need to learn about incontinence part of it.* ***S604*** *It (post bladder removal) is an overwhelming period of time. You don't have the hospital call bell. There is a lot in that transition (back home into the community).* ***S605*** *Do you think that there is more information in the last five years for neobladders?* ***S607*** *I also had menopause to deal with (post bladder removal). So there is tons of stuff going on.* ***S629*** *My stoma is in a good place because it is below the waist, but if I put a lot of pressure on it after gardening all afternoon I will have a few leaks.* ***S630*** *Travelling in a car with a seat belt, you have to be careful that it isn't too tight.* ***S631*** *Having a shower, the procedure in the bathroom can be easier, rinsing out the bag and all that stuff…* ***S781*** *…I'm thinking about travel in particular. I get stressed about travel. I have to think about bathrooms. .* ***S783*** *I went to Maui and had to do self-catheterization and irrigation. I didn't bring saline because technically you should be able to get it off the shelf. I needed a prescription and had to go to a clinic. That stress was huge.* ***S784*** *I'm always in an aisle seat now when on a plane.* ***S785*** *Talking about the automatic flushing toilets…Oh jeesh, I have to manually compress my bladder and lean*

	forward so it is a constant douche! ***S786*** *You can get these little pre-lubricated catheters. Just little things like that! I didn't know these catheters existed. It is amazing the technology out there. It is the little things that make you feel human.* ***S789*** *Learning how to self-cath is a huge component. If I wasn't a nurse I don't know how I would have managed it.*

5. Patient Experience of Waiting Throughout The Bladder Cancer Journey

Figure 5



There are three subthemes with regards to the Patient Experience of Waiting a) Experience of Waiting at Different Stages of Journey b) Perceived Isolation While Waiting and c) Speedy Access

a) Experience of Waiting at Different Stages of the Journey

All participants reported that waiting between the various stages of medical testing or medical intervention was extremely stressful as they usually had no idea of how long they might have to wait and often what would be facing next. In most cases they perceived they were waiting in isolation for a phone call with no-one to contact for advice or information. There was a sense of fear around what might be happening within their bodies as they waited.

Table 18

Subtheme	**Exemplar Quotes**
Experience of Waiting at Different Stages of The Journey	***S735*** *They (doctors) need to understand that waiting (for results) is hell.* ***S740*** *There are levels of waiting; waiting for results, waiting for bookings, waiting for surgery. Some of that is extremely stressful.* ***S416*** *Well, when you are waiting outside the protocol time (for bladder removal surgery), I can't even imagine (the*

	stress). ***S417** For me when I bled in September, I wasn't diagnosed until Christmas Eve. That was challenging.* ***S095** Maybe it (pathology results) came back in two weeks but you don't know until you see your doctor in 6 weeks. You're sitting waiting for six weeks and wondering.* ***S096** It was the same with the CAT scan that I had. I haven't received any word back. There was an assumption that something was there but I haven't received any confirmation.* ***S257** I thought my wait time for the scope surgery was unreasonable. That is 8 weeks of stress.* ***S266** That went through my mind too. How fast is this stuff (cancer) growing? Why do I have to wait so long for the next appointment?*

b) Perceived Isolation While Waiting

Most participants reported that, in addition to sometimes waiting lengthy periods of time for test results, surgery dates and follow up appointments, they felt very isolated because there was little or no connectedness with their providers in between times. They perceived they were waiting in the dark with no support. Many expressed the need for some kind of follow up call or appointment to reassure them that they had not been forgotten. They wanted to have someone to call if they were concerned. All wanted to feel ongoing connection with the health care system.

Table 19

Subtheme	**Exemplar Quotes**
Perceived Isolation While Waiting	*S736 When you are having a TURBT or a cysto, they are just talking to you at the gate but we are living between those gates. They don't see the need but that is when we need to hear from them.* *S737 I know it is a lot to ask, if they could follow up then we wouldn't be so anxious and thinking that we have been dropped. That is a hard thing that I hate to put on them but there has got to be a way.* *S741 There is a care component in the waiting time. Make them feel that they haven't been dropped off the face of the earth. Make them feel that they are important.* *S480 …The communication piece needs to be tighter and it needs to be timely. Here is where you are now and here is what is going to happen now and what you can expect. So we always know.* *S745 What is the next step? That is important because you*

	are waiting and sometimes you don't know what you are waiting for. So tell me what is the pathway? *S249 When you are in that "can't get answers" mode, your stress level is so much higher. If I had known who to go to my stress level would have been much more acceptable.*

c) Speedy Access

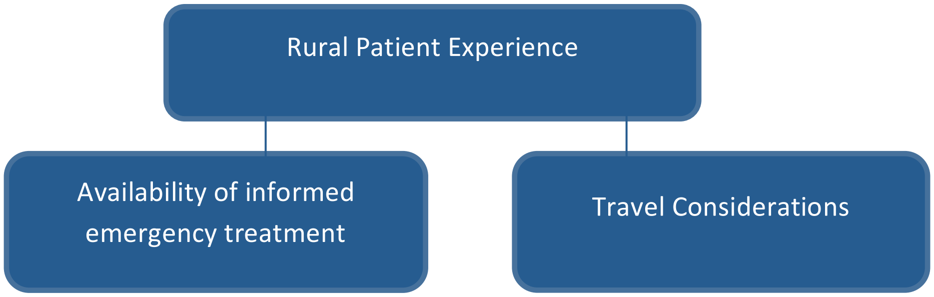
Despite the concerns that most participants had with their wait times for surgery, appointments, tests and treatments, a few participants had speedy access to their specialist and getting into the system. These participants appeared to experience less anxiety and stress.

Table 20

Subtheme	Exemplar Quotes
Speedy Access	***S412*** *If you are here (Edmonton), it (fast bladder removal surgery) seems to happen, but I don't know (about) if you are outside of here.* ***S414*** *Well, I had bleeding in March. I got to the urologist in April and had the surgery May 7th. I don't think that was too much. But looking back it was pretty scary.* ***SN378*** *I thought that it was excellent (access). Coming from Ft. McMurray, Edmonton has to feed lots of little towns and one would expect a long wait time.* ***SN379*** *The girl at the uro's office squeezed me in the day he arrived back. He came in early in the morning to see me so that I could get onto the cysto list for the next week which I thought was fabulous.* ***SN387*** *No. The results took two weeks and my uro called me and explained what was going on.* ***S526*** *They (cancer clinic staff) worked with me all the way. It was intensive and very fast. They were partners.* ***S066*** *When I had blood in my urine I went to him (GP) right away. He got me in within 48 hours for an x-ray and ultrasound. The results came back within the hour and he got me in to see an urologist the same day. I went and saw the urologist.*

6. Rural Patient Experience

Figure 7



Two subthemes emerged from the data with regards to rural patients; a) availability of informed emergency treatment and b) travel considerations.

a) Availability of Informed Emergency Treatment

Rural patients noted that Informed emergency treatment was sometimes minimal in rural communities due to the lack of knowledgeable and experienced staff. The hospitals often did not have the specialized medical equipment to deal with some of the necessary emergency procedures.

Table 21

Subtheme	***Exemplar Quotes***
Availability of informed emergency treatment	***S615*** *It (post neo care) is definitely a problem. I had to go to the small community hospital in Tofield and they didn't have a bloody clue (about a neobladder). Maybe an IC they would have.* ***S616*** *They (community hospital) didn't know what I was talking about. Nobody knew. I had to advocate and talk about my electrolyte balances. But luckily again, because I'm a nurse I could talk about it on my behalf.* ***S617*** *Most of the time, unless they can manage it there (community hospital) which would mostly be infections they would be calling a major hospital and they would say if you are in trouble to come there (major hospital). Then I would have to travel and to be honest, that is not safe.* ***SN391*** *It could be. If I'd had to have any (post op) treatment I would have had to make more arrangements. I would have had to make accommodation and travel arrangements and looking after the place back home. My husband would have*

	had to look after himself. ***S149*** *When I had a TURBT I ended up in the Emergency in Canmore and spent 5 days in there with an infection. They didn't have the three way catheter and (the nurse) had to use a syringe and pump water in and she went woosh! And it caused me all kinds of problems.*

b) Travel considerations

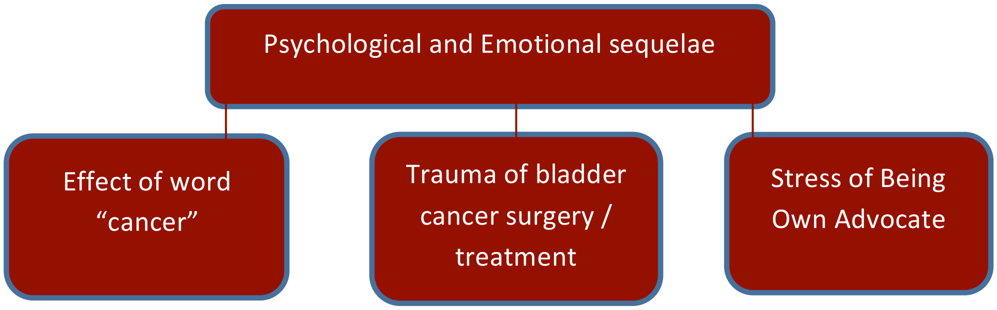
Travel considerations cause issues related to the time and expense involved, especially if a stay away from home was warranted. Sometimes travel became a risky venture based on a person's health condition or the travel conditions.

Table 22

Subtheme	Exemplar Quotes
Travel Considerations	***SN328*** *With living in Ft. McMurray it was very difficult. You have to either drive yourself 450 kms (to Edmonton) or catch the bus or the plane.* ***SN329*** *My appointments were always early in the morning so I would leave the day before, go to my appointment (in Edmonton) and catch the bus back that same evening. That's what I did I don't know how many times.* ***SN384*** *But the winter was scary (going to Edmonton for cystoscopy exams) because that was before Highway 63 was twinned.* ***SN385*** *It was known as the highway of death. The bus would be full of these guys. I was often the only girl on the bus (when going to Edmonton for cystoscopy exams). That used to scare me a little bit.*

7. Psychological and Emotional Sequelae

Figure 8



The participants revealed three principal areas of psychological stress during their journey with bladder cancer; a) Effect of the Word "Cancer" b) Trauma of Bladder Cancer surgery/treatment and c) Stress of Being Own Advocate.

a) Effect of the word "Cancer"

All of our participants reported that hearing the word "cancer" when first diagnosed caused an almost immediate shutdown or fogginess in their thought processes. Some reported that they equated the word with death and that is was a constant in their mind and that it affected all aspects of their lives. This made it especially difficult for many to hear any explanations that were being given or ask for further information. They believed that post diagnosis follow up appointments with staff, not necessarily physicians, for explanations and information would significantly improve their understanding and decrease their anxiety.

Table 23

Theme	**Exemplar Quotes**
Effect of the Word Cancer	***S197*** *It's the whole cancer thing. When you first hear the word "cancer" you think it equals death.* ***S198*** *Most people link cancer to death so when you hear the "c" word your mind goes in all kinds of places. You look at your life and all those things.* ***S200*** *When I was diagnosed with bladder cancer I didn't sleep as well because I was stressed. When you don't sleep as well your body doesn't recoup as well. My cold became pneumonia and I ended up in the hospital.* ***S203*** *You don't function as well. You are thinking about that big "C" word.* ***S205*** *That's true. When I got the "C" word and then when I found out I couldn't have chemo, it was a relief.*

	S206 *I was told that I had the "best" kind of cancer. It was self-contained and could be dealt with the immunotherapy.* ***R069*** *I remember something that ___ said about when she went for BCG and had to go to the Cancer hospital. That is another level of knowing that you have cancer.* ***R070*** *It is a different feeling going into a cancer hospital.* ***S694*** *Cancer is notorious for that. We see that at Wellspring every day. All of a sudden you hear three words, "You have cancer." You might as well take me by the throat and my life is not my own.*

b) Trauma of Bladder Cancer Surgery/Treatment

Several participants reported that they had psychological after effects from their surgeries or treatments. These ranged from childhood flash backs to difficulty coping with and/or fear of future surgery and/or cystoscopies and TURBTs. Some patients reported their difficult psychological struggles with the physical changes in their bodies including dealing with incontinence, body image adjustments and sexuality post cystectomy surgery.

Table 24

Theme	***Exemplar Quotes***
Trauma of Bladder Cancer Surgery/Treatment	***S790*** *For me that was part of my journey, because as a kid I had other urology issues and was pinned down by a nurse and had a catheter shoved up me. I had nightmares to deal with when I had to deal with that process here (for BCG treatments). So I had someone tell me that that was (PTSD) trauma.* ***S793*** *Going through some of what we have gone through, PTSD is alive and well.* ***S794*** *I am so traumatized to this day by the chemotherapy. I have no veins. To have an IV put in me is absolute hell for me. I will vibrate.* ***S795*** *I had my gall bladder out two years afterwards (neobladder surgery) and I was totally traumatized having to do surgery again.* ***S570*** *There is this whole conversation about body image. Nobody is talking about body image.* ***S572*** *I have seen it where they don't want to touch it (stoma) because it is not part of my body. It is upsetting me. I'm ugly. That is huge. Nobody is talking about this stuff.* ***S574*** *Whether it is a female thing or a neo thing, but the*

	guys are cut done and gone. They don't care but you're different. Women have a different perception. Even for myself; I struggle sometimes. ***S575*** *When you have accidents, loss of continence like in the middle of a mall, what does that do to your self-worth? Those are all part of your adjustment.* ***S770*** *I would like to talk about sexuality. Nobody talks about it. I have heard ____ talk about it in the support group. It is a difficult topic. For women there is not an ounce of information on it.* ***S771*** *With men having a radical cystectomy, they remove the prostate and there is about an 85% impotency rate. This is huge.* ***S772*** *It gets back to body awareness, sexuality and feeling good about yourself. Even during chemo there are all kinds of issues surrounding this. You are fundamentally changed.* ***S773*** *Nobody is talking about the gynelogical issues around women with surgical menopause. There was no support for this. I had to do everything on my own. I was 48 and hadn't gone through menopause yet.* ***S777*** *She used the word "rape" not meaning that she was sexually assaulted but that her whole body was ripped apart. Her sex life is affected. Everything is affected. It was a lot.*

c) Stress of Being Own Advocate

Participants described the enormous effort it took them to find things out or get any response or action from providers when they encountered problems. They believed the physical and mental energy required to advocate for themselves added another level to their already high psychological stress and anxiety.

Table 25

Theme	**Exemplar Quotes**
Stress of Being Own Advocate	***S356*** *So I had to be my own advocate. That was something I did throughout my journey.* ***S368*** *If I'd been better at advocating for myself, it (the process) might have gone faster.* ***S418*** *I'm a nurse and I know the system. I had to phone and prod people to get the cystoscopy done, the ultrasound done, the biopsy done. I had to push to get myself through all those things.* ***S419*** *In the end, I had to call one of my colleagues, a GI*

	specialist to say, "Can you please phone these people because I can't get anywhere?" This is after bleeding, like visible haemorrhaging and even with the support of a GP. It took 4 months to push through the gates to get a diagnosis. ***S422** You need to be an advocate for yourself and push to make it happen.* ***SN120** That was one thing that happened to me in this journey that I think, "What would have happened if I hadn't asked (to have my urine checked for cancer cells)?"* ***S739** but what about the guy who is just coming to grips with it (diagnosis) and is having to make the phone calls to find out if he is still on the (surgery) list, where am I on the list and he is now outside the protocol? Having to make those phone calls, that's not right. His agony and stress is now. That is going to set him up for surgery in a very different way.* ***S743** Don't let me sit here and now destroy my mental health which is so important as I go into surgery. Don't make me beg for it*

Discussion

Patient experience in this study with respect to a general lack of information from providers concurred with findings in the literature (Arora et al., 2011; Fitch et al.,2010; Heyes et al.,2014; Leydon et al., 2000; Mossanen et al., 2016; Mohammed et al., 2014; Skea et al., 2014). Our participants, like those in the studies, were given limited information about options, and had difficulties having conversations with providers about the specifics of their disease as well as full descriptions of the next steps to be taken. Follow-up and necessary coping information, especially for those patients who had cystectomies, was incomplete, a finding supported in the literature (Arora et al., 2011; Beitz & Zuzelo, 2003; Mohammed et al., 2014). Our participants also noted the struggles with body image and sexuality described by Fitch et al., 2010 and Heyes et al., 2014.

The participants in this study described the psychological issues around shock and fear at diagnosis and the ongoing anxiety allied to ongoing surveillance cystoscopies noted by Heyes et al., 2014 and Koo et al., 2017. They also had the concerns about being treated as a "whole person" with dignity and respect recorded in the literature (Arora et al., 2011; Koo et al., 2017; Skea et al., 2014; Garg & McMullen, 2016). While the topic of a multi-disciplinary team (Prades et al., 2015) did not emerge, some patients described the benefits of a multi-specialist clinic.

Our participants believed that the most difficult parts of their journey were the multiple periods of waiting between tests, meetings with providers and treatments or surgeries. They perceived that during the wait periods they were totally disconnected from the system and their providers. They found there was no-one who could answer the questions that inevitably arose, and perceived themselves abandoned without support. Some participants who tried to reach out for information from their doctor's office were told they would be contacted if or when necessary. All participants, even those with better information, described the anxiety and stress engendered by the various unsupported wait times between appointments with providers.

As noted in the results section at least half of our participants experienced a delay in diagnosis at the primary physician level, which was seen as a lack of knowledge and awareness of bladder cancer. All participants believed there were awareness problems at the provider and community levels. Speedy screening testing for bladder cancer was seen as vital in any revision of the bladder cancer pathway.

Strengths and Limitations

This study was conducted through all phases of the research by patients, one a bladder cancer survivor the other with chronic illnesses. Recognition by participants that the researchers shared their experiences of navigating the health system and that one was a bladder cancer survivor may have allowed participants to openly share their lived experience at a deeper level than would have been possible with "traditional" health care researchers. There was no perceived power imbalance and both researchers and participants were focused solely on patient concerns and perspectives (Gillard, Simons et al., 2012; Berger, 2015). The direction of the research was driven by the patient participants as co-design partners and they were an integral part of the iterative analysis process (Marlett, Shklarov et al., 2014; Gill, Bagshaw et al.,2016; Miller, Teare et al., 2016; Gillis, Gill et al., 2017). We engaged with 13 bladder cancer patients from Edmonton, Calgary and rural Alberta gathering authentic, thick and rich data (Lincoln &Guba,1986). Saturation was reached after the second narrative interview, the tenth participant, but we decided to continue with our remaining three scheduled interviews to enrich the data.

Transferability of the findings may be limited as the participants were all from the same large healthcare system (Alberta Health Services), so there may be differences of experience and bladder cancer service delivery within other systems. While we attained diversity in age, gender, and home community, all of our participants were Caucasian. Participants from different cultural, ethnic and socioeconomic groups may have different lived experiences and further research is recommended. It should be noted that we were unable to engage with bladder cancer patients who had experienced metastases owing to the frailty of such patients. We recommend further research in this area to provide a complete account of all bladder cancer patients' experience.

Recommendations

1) The aid of a nurse or navigator "go to person" would be a valuable resource for patients especially when they are first diagnosed and learning about the disease and what their journey may entail.

2) A centralized clinic for the different specialists was seen as a real benefit in terms of speed of diagnosis and treatment and convenience.

3) Centralized records were seen as a benefit especially when dealing with emergencies

4) Provider system organized support groups were viewed as an improvement to the patient led support groups that currently exist. Patients expressed the need for a combination of medical and peer support.

5) Participants expressed the need for the cystoscopy exam to be replaced with some other type of diagnostic procedure like a urine test similar to the FIT stool test for colorectal cancer. They believe that a less invasive but accurate screening test that could be done regularly possibly as part of an annual screening after a certain age could potentially catch bladder cancer sooner.

6) A desire was expressed for classes for each stage of their journey with bladder cancer. Many felt that it was necessary to have time to partialize and absorb the information that they had received. The availability of classes would allow the opportunity to learn about each step of the journey in more detail and timeto ask questions and review what they have learned. They would also be in contact with other bladder cancer patients, allowing sharing of experience.

7) A compilation of Tips/Resources from “expert” patients, those that had gone through the journey before them. This was thought to be an excellent backup for those that may not have access to a support group.

8) The participants expressed the need for increased awareness of bladder cancer both amongst medical professionals, especially primary physicians, and the greater community.

9) The provision by medical providers of a list of reliable websites

References

Arora, N.K., Reeve, B.B., Hays, R'D', Clauser, S.B. & Oakley-Girvan, I. (2011). Assessment of quality of cancer-related follow-up care from the cancer survivor's perspective. *Journal of Clinical Oncology.* 29(10), 1280-9. doi: 10.1200/JCO.2010.32.

Beitz, J.M. & Zuzelo, P. R (2003). The lived experience of having a neobladder. *Western Journal of Nursing Research.* http://journals.sagepub.com

Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research,* 15(2), 219-234.

Bogdan, R. & Taylor, S.J. (1975) *Introduction to Qualitative Research Methods.* New York: John Wiley & Sons.

Canadian Cancer Society's Advisory Committee on Cancer Statistics. Canadian cancer statistics 2016. Toronto, ON: Canadian Cancer Society; 2016. Available at: cancer.ca/Canadian-Cancer-Statistics-2016-EN.pdf (accessed 20 March 2016).

Fitch M.J., Miller, D., Sharir, S. & McAndrew, A. (2010). Radical cystectomy for bladder cancer: A qualitative study of patient experiences and implications for practice. *Canadian Oncology Nursing Journal.* 20(4), 177-181.

Garg, T. & McMullen, C.K. (2016). It is time for a patient centered approach to non-muscle invasive bladder cancer in elders with multiple chronic conditions. *Urologic Oncology: Seminars and Original Investigations.* 34(10), 427-429.

Gill M, Bagshaw SM, McKenzie E, et al. (2016), Patient and family member-led research in the intensive care unit: A novel approach to patient centred led research. *PLoS One* 11:e0160947

Gillard, S., Simons, L. (2012). Patient and public involvement in the co-production of knowledge. *Qualitative Health Research,* 22(8), 1126-1137.

Gillis, C., Gill, M., Marlett, N. et al. (2017). Patients as partners in enhanced recovery after surgery: A qualitative patient-led study. *BMJ Open.* http://dx.doi.org/10.1136/bmjopen-2017-017002

Glaser, B.G. & Strauss, A.L (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research.* New Brunswick (U.S.A.): Aldine Transaction, A division of Transaction Publishers.

Heyes, M., Harrington, A., Bond, M.J. & Belan, I. (2014). The lived experiences of people with bladder cancer and their partners. *Cancer Nursing Practice.*

https://doi.org/10.7748/cnp.13.9.25.e1130

Kirk, J. & Muller, M.L. (1986). *Reliability and Validity in Qualitative Research.* Newbury Park: Sage.

Koo, K., Zubkoff, L., Sirovich, B.E., Goodney, P.P., Robertson, D.J., & Seigne, J.D. (2017). The burden of cytoscopic bladder cancer surveillance: Anxiety, discomfort and patient preferences for decision making. *Urology. https://*doi.org/10.1016/j.urology.2017.07.016

Leydon, G.M., Boulton, M., Moynihan, C., Jones, A., Mossman, J., Boudioni, M. & McPherson, K. (2000). Cancer patients' information needs and information seeking behavior: In depth interview study. *British Medical Journal. https://*doi.org/10.1136/bmj.320.7239.909

Lincoln, Y.S. & Guba, E.G. (1986). But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. In D.D. Williams (Ed.) *Naturalistic Evaluation* (pp. 73-84). San Francisco: Josey-Bass.

Marlett, N. & Emes, C. (2010). *Grey Matters: A Guide to Collaborative Research for Seniors.* Calgary: University of Calgary Press.

Marlett N, Shklarov S, Marshall D, Santana MJ, Wasylak T. (2014). Building new roles and relationships in research: A model of patient engagement research. *Quality of Life Research, November 2014.* DOI 10.1007/s11136-014-0845-y http://link.springer.com/article/10.1007/s11136-014-0845-y .

McMullen, C.K., Danforth, K.N., Kwan, M.L., Bulkley, J.E. et al. (2016). Recovery challenges faced by bladder cancer survivors after recent cystectomy and urinary diversion. *Journal of Clinical Oncology.* 34(3), 90-90.

Miller, J.L., Teare, S., Marlett, N. et al. (2016) Support for living a meaningful life with osteoarthritis: A patient-to-patient research study. Patient; 9:457-464.

Mohamed, N.E., Herrera, P.C., Hudson, S., Revenson, T.A., Lee. C.T., et al. (2014). Muscle invasive bladder cancer: Examining survivor burden and unmet needs. *The Journal of Urology.* 191(1), 48-53.

Morse, J.M. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2), 13-22.

Mossanen, M., MacLeod, L., Chu, A., Wright, J.L., Dalkin, B., et al. (2016). Comparative effectiveness of a patient centered pathology report for bladder cancer care. *Journal of Urology.* 196(5), 1383-1389.

Palapattu, G.S., Haisfield-Wolfe, M.E., Walker, J.M., Brintzenhofeszoc, K. et al. (2004). Assessment of perioperative psychological distress in patients undergoing radical cystectomy for bladder cancer. *Journal of Urology.* 172(5) 1814-1817.

Patton, M.O. (1990). *Qualitative Evaluation and Research Methods.* Newbury Park: Sage.

Prades, J., Remue, E., van Hoof, E. & Borras, J.M. (2015). Is it worth reorganizing cancer services on the basis of multidisciplinary teams (MDTs)? A systematic review of the objectves and organizations of MDTs and their impact on patient outcomes. *Health Policy.* 119(4), 464-474.

Shenton, A.K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information,* 22, 63-75.

Skea, Z.C., MacLennan, S.J., Entwhistle, V.A. & Dow, J.N. (2014). Communicating good care: A qualitative study of people with urological cancer value in interactions with health care providers. *European Journal of Oncology Nursing.* 18(1), 35-40.

Taram, E., Schacter, C.L. & Stalker, C.A. (2005). The case for integrating grounded theory and participatory action research. *Qualitative Health Research*, 18(8), 1129-1140.

Acknowledgements

PaCER researchers would like to acknowledge the extensive work on the preparation of the protocol for this study done by Dr. Nimira Alimohamed.

We acknowledge the guidance and support throughout this project from Dr. Nimira Alimohamed, Chris Normandeau and Anna Pujadas Botey.

We thank all of the patient participants for their participation and valuable contributions to this research.