PaCER REPOR**T**

PATIENT EXPERIENCE OF WAITING FOR ELECTIVE SURGERY

MARLYN GILL, SUSAN NGUYEN, BARB SARSFIELD, SVETLANA SCHLAROV

PRINCIPAL INVESTIGATOR: DR. PAUL PETRASEK

PaCER ACADEMIC SUPERVISORS: NANCY MARLETT, SVETLANA SCHLAROV

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Marlyn Gill, Susan Nguyen, Barb Sarsfield, Svetlana Shklarov

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Introduction

This qualitative research study informs the Adult Coding Access Targets for Surgery (aCATS) initiative of patient experience while waiting for elective surgery from ready to treat date to day of surgery within three Alberta Health Service zones, Calgary, Central and Edmonton and across five surgical services, orthopedic, plastic , general, gynecological, and ENT. It covers patients who are waiting for elective surgery in the 12 and 26 week wait time categories.

PaCER Methods

PaCER enables specially trained patient researchers to engage in peer-to-peer research. There were two phases fully completed in this research, a Set or co-design focus group and a Collect phase consisting of narrative interviews. The research was iterative, following the pathways indicated by the patient participants. The data were analyzed using participatory grounded theory (Teram, Schacter & Stalker, 2005), a variation of Glazer & Strauss' (1967) grounded theory especially appropriate for patient-to-patient qualitative research.

Results

Over a period of four months we recruited 18 participants with representation from all three AHS zones and five surgical services, which were designated as having surgery within either a 12 or 26 week wait time period. Our results indicated that waiting for elective surgery engendered common experiences within the five different surgical services of the three Alberta Health Service zones. The intensity of the experience differed based on the length of wait time and whether they had an assigned firm or estimated surgery date. Participants perceived service gaps, especially with respect to ongoing contact and transparency of the triage system. They believed this made waiting for surgery more difficult and might have contributed to decreased levels of confidence in the overall system.

We identified four main categories, within two basic aspects of the experience – the Problem (the impact of waiting for surgery) and the Action patients take, or the processes they use (or would like to use) to deal with the problem:

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Discussion

The patients in this study were faced with differing wait times, medical conditions requiring surgery and knowledge of their surgery dates yet the themes and sub-themes across all eighteen were remarkably consistent. As noted in the results section, those patients with only an estimated surgical date appeared to have increased difficulty with waiting as they lived with the uncertainty of when the wait would end, but their experience while waiting was similar. Knowing their surgery date did not ameliorate the level of pain, perception of deteriorating health or level of anxiety experienced, patients still had hope as they could see a definite end in sight.

Recommendations

Waiting affects us in many ways – we experience waiting as frustrating, risky, and often harmful. We are trying to manage our situation by seeking more information, making sure that everything possible is done to support us while we wait, and trying to do the right thing to help ourselves. We are told that nothing can be done about having to wait– it is a systemic problem. We accept the waiting problem as inevitable, and know that healthcare providers are generally doing their best, but we also believe that there are gaps or flaws in the current system that could be mended. We would like to have more support from our providers – more transparent information, reassurance, open communication, and access to timely available treatments while we wait. More precisely, we suggest the following:

1. Provide simple, easily understandable and transparent explanations of the current triaging system for elective surgery.
2. Provide initial and ongoing support and information, including whom to contact if there are changes in their health status, to patients as they wait for elective surgery.
3. Provide check-ins on those waiting for elective surgery by staff on a consistent basis. Openly discuss and answer patients' questions on what they can do to maintain their health while waiting.
4. Attempt to increase the number of firm surgery dates by extending forward planning and triaging.
5. Consider exploring patient sense of coherence when triaging for elective surgery.
6. Continue to strive for equity across zones.

Patient Experience of Waiting for Elective Surgery

Introduction

Adult Coding Access Targets for Surgery (aCATS) is an Alberta developed, standardized system to help prioritize elective surgeries offered at facilities throughout the province, depending on a patient's diagnosis and level of urgency. It is a project initiated by Alberta Health Services (AHS) Surgical Strategic Clinical Network (SSCN). The process is clinically and operationally driven lacking the perspective of patients about waiting for elective surgery.

This Patient and Community Engagement Research (PaCER) qualitative research study is the patient experience component of the Surgical Strategic Clinical Network (SSCN) sponsored adult Coding Access Targets for Surgery (aCATS) project. It informs the larger project about the patient experience of waiting for elective surgery from time of being assessed as "ready to treat" or, as patients perceive it, in need of surgery for what has been diagnosed as a non urgent medical condition until the surgery date.

Patient and Community Engagement researchers (PaCERS) are patients trained in qualitative research and patient engagement at the Cumming School of Medicine, University of Calgary. All of the researchers in this study had previously undergone elective surgery. Using trained patients as researchers may reduce any perceived power imbalance between researcher and interviewee (Gillard, Simons et al., 2012; Berger, 2015) as participants view interviews as peer-to-peer interaction. The direction of the research is driven by the patient participants and they are an integral part of the iterative analysis process (Marlett, Shklarov et al., 2014).

Background and Context

Alberta Health Services through the work of the Surgical Strategic Clinical Network has initiated a system for triaging patients waiting for elective surgery. Missing from the algorithms is a patient experience of waiting for elective surgery component. We reviewed the available literature to try to find any previous studies undertaken in this area, especially any qualitative research studies. We found no other studies being undertaken by patient researchers i.e. peer-to-peer research but several quantitative studies and a few qualitative inquiries.

A recent study in British Columbia noted that they found there was no relationship or congruence between how the patients in their study saw their health and how they had been prioritized by the triaging system (Crump, Liu et al., 2016). The authors noted that the important factors impacting waiting for surgery from the patient perspective were pain or discomfort, an inability to live a "normal life", depression and /or anxiety and lack of mobility. These four circumstances were found in several studies of patients waiting for surgery (Gillis, Gill et al., 2017; Johnson, Horwood & Gooberman, 2014; Conner-Spady, Johnston et al., 2007a;

Sanmartin, Berthelot & McIntosh, 2007; Edwards, Boland et al., 2003). Two studies focused solely on the anxiety levels of patients. The review of literature study by Mitchell (2003) acknowledged the anxiety produced by waiting, explored the causes of anxiety and how to manage the anxiety while the Fung-Zak Tsang, McKnight et al. (2016) study of patients waiting for endoscopic sinus surgery noted no increase in patients' anxiety or depression.

Patient knowledge of the expected wait time, especially being given a surgery date, and transparency of the prioritization for surgery triaging system were seen by patients as making the wait time seem less onerous (Conner-Spady, Johnston et al., 2007b; Conner-Spady, Sanmugasunderam et al., 2004). Other studies have noted that patients found their lives were in a holding pattern with no contact from the healthcare system to give them a sense of connection (Carr, Teucher & Casson, 2014; Carr, Teucher, Mann & Casson, 2009; Sjoling, Agren et al., 2004). The longer the wait time the more unacceptable the wait time became (Carr, Teucher, Mann & Casson, 2009).

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 which combines grounded theory (Glaser & Strauss, 1967) with participant involvement in all aspects of the research including analysis and theory building (Gill, Bagshaw, Mckenzie et al., 2016; Miller, Teare et al., 2015; Teram, Schacter & Stalker, 2005) as we wanted to understand the patient experiences with, and beliefs about waiting for elective surgery in the hope of developing some theory around the patient experience of waiting for elective surgery.

Please note that the language we use in some portions of the Discussion and Recommendations sections (the first-person plural "we") is common for peer-to-peer PaCER studies and reflects the participatory nature of analysis and interpretation. Through this language, researchers who have relevant patient experience can express their study conclusions on behalf of the common "we" of the patient community, based on the authentic input of their participants – the patient research voice.

Recruitment and Inclusion Criteria

We used purposive sampling to recruit patients who had been assessed by a surgeon as ready to treat. They were over 18 years and spoke English well enough to participate in an interview.

The patients were from three AHS zones, Edmonton, Calgary and Central and were receiving surgery from the general, orthopedic, ear nose and throat (ENT), plastic, and gynecological surgical services. They had been designated as having surgery within either a 12 or 26 week wait time. In accordance with our research protocol, we had the aCATS lead from each zone call patients from a randomized list of patients who had been assessed as ready for surgery informing them about the study. Each patient was asked if they were interested in learning more about the study and those who were interested agreed to have their contact information given to a researcher.

Participants

Despite having a large pool of prospective patient participants, we encountered difficulty in recruiting patients for inclusion in this study. Over a period of four months we successfully recruited 18 participants with representation from all three zones and five surgical services we wished to include in the study. ACATS leads in all three regions each called at least 100 patients with 44, 20 and 17 respectively interested in learning more about the study in Calgary, Central and Edmonton zones respectively. All prospective contacts were called by a PaCER researcher, and seven Calgary zone, five Central zone and six Edmonton zone patients participated. We will address the recruitment problems in the discussion section of this report.

Participant Demographic Table (Table 1)

Participant Code	Gender	Age	Surgery Site	Wait From Ready to Treat Till Surgery Date	Wait From GP to Surgeon Consult	Service
S1	F	73	Calgary	8 months	18 months	Orthopedics
S2	F	49	Red Deer	Unknown, estimate 8–10 months	6 months	Gynecology
S3	M	57	Edmonton	Unknown, estimate 6– 8 months	2-3 months	Orthopedics
CM1	M	62	Camrose	Unknown, estimate 9-10 months	3-4 months	Orthopedics
CM2	F	47	Edmonton	Unknown, estimate 6 months	4 months	General
CM3	F	67	Calgary	3 months	9 months	Orthopedics
CM4	M	65	Red Deer	Unknown, has given up waiting after 2 years	6 months	Orthopedics

CM 5	F	32	Red Deer	Unknown, estimate 8 months	5 months	General
CM6	F	75	Red Deer	Unknown, estimate 7 – 8 days (was immobilized at home in bed with severely broken ankle	Came to ER and sent home to wait	Orthopedics
CN1	M	62	Calgary	3 months	3 months	Ear Nose and Throat
CN2	F	56	Edmonton	Unknown, estimate 4 months	Taken to ER	Gynecology
CN3	F	58	Edmonton	Unknown, estimate 6 months	11 months	Orthopedics
CN4	F	44	Calgary	Unknown, estimate 1 year health related wait	6-8 weeks	Plastics
CN5	M	75	Innisfail	3 months	2 months	Orthopedics
CN6	M	53	Calgary	4 months	2 weeks	General
CN7	M	32	Calgary	1 month	1 month	Ear Nose and Throat
CN8	M	74	Calgary	9 months	6 months	Orthopedic
CN9	F	56	Edmonton	Unknown, estimate 18 months	6 months	Plastics

Data Collection and Analysis

Following the PaCER methodology (Marlett & Emes, 2010) we planned to hold a five hour SET or Co-design group in Calgary and hoped to follow this up with SET groups in Red Deer and Edmonton. Our patient engagement research process is iterative and participatory and amenable to changes in direction depending on the information received from any group or interview (Marlett, Shklarov et al., 2014). The SET or Co-design group is used to indicate what topics are of the highest importance to the patient participants and directs the initial guiding questions for the COLLECT interviews. This means that the patient participants and the patient researchers collaborate in the co-design group to determine the direction of the study.

Each group or interview participant was asked the same initial question: *Please tell about you experience of waiting for elective surgery.* This opened the door for participants to describe their varied experiences of waiting and their opinions about the waiting process. Narrative interviews encouraged participants to "tell their story" once more using prompts sparingly to elicit greater depth. PaCER researchers audio record and transcribe all groups and interviews. We use a flip chart to take notes of participant conversation and take process-recording notes in each group. Use a flip chart to take notes of participant conversation and take process-recording notes in each group. All three sets of data are used in the analysis process. Using flip chart notes also allows participants to review the information gathered during group sessions and provide their comments and clarifications, adding to the richness of the data and ensuring that our understanding of the data is accurate. This process is consistent with the participatory nature of the method, in which we rely on participant input in both data collection and analysis.

Since we analyze our data iteratively, we would be expanding our questions as we worked with each group or individuals. Unfortunately, only one of our three recruited participants in Calgary and one of our four participants in Red Deer came to the group. Attempts to find a date for a focus group in Edmonton failed, as we had decided that our two experiences of high no show rates for this study merited a group with a minimum of five participants. We chose to interview the one Edmonton participant who was willing at that time, using an extended narrative format based on the data from the first and second SET conversations. It should be noted that the high no show rate is unusual for PaCER as we have telephone conversations just prior to group to ensure all is well, and that the participants are comfortable with the plans. We only received one call on the morning of group explaining that the participant could not attend. Once more this will be addressed in the Discussion section.

SET

We had three SET participants from whom we developed our COLLECT interview guiding questions. We ran the Calgary and Red Deer "groups" as extended peer to peer narrative interviews going through all the steps we would normally complete in a SET or co-design group. This meant we had flip chart notes for the participant to check and discuss, as well as a tape recording of the conversation, which we transcribed and coded. We also recorded, transcribed and took process notes of the Edmonton SET interview and used the data from all three zones to create the guiding questions for the COLLECT narrative interviews.

COLLECT

We interviewed 15 participants for the COLLECT phase of the study transcribing and coding the data iteratively. All participants were asked the same initial question: *Please tell me about your experience waiting for elective surgery,* which was followed up with probes and exploration of themes and sub themes that had emerged from our previous interviews.

REFLECT

Once more, despite having asked participants about their interest in being part of this group and having at least five express interest, we were unable to find a date, time and place that would accommodate a sufficient number of participants. This has happened once before in one of our previous studies when we were conducting a province wide study that included all five zones. We followed an alternative procedure that we had successfully used in the previous project i.e., sending out simple and short result figures and tables, providing space for feed-back to all 18 participants. We received two responses telling us "all looked good". Follow up with the five participants who had appeared most enthusiastic elicited no further responses. Once more this lack of response, which did not happen in our previous study will be presented in the Discussion section.

Consistent with the analytical strategies of the classical grounded theory method, we explored our data in an iterative manner, analyzing each data set as it came, beginning with an open coding of the data line by line, and using constant comparative techniques throughout the process. Our analysis focused on trying to discover and explain "the basic social psychological problem and the process by which it is resolved" (Glaser, 1978, p. 50), with all our theoretical interpretations grounded in the authentic input from the participants. Accordingly, our results represent the nature and various aspects of *the problem* or concern encountered by participants within their experience of waiting, and *the basic processes* they use to deal with the problems – the patients' actions and recommendations based on how patients react to their obstacles, the strategies patients use or would like to use, tools they have or wish to have available, and supports and information they seek.

Research Credibility and Trustworthiness

We used several strategies to raise the credibility and trustworthiness of the research: (1) The patient researchers (PaCERs) 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 patients who had waited for elective surgery, 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 (Teram, Schacter & Stalker, 2007) and two different data collection techniques as well as iterative analysis and rigorous constant comparison strategy (Glaser & Strauss, 1967; Glaser, 1978. (6) We completed a literature review to assess the congruence of our findings with previous research (Lincoln & Guba, 1986; Morse et al., 2002; Shenton, 2004). (7) Patient to patient or peer-to-peer research tends to lessen the reflexivity present when traditional healthcare providers are used (Berger, 2015).

Results

While the focus of this study is to explore patients' experience of waiting for elective surgery from the time a surgeon decides a patient is ready to treat until the day of surgery, all of the patients, apart from two who presented in the ER noted that they believed that they had waited a considerable time for the surgical consult. They all reported that they were relieved to have had the consult and know that they would be having surgery sometime in the future. The seven participants who received a surgery date at consult told us that the one factor that helped them during the wait period was that they knew it was finite and that they could fix their sights on an end to whatever they were experiencing during the time they waited. The eleven participants, who were not given a definite date, but were given only estimates of a surgery date had to cope with similar concerns with the additional burden of disappointment and uncertainty. These are explored in a dedicated sub-theme.

We discovered during our conversations with Central Zone patients that there had been considerable media coverage and politicizing of perceived current capacity issues with the Red Deer Regional Hospital. These participants told us that their hospital (Red Deer Regional Hospital) was unable to adequately serve the Central Zone. Some patients were being sent for surgery to smaller, less well equipped hospitals in the zone. All but one of the 11 participants who were given no surgery date came from either Red Deer or Edmonton. The Calgary patient had medical reasons for no firm surgery date.

We identified four main categories, within the two basic aspects of the experience – the Problem (the impact of waiting for surgery) and the Action patients take, or the processes they use (or would like to use) to deal with the problem. Each of the two basic aspects is explored in detail in this report:

<u>The Impact of Waiting: The Problem:</u>

A)" Does Waiting for Surgery Impact my Health?"
B) "Life on Hold"

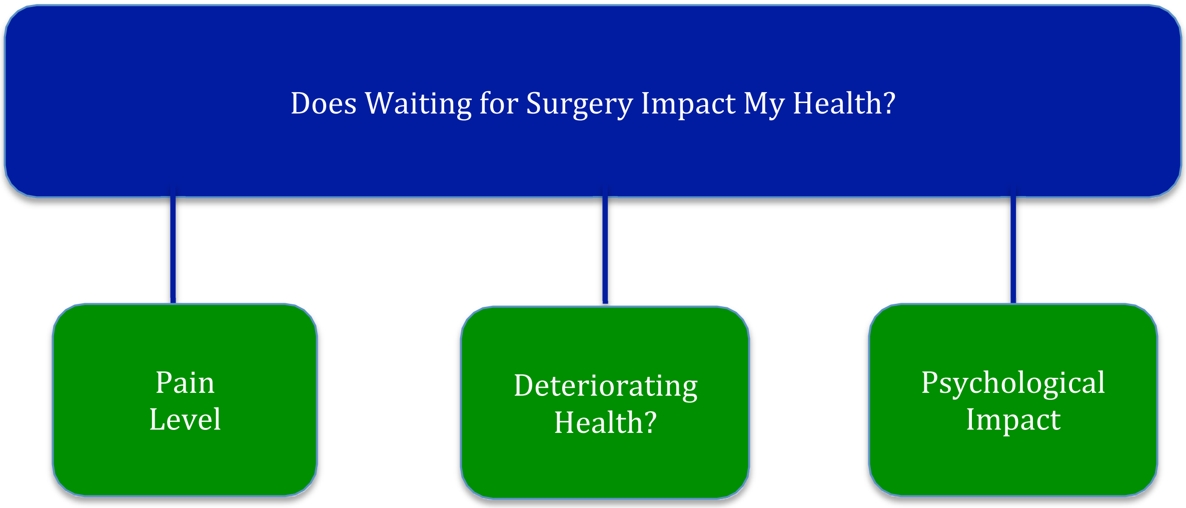
<u>Patients Taking (and Recommending) Action: What We Do:</u>

C) Getting Ready for Surgery While Waiting
D) Making Sense of the System

A) Does Waiting for Surgery Impact my Health?

All of the participants believed that waiting had some negative effect on their health no matter how minimally.

Figure 1



Ai) Pain Level

All of the patients apart from two reported that they were in some level of pain or discomfort, some indicating, most notably the orthopedic patients, that the pain was severe and often affected their mobility. They indicated that pain interfered in some way with their lives, with those in the work force unable to go to work some days. Some patients expressed a considerable worry that their pain level or health deterioration was progressive during the period of waiting, or a fear of having to deal with new attacks of pain before the surgery was done.

Table 2

Does Waiting for Surgery Impact My Health?	**Exemplar quotes**
Pain Level	***NS043*** *You are in pain and you want to get rid of the pain but it can't happen until you have the surgery. The waiting is hard.* ***NS032*** *I'm taking_____, I do massage, heat pads, things like that. That helps relieve the pain. It's hard because I also have this urge to go to the bathroom.* ***S041*** *No, it's uncomfortable, kind of like when you are getting your period. It's (uterus) big so there is kind of a pressure on my back. It is a pain in the butt, is what it is.* ***S453*** *Yeah, when it (ear fluid build-up or infection) happens I have a hard time hearing and it is pretty painful and the*

	pain doesn't go away until after the (tube insertion) procedure is done. ***SN212*** *My partner would hear me groaning, sometimes crying out loud because I would move the wrong way and the pain would go through.* ***SN270*** *The worst was the progressive pain and dealing with that on a daily basis. It kept getting worse*. ***SN075*** *I'm probably pretty lucky because my symptoms aren't that horrible. I haven't had an acute gall bladder attack since August so I've been lucky that I haven't had that. If I had had more symptoms I would probably have had a worse wait. Right now, I'm okay with it because I've been able to manage the symptoms* ***12)*** *There are days when I don't think I need surgery and days like today when I'm saying get me in now/* ***S641*** *And (pain) in my shoulders. I have massive, massive divots from my bra straps.* **SN270** The worst was the progressive pain and dealing with that on a daily basis. It kept getting worse. At least I know that I have an end in sight but it seems so long away. The time will come and it will happen.

Aii) Deteriorating Health While Waiting

About half of the patients believed that their health was deteriorating while waiting. They perceived that, either their presenting health problem was becoming worse, or there were new symptoms indicating some other aspect of their overall health or even the prospective outcomes of their upcoming surgical treatment were being compromised by the wait.

Table 3

Does Waiting for Surgery Impact my Health?	Exemplar Quotes
Deteriorating health While Waiting	***NS162 …****If you have very heavy periods and you are constantly bleeding out as I was, you can get extremely anemic. I didn't know I was anemic. I went for blood work but no one told me that I was anemic. I didn't think to ask because I didn't know what to ask.* ***CN1040****: I don't know but I go into atrial fibrillation a lot. Sometimes I wonder if the discomfort of eating with the esophagus can trigger the episodes of atrial fibrillation but I haven't been able to pin that down for sure.*

	S132 *Well, actually my blood pressure went up. I'm on blood pressure pills. I basically started in February when the pain started getting worse.* ***S255*** *He had to wait almost 4 months for surgery because he was considered low priority because he was stable with medication… He couldn't exercise during this time because he would get chest pains so he lost more and more fitness and lost muscle mass. His recovery will be even longer. If he had been operated on within a couple of weeks, he wouldn't have lost. He lost 15 lbs. and most of that is probably muscle. That will take him a lot longer to get back.* ***S103*** *I'm just concerned about my memory. I have brain fog. I'm just tired and that "bloaty" back pain. I really have nothing to complain about.* ***SN213*** *The pain got constantly worse in the hip area. The knee got bad as well. It was progressively worse. I went from not using any walking aids to a cane to using 2 canes.* ***05)*** *The symptoms are getting worse, they are not getting better and they are not staying the same. While I'm waiting for surgery, I'm getting worse.*

Aiii) Psychological Impact

Approximately one third of the participants reported significant increases in depression and /or anxiety, while almost three quarters expressed a high level of frustration and anger, which they believed impacted their overall well-being.

Table 4

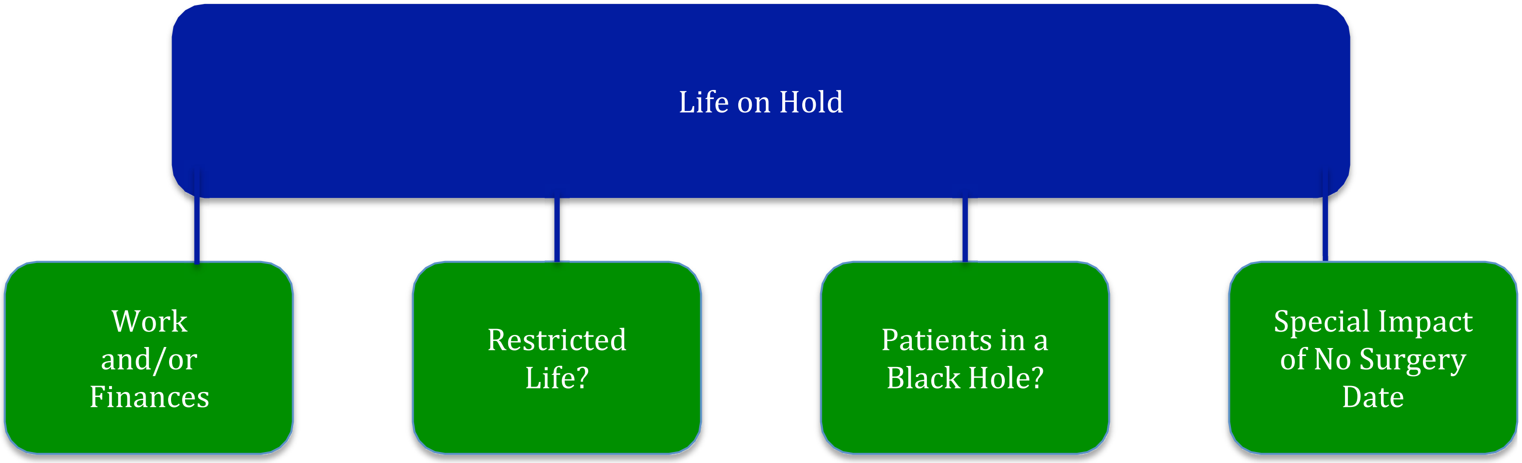
Does Waiting for Surgery Impact my Health?	Exemplar Quotes
Possible Psychological Impact	***NS001*** *I'm feeling apprehensive, anxious. (not knowing surgery date). I have to consider so many factors before that surgery.* ***NS118 (****I need) psychological and emotional support. I don't know how I would get it.* ***S2036*** *I think some days I get depressed. You're feeling like, when is this going to get done?* ***S232*** *Well, I've had chronic anxiety for over a year… Looking at that experience, it was incredibly stressful* ***SN264*** *I didn't hear from them until late September and then had an appointment for January 9th. I was just crushed.*

	SN318 *…I'm very agitated. I'm not a very happy man (because of long wait for knee replacement surgery). On top of it all, I'm a veteran so I have 75% PTSD so things get me angry very quick.* ***S675*** *Yes…The wait when you think about it, it does cause you anxiety because it is elective. "Should I be doing this, or should I just leave it?" Is this really going to help?" because there is no guarantees with any surgery. "Is it going to alleviate the pain?"* ***SN334*** *You can tell I'm an angry man.*

B) Life on Hold

All of the participants perceived that their lives were "on hold" as they waited for surgery. It did not appear to matter if they believed there had been a high or low impact on their health as a result of waiting for surgery, all had a sense that their lives were in a holding pattern until the surgery was performed. Length of the expected or unknown wait time did not seem to affect the perception that their lives were "on hold" during the waiting time, although most of those with no firm surgery date expressed some frustration with the uncertainty of how long they would be in this stage of suspended ability to plan.

Figure 2



Bi) Work and /or Finances

Participants who worked believed that living life “on hold” affected their work and financial situations. Those who had a surgery date believed they had to “ration” their sick days so that they did not run out before surgery or put themselves in the situation of possible termination when they returned to work after surgery. All had to balance out how to keep their jobs and ensure they stayed eligible for temporary sick leave, which was better financially for them. Patients with no firm date had these and other problems, which will be outlined in last sub-section below (Special Impact of No Surgery Date).

Table 5

Life on Hold	Exemplar Quotes
Work and /or Finances	***NS098*** *Yes. Knowing that I will have surgery sometime this year, I want to reserve my sick days for when I have the surgery. I get probably about a week sick time.* ***S2011*** *I'm fortunate that I have a job that I don't have to be on my feet too much but if I had to I wouldn't be working.* ***S130*** *My job requires me to travel in Canada and I've had to tell my work I'm not travelling any more. It is too much on my body.* ***S458*** *Well, I'm in heavy duty sanding so I'm around noise all day so it (ear fluid build-up or infection) affects my work a lot. When I take something for the discomfort and pain (in ears) I tend to be a bit grumpy and drowsy. So that does affect my work life.* ***SN082*** *I guess that I've missed some work when I've had an attack. I've missed a few days of work here and there because I've had increased symptoms and I've been up all night I don't go into work the next day.* ***13)*** *There are days when it absolutely impacts the way I manage work. My old employer…I just recently changed jobs…who I used to report to is aware of it but who I report to now is not aware. I need to make her aware of it.* ***S052*** *I've hired a lady to fill in for me…That is absolutely correct. (can't complete all work duties)* ***S269 …*** *we are both making significantly less money than we normally do and it is for an extended period of time. To be honest if he had been able to have the surgery done within a few weeks he probably wouldn't have lost any pay but now he is in a situation where he isn't making his full pay because he ran out of sick leave. So that's not great. (both partners waiting for surgery)* ***S293*** *Plus with me having another upcoming surgery, I will be going into another salary reduction part of the year too. I will be making a smaller percentage of my salary. It seems that one*

	of us is always on long term. It's not good. ***S463*** *When it (ear fluid build-up) happens, I can't hear. It feels like I'm under water… When the sound comes in (my ear) it is distorted on one side so over the course of the day I get dizzy from not being able to hear. It is sort of like vertigo, you know what I mean? It makes it tough to work*

Bii) Restricted Life

All participants noted some restrictions in their lives during the holding pattern period. Almost two thirds believed that their lives were greatly impacted , with mobility limitations, sleep disturbances, inability to plan vacations, limitations in leisure activities (e.g. theatre going, golf, walking or exercising) or inability to make commitments to family and friends. Patients often felt that having to wait affected their overall enjoyment of life. "I just can't follow a normal life" was the most common comment.

Table 6

Life on Hold	**Exemplar Quotes**
Restricted life	***NS137*** *When you have pain you don't want to walk. I used to walk. We have a very good walking path near us… I'm not exercising* ***NS203*** *Every year I go back to the Philippines for two weeks to visit my parents. My parents are in their eighties. If I already take my sick time…how can I go home?* ***S2031*** *The biggest problem for me is that I can't do a lot of stuff. I go outside and walk for 5-10 minutes and I have to sit down because of the pain. I can't do anything. I can't golf or do things with my kids. (because of hip pain.) It's taken my life away.* ***CN1022:*** *The biggest problem with it is that eating not very enjoyable. It is almost like work forcing down a meal with water and as a result I end up eating less. I'm a third of a way through a meal and everyone else is finished and I'm bloated with water so where I used to be able to eat more I just can't eat as much now… It's (eating) just not pleasurable: We used to enjoy going out to dinner a lot and go to The Keg for a nice steak. That's kind of put on hold.* ***S140*** *I'm only 58. I can't golf. I didn't golf the last time I went to Phoenix. It's too hard on me.* ***S061*** *Well, just planning an anniversary trip… but this (hysterectomy surgery) is a priority, so I'm going to say no to that (life on hold).* ***S449*** *When it (ear fluid build-up or infection) happens I'm tied*

	up and pretty much out of commission for a couple of months, taking Dayquil. ***SN189*** *Waiting has been very bad because I've had restrictions. I'm restricted from activities or even just basics like shopping, trying to get groceries, trying to get anything done. I didn't go to events because it required walking on concrete in the venue so I wouldn't go because of that… My grandson was playing hockey and I didn't go to the rink because it was too difficult to walk on the concrete to go to the bleachers to watch him and then to climb the stairs in the bleachers.* ***SN021*** *I can't do what I want to do. (because of waiting for knee replacement). Well, I'd like to be able to walk without pain. I would like to be able to do more activities but I'm limited.* ***SN388a*** *My lifestyle was impacted quite seriously because I couldn't walk. but I had friends doing things for me. They got some groceries and that sort of thing.* ***S2039 …*** *it's like I'm losing two years of my life because I can't do anything. I can't go on holidays. What's the point of going on holidays if all I can do is sit by the pool? For two years of my life I basically go to work and come home and sit on the couch.*

Biii) Patients in a Black Hole?

Most patients felt they were waiting without any connectedness to a healthcare provider. They were unsure who to call if they needed to discuss any health problems or simply wanted more information about their surgery. As they waited, questions seemed to emerge and many seemed to believe that they had not received adequate information at the time of their surgical consult. Some patients expressed readiness to take responsibility and make active efforts toward self managing their health while waiting, but lacked adequate access to information and guidance that would enable them to do so. They had been given no ongoing contact information and felt they were in limbo with no means or information to maintain their health well enough while they wait.

Table 7

Life on Hold	Exemplar Quotes
Patients in a Black Hole?	***NS027*** *The information I got about the surgery was good but not sufficient* **NS040** *I'm getting no support while I wait. I want communication. They should communicate with me. I don't know who will communicate with me.* ***Msc3*** *No, no one gave me any advice about what to do while waiting. I just advise myself. That's why I decided to try the… I*

	did try physio and I quit because It was too far to walk ***Msc14*** *It would be nice to be able to call somebody (while I'm waiting). Like I made the decision about physio and about chiro all on my own. Now it would be nice to be able to phone some body and say I'm looking for suggestions. What do you suggest? Or Do you think it's a good idea or could you run it by the surgeon?.. I have no wish that I could see the surgeon to consult. I think his time is better spent elsewhere. But if he had a little group of people that you could maybe talk to that would be valuable…A little feedback as to advice …or suggestion (around what you might do while you're waiting as your back is getting worse).* ***NS125*** *No, I don't think…not enough time to ask questions… It was such a shock. I didn't know what to ask. All these thoughts would come after. It was getting all the details (about the surgery) that shocked me.* ***NS179*** *… when I went there (surgical consult), he was busy and his mind was focused on other things. He was talking to his secretary about other stuff. They have problems. I'm not eavesdropping but I sensed that he wasn't totally focused on me.* ***S047*** *I'm just taking it. I wasn't told to. (iron supplements) I just decided to (take iron supplements) because I was tired and had no one to ask* ***SN232*** *The only thing that they discussed with me (pre-op) was the pre-op exercises. I got a whole packet (exercises) from the clinic when I was there. Some of them were very painful to do. I just thought I can't do it. It will have to wait until after my surgery. I didn't do many of them (pre-op exercises). The other thing is that I would forget about it altogether or I would think about it while I was in the shower.* ***S682*** *I originally asked to be put on the waiting cancellation list…I'm just coming up to a year and I'm not on the waiting list.*

Biv) Impact of No Surgery Date

Eleven of the participants were given no surgery date at their surgical consult; all, apart from the patient whose surgery was delayed for medical reasons, were given estimates that mostly varied by one or two months. The lack of firm date and the eight or nine week span of a possible surgical date made any long range planning impossible. As noted previously this greatly increased all of the concerns expressed by those who had been given a firm date. Five of the patients with no firm surgery date stated that they had been waiting, with no contact from health providers, longer than the estimates they had been given. They noted this increased their uncertainly and anxiety. Three of the participants had been called for surgery much earlier (at least two months) than anticipated and had had to refuse the surgical date as they had made plans that could not be altered. They noted that five days notice was not really sufficient time to alter their wedding date or house move. One participant did cancel vacation plans to have the surgery.

Not having a specific surgery date caused huge problems for those with jobs. They could not prearrange their sick leave causing problems with their employers and co-workers who would be covering for them. This was especially difficult over the summer months as some co-workers were unable to plan their own vacation times. The affected patients discussed strained relationships at work and feelings of guilt around their inability to plan their sick leave. All of this added stress and anxiety to the symptoms they were already experiencing. Two patients noted that they went to work when they were unfit as they were worried about the financial repercussions if they had to go on long term disability as a result of using their sick leave and their temporary disability while waiting for surgery. Generally, these non-date patients felt more disconnected from their health providers than those with a surgery date and some believed they had almost been abandoned by the system. One informed his surgeon he had given up waiting and to take him off the list. It should be noted that one participant who had some knowledge of the aCATS system did not experience any real concerns, but believed that the system should pay more attention to communicating with patients around their status.

Table 8

Life on Hold?	Exemplar Quotes
Additional Impact of no Surgery Date	***S2040*** *If I can't work at my job at some point they might just you know…if I was a mechanic on the shop floor and I can't work, how long are they going to put me on leave? You never know, they just might say "It's slow right now and we have to let you go. They won't tell you the real reason but people could lose their jobs because of these long wait times."* ***NS098*** *Yes keeping going to work. Knowing that I will have surgery sometime this year, I want to reserve my sick days for when I have the surgery.* ***SN012*** *I don't have a surgery date but they said it would probably be 9-10 months**…** Well, it is very frustrating. Although we are publicly funded, we don't have any choices. We are a victim of the circumstances…and if there aren't enough surgeons, hospital space or surgery time, whatever the reason is people have to wait… I understand that it is elective but at the end of the day it is frustrating.* ***S647*** *It's hard to plan (your life when you have no date) and then you get nervous because you think should you be doing this or not because it is elective (surgery)* ***S685*** *When I had my original consult (over a year ago) I*

	figured I could spare the $2,000 but what concerns me is by the time I get there "What if I can't?" I might have to cancel. Whether I can afford the liposuction is a huge anxiety for me actually if I don't have that cash when they call ***01)*** *It's hard waiting for surgery and not knowing the date. You have to plan, You know you have to plan certain things around your vacation time and schedule, who will drive you to the hospital. All that stuff.* ***02)*** *Suddenly getting a phone call for pre-op, asking them why they are calling and finding out you are booked for surgery in five days, the day you are moving house, a date you were never made aware of, is really frustrating. I just couldn't change everything and go in for surgery. If they had given me 2 weeks I could have done it. Now I have to wait at least another 6 months and that's flexible. I could be bumped by an emergency.* ***S062*** *Life is on hold and you can't make any plans until you know what date you are going in and then 6 weeks after that for recovery.* ***NS006*** *They want to know. (Work wants to know surgery date). At least my co-worker that is giving birth knows the date she will give birth. Everyone, everything is dependent on my leave for surgery.* ***S694*** *I have a daughter in university and my parents need help…There is nothing I can do about it until I have a (surgery) date.*

C) Getting Ready for Surgery While Waiting

The patient participants believed that their time spent waiting for surgery could be more usefully spent getting ready or preparing themselves for surgery; some kind of pre-habilitation (Gillis et al. 2015) that would ensure they were physically and emotionally in the best shape possible for surgery. Only one participant, one of the few who had been given advice in the form of an exercise booklet, chose not follow directions. She believed the exercises were too difficult and painful for her. While this example might, on the surface, illustrate an "unwillingness" to work toward better health, this patient provides a clear demonstration of self awareness, a self care effort and the need for individually tailored guidance (in addition to the standardized booklet information).

Ci) Patient Responsibility

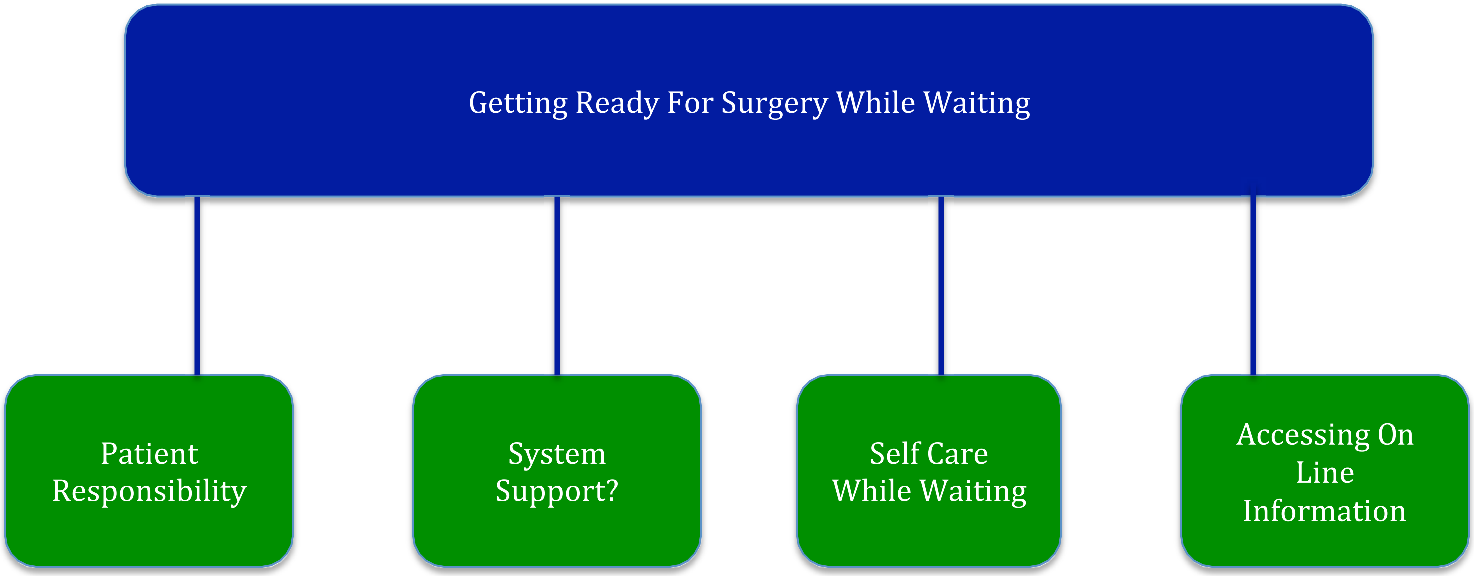
Almost every patient believed that it was their responsibility to be as healthy as possible on their surgery date and that their wait time could be spent educating themselves and exercising as much as possible. The majority wanted provider guidance and some kind of ongoing connection that would encourage them to keep as fit as possible. Apart from some orthopedic patients who were waiting for hip or knee replacement and given exercise booklets, few of our participants had received any information or encouragement from healthcare providers. They felt that they were responsible for working hard and "advocating "for themselves just to get access to helpful information and support sources. Those with some information cited their family physicians as the source for their knowledge mostly provided at patient request.

Table 9

Getting Ready for Surgery	Exemplar Quotes
Patient Responsibility	***NS187*** *To do research, and find out more about the surgery, and what life will be like after surgery. I need to know how to take care of myself too… I know that I need to lose some weight because it's hard to do surgery if you are fat.* ***S080*** *Going in and being as healthy as you can. Diet, strength…Physically and mentally as strong as you can be. (patient responsibility prep for surgery)…* ***I****'m just making sure that I'm as rested as possible. I'm eating very healthy… My mental outlook is that things could be a lot worse, you just believe in the system and that it will take care of you.* ***SN153*** *I need to maintain a certain level of health. I'm going to be having surgery. I have to responsible for my own health is the bottom line and not go off and do risky behaviours like smoke and drink.* ***S665*** *To be informed and follow up… One thing that has definitely changed as I look at my parents, and their expectations of doctor's offices, is to call them back or wait for this… You have to be your own advocate.* ***S670*** *The system is so overwhelmed that you have to advocate for yourself.* ***SN156*** *Realize that you are one of many, many people that need surgery and be accommodated, and when you are offered a date don't say "Well, I'm getting my hair done that day. Can we do it next week?" Be reasonable as well, when you do get dates offered to you* ***Msc5*** *Let me tell you some of the things I'm doing on my own. I know I have a weight issue…In these last couple weeks I've tried to quit sugar, add fruits and veggies, and ride my bike. I can only do that about 4 or 5 minutes. It's kind of a joke. I just thought if I could make some changes even if I could lose 10 pounds it would all help right. I've tried not to set the goal*

	ridiculous cause then you just don't do anything. ***S668*** *It gets to the point that some people have to almost bully the staff. What is that quote, the person that makes the most noise gets heard?*

Figure 3



Cii) System Support

Three quarters of the participants believed that they had no support from any one as they were waiting for surgery. They perceived that they had attended their surgical consult and had either been given a firm date or an estimated wait time and left totally alone as they waited. They did not perceive that they had any way of connecting with the system to either check their wait time or access any advice or support. Some patients realized that the system was severely overstretched to the extent of feeling inadequate or guilty about asking for support from over burdened providers. Many felt abandoned and really needed to know that they had not been forgotten.

Table 10

Getting Ready for Surgery While Waiting	Exemplar Quotes
System Support	***NS029*** *No there was no information. That would have been*

	helpful. (pre-surgery) ***NS041*** *Communication. They should communicate with me. I don't know who will communicate with me...pre-surgery class would be useful* ***Msc14*** *It would be nice to be able to call somebody (while I'm waiting). Like I made the decision about physio and about chiro all on my own. Now it would be nice to be able to phone some body and say I'm looking for suggestions. What do you suggest? Or Do you think it's a good idea or could you run it by the surgeon?.. I have no wish that I could see the surgeon to consult. I think his time is better spent elsewhere. But if he had a little group of people that you could maybe talk to that would be valuable…A little feedback as to advice …or suggestion (around what you might do while you're waiting as your back is getting worse).* ***NS 057*** *No, I got no information on the surgery and I am afraid of the surgery…Because it is a hysterectomy that there will be some hormonal issues around the surgery and how to care for the sutures…Information again would be useful…there was not enough time to ask questions* ***SN109*** *At the time of my appointment I was given some directions and a day surgery booklet with some instructions in it, and a requisition for some lab work that I will have to do two weeks prior…* ***CN7*** *I wish... I don't unfortunately have a family doctor. I had a family doctor from the eighties up until the time I moved to Calgary from Saskatchewan. I haven't had a family doctor for 11 years. I've went to Walk-In clinics where they basically don't really care about you. They just want you in and out. They give you some generic crap medicine that was referred to them by their memo at the beginning of the month and that's what they do. If it doesn't work you come back in three weeks and they give you another medicine and then if that doesn't work you come back in another three weeks. That is a painful procedure as well. I have tried to get a family doctor over the years but not found one.* ***SN141*** *I think one of the things that would be critical and should be instituted is that they (patients) should be followed up on…I think that you should be getting a call from your doctor's office once a month. (while waiting for surgery) On that basis, I think a quick call from the office, inquiring about your health status and has anything changed* ***SN381*** *No medical support prior to surgery. They (doctors) didn't tell me anything, just that it was broken so I assumed that I shouldn't walk on it… Well, maybe telling me what to do*

	while I had to wait (at home) and how long I might have to wait would have been good. I had no idea how long I would have to wait

Ciii) Self Care While Waiting

One third of the participants decided to reach out for some kind of alternative support or care while they were waiting. They accessed chiropractors, acupuncture, massage, exercise classes and nutrition advice in an effort to decrease pain, increase mobility and generally stay as healthy as possible during the wait period. All did express that they had to pay for these services and some people without health care insurance or adequate financial resources would be unable to do this.

Table 11

Getting Ready for Surgery While Waiting	**Exemplar Quotes**
Self Care While Waiting	***S154*** *I do go to a physiotherapist every now and then, who will give me a good stretch because I have limited hip stretch I do stationary bike riding and that helps a little bit. That gives me minimal (hip) pain.* ***S272*** *Also I think it is important for patients to educate themselves as much as they can on whatever procedure or illness that they are going through so when they do go in to see the surgeon they are armed with a good list of questions and they already have a pretty good understanding of their health situation and what their options are. I think that the doctor does need to be open and share all this information… when you go to see a specialist you may wait 6 months to see that specialist and only get 15 minutes with them so you should be making the best of that 15 minutes.* ***S157*** *So, I have just been very sparingly using my Tramadol. The prescription is for two pills a day, twice a day. I might take two pills every couple of days. I prefer to manage I guess being in pain rather than start taking a bunch of pills.* ***06****) I'm getting worse and there is nothing I can do about it. I phoned the surgeon's office and asked to be put on a cancellation list.* ***S048*** *I just decided to (take iron supplements) because I was tired.* ***09)*** *I call and say it's getting worse and I need to see him or something but I think there are people worse than me. It's probably not a good way to think… I was told you just have to be persistent and not go away without answers. Actually*

	*I was told that yesterday and I was… I've always not put myself first**...** My personal trainer told me. She's supportive.*

Civ) Accessing On-line Information

Approximately three quarters of the participants had accessed information on line about their surgery procedure and /or their medical condition necessitating surgery. A common comment was that they would have preferred to be informed about reliable sites they could consult by their surgeons. They found conflicting advice on some sites and did not know what to believe. They also noted that some of the information did not fit procedures common in Alberta. There was a belief that surgeons must be aware that patients consulted "Dr. Google" and the provision of a list of suitable and reliable sites would be of benefit to both surgeons and patients.

Table 12

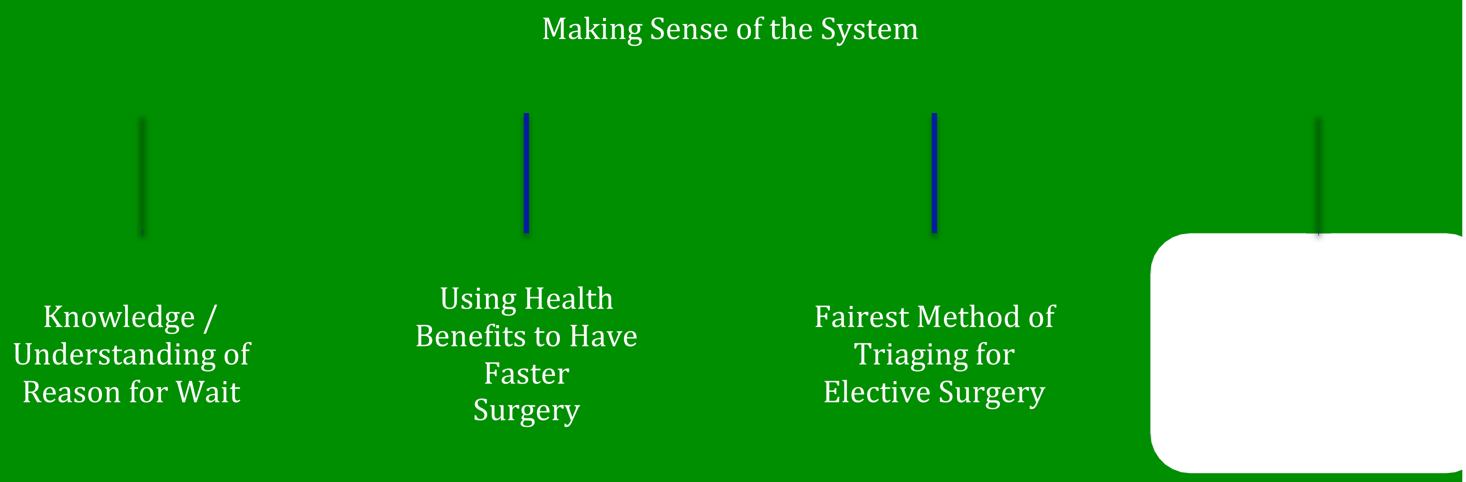
Getting Ready for Surgery While Waiting	Exemplar Quotes
Accessing On-line Information	***NS050*** *But again you have to be careful with Dr. Google. Yes, you don't always know which ones are accurate. Sometimes the information you get on the Internet doesn't pertain to what happens here (Alberta). I found that out with surgeries that I've had… You may read something on the Internet and find out that it is done differently here. Hospitals and surgeons have different protocols too.* ***S248*** *My mom who went through breast cancer, said to me "Do not Google, but if you need look up information on-line go to reputable sites like the Canadian Breast Cancer Society website or the Canadian Cancer Foundation website. Go to the ones that are the official organizations."* ***S064*** *Yes. (I went online) I did my homework before I went in to see him so I could clarify some things I'd read. Again, between him (surgeon) and I, we had a very good discussion and coming out of there I felt that we had a good plan.* ***SN229*** *No, I didn't go online. I had a friend who had a hip replacement done a few years ago and knew what she had gone through and how hers had worked. I wasn't concerned (about finding online information). I just wanted to get it done.* ***SN103*** *I think it's risky. You have to be able to validate the source of the information that* **you** *are googling and you have to be able to interpret it. I think without some background knowledge it is very easy for people to either become over or under anxious depending on what they are*

	reading and looking up. **NS025** I checked the web pages. (for post-surgery information)…I did it on my own. (looked for own info on Internet)

D) Making Sense of the System

This theme brings together participant opinions and beliefs about the Albertan Healthcare System engendered by their experience of waiting for surgery. Most of the participants, whether mostly satisfied or highly unsatisfied, believed that healthcare providers were generally doing their best but that there were gaps or flaws in the current system that could be filled or changed to improve their experience of waiting for surgery. Only one participant was so angry with the system and what he saw as political interference that he had given up on waiting and was relying on eventual urgent need to provide his surgery.

Figure 4



Di) Knowledge and Understanding of the Reason for the Wait

None of the participants were given a reason for the wait time for surgery and none of them had asked their surgeons or nurses when being given either a surgery date or an estimated wait time why they had to wait. When asked why they had chosen not to try to find out the reason why they had to wait, all appeared surprised and noted that it had not occurred to them to enquire. They then surmised that it was because there were not enough surgeons, operating room facilities or some other necessary resources that were not immediately available or were scarce. It should be noted that only two of the participants, both AHS employees, had some knowledge about the current aCATS initiative and both believed that transparency around the triaging system would benefit both patients and providers.

Table 13

System Topics	Exemplar Quotes
Knowledge or Understanding of Reason for Wait	***NS010*** *No. I've no idea about the reason for long wait for surgery. I'm aware of it because I worked for a senior's complex in my previous work. So I know that our residents are waiting that long so I thought it was a given.* ***S2016*** *So I went to see him (doctor at Hip and Knee clinic) in March, and didn't see the surgeon until November and from there, I was told anywhere from 8-10 months. That is what the waiting list is right now. They just said because of a lot of people on the waiting list and didn't say anything other than that.* ***S2061****. My dad had his hip replaced in Medicine Hat. In Southern Alberta the wait times are nowhere near as long what they are in Edmonton. They have this big fancy hip and knee clinic that they just put in the Royal Alex. I don't know what the problem is.* ***S2069*** *I talked to my GP and he said to me…he knows that orthopedic surgeons that come out of school and don't have work…There is not enough operating space… If that's the problem, then let's fix it. If we don't have enough OR's, and we know this, then let's figure out how to open that up…* surgery. ***S2079*** *I would love to see how this works and why it takes up to two years to get a hip replacement. I know when you go on the site it says a lot less but in my case it's not…It was 8 months until I got to see Dr._____. I got to see him and in my little book that I got it said that the approximate wait time is 8-10 months. So right out of the gate they told me…I said "You're kidding, I have to wait 8-10 months?"…They just kind of threw their hands up in the air…but it is what it is I guess.* ***CN1016****: No, the surgeon did not tell me why I had to wait…My thoughts are this: These guys get you in as fast as they can. You know the surgeons, they're doing their level best and I know that there's only so many hours in the day for them to work. There's only so much availability for the surgical suits as well. And so what are you going to do? Get mad at them?.* ***Msc13*** *No he didn't tell me and I don't think I asked (about wait time)… I think we all just know there's a wait period and*

	that's what it's like in Calgary or Alberta…we wait…I think if I had… something really acute happened and I'm in such bad shape now I just might say why do I have to wait?... but the way I am…it's coming up and it'll be what it'll be. ***S123*** *No he didn't tell me why I had to wait … but when I went to the Hip and Knee clinic he did show me what he was going to do with one of those dummy bodies.* ***S033*** *There is a protocol they have to follow, it's not like that they can tell me when they are going to do the surgery.* ***S473*** *No idea of why a long wait time, but what I've gathered over the years is that specialists are usually pretty busy and they don't take walk-ins. You have to have an appointment (to see specialist) and they are so booked up and when you have a problem and call it takes about two months to get in unless they have a cancellation.* ***SN014*** *I didn't talk to him but I talked to his staff and they said that it is because of the line-up of people ahead of you. They go in sequence. There are too many clients* ***SN136*** *Yeah, they tell you that you are going to wait 6-8 months, but they don't say "Well, I've got a 103 people on my wait list that are much sicker than you are, and unfortunately they have to be done prior to you. You are not that ill or your symptoms are fairly benign, you can wait longer."… If the surgeon is being fair and honest, I honestly do believe in aCATS… I think that the surgeon should be able to place his particular patients in a category which is responsible and reasonable. If that means I wait longer, that's okay.* ***SN367*** *That there was a huge backup. Red Deer doesn't have enough operating rooms. The doctors have banded together and are trying to get that (lack of OR space) fixed but Red Deer hasn't received any funding from the province for three years.*

Dii) Using Health Benefits to Have Faster Surgery

PaCER researchers were asked by the Principal Investigator to ask a question about patients' opinions of using healthcare benefits to lessen time spent waiting for surgery. Since our methodology entails allowing analytical categories and probe questions to emerge spontaneously from the data and go forward iteratively, we were fortunate that one of our SET participants raised this possibility without any prompting, allowing us to stay true to our usual approach. (We note that this incident indicates the natural affinity and synergy between problems and strategies relevant to patients and providers – the common interests are inherent). We noted that two other participants raised this possibility without encouragement from the interviewer.

Not surprisingly, the five participants without health benefits were not enthusiastic about the idea, while all but two participants with health benefits approved the suggestion of possibly changing the rules. Some saw the move as benefitting only themselves but others believed it would be good for the overall system.

Table 14

System Topics	Exemplar Quotes
Using Health Benefits to Have Faster Surgery	***NS016*** *I was employed so I had insurance coverage in the Philippines and used it there so i definitely would use insurance to be seen faster if allowed in Alberta.* ***S2019*** *We're looking at up to two years and personally I'm thinking everyone says that our health care system is so great but right now I'm thinking that private is the way to go… I have friends in the states… and they've had hip replacement surgery, they've been diagnosed and within three weeks they're done. The cost to them (friends in US) is nothing. Within their company they are covered up to a certain amount and then kind of like Alberta Health care they can pay to get the coverage for the rest.* ***S2068*** *…if I had the opportunity to go through my company like dental for example, if I have anything wrong with my teeth I'm in within 2-3 days and getting work done because it's private. If hospitals were the same way, there would be no issues any more. This problem would disappear…* ***S2090*** *That's the thing. If I was to go somewhere else and get it done would Alberta Health Care pay for part of it? They are too busy to take anybody and I'm relieving the system and all they would have to do is pay the surgeon that did it. Is that possible?* ***Msc 8****I don't think so. (Got in faster by having insurance pay part)… I might have changed my mind right now because my back has gotten so much worse. But at the beginning …I guess I thought I could just tough it out.* ***SN219*** *Yes. I would have done it even not through an insurance plan and paid it on my own… but I would have paid extra out of my own pocket to have been seen sooner* ***SN025*** *I would definitely consider it. (using health benefits to pay for some of the surgery)… I would like to have an option. (paying for some of the surgery to get in faster). I think the thing that should be allowed is that there should be private and to have access to private and pay for services and maybe*

	the government funds part of it. ***SN031*** *The individual might pay for it so it might offer an alternative that would be good for the client and good for the system because it would take pressure off the public system. To do that is a win-win for everybody.* ***SN090*** *Not for this particular (gallbladder) issue. (wouldn't use benefits to get seen faster. There are certain things that I think have merit. Again, if I was waiting for a different type of surgery for a different type of reason, I think there would be merit.* ***S2029*** *There you go again. Everyone says that we don't have a two tier health system in Alberta but you know what? That is the biggest crock I've ever heard… We have a two tier system as much as they are telling us that we don't.*

Ciii) Fairest Method of Triaging for Elective Surgery

It seemed that most participants had no idea how surgeons decided precedence for surgery, appearing to believe that they just joined the queue and took their turn. When we probed with questions about their opinions of the fairest method of triaging for elective surgery, most were unsure what was the fairest way. Some thought level of pain while others thought maybe those in the work force should have precedence; there was no consensus and most negated their first thoughts by musing about the unfairness of their choice. The two participants with knowledge of aCATS believed, if the triaging procedures outlined were rigorously followed by all surgeons, it was the superior and fairest method. Along with the majority of the participants, they wanted transparency of how surgeons triaged elective patients. Although participants realized that the fairness of triaging would not solve the problem of individual harm from lengthy waiting, everyone believed if they knew the system of triaging, they would have more confidence in its fairness. There was also discussion about the fair choice and objectivity of triaging criteria e.g. health criteria such as pain or loss of function, individual variations of perception (e.g. pain threshold, overall physical fitness or stamina), general life concerns such as serious danger of job loss or severe stress, or a simple "*first* come, *first* served consideration.

Table 15

System Topics	Exemplar Quotes
Fairest Way of Triaging for Elective Surgery	***NS154*** *I think that I should be given priority. (because of being in pain). Some women with fibroids are asymptomatic. They don't experience any pain. I told my gynecologist that I'm in pain. He's aware.* ***S2064*** *If it is that nobody should jump the queue then I guess it doesn't matter but at the same time if you are working and have*

	a job and your job is on the line if you don't get this done…you are a taxpayer right? I'm not saying that people in their seventies should be bumped back but… ***S2066*** *Who is to say who is in more pain? My pain, I may have a higher threshold for pain than somebody else. I don't know. How do you rate somebody's pain level? It's hard to do that, right?* ***CN1047:*** *They need to triage (for elective surgery wait time) based on how critical the situation is. You don't want someone dying while they are on the waiting list. Number two priority (criteria for considering surgery wait time) would be pain and discomfort.* ***Msc12*** *If some poor soul jumps ahead for me because they're just beyond pain so be it...* ***S254*** *Well, my husband unfortunately just had coronary bypass surgery two and a half weeks ago. He had an artery that was 100% blocked in his heart. He had to wait almost 4 months for surgery because he was considered low priority because he was stable with medication. Looking at that experience, it was incredibly stressful for both of us. (waiting for husband's coronary bypass). Even though he was stable, he was still waiting, waiting, waiting for surgery. He couldn't exercise during this time because he would get chest pains so he lost more and more fitness and lost muscle mass. His recovery will be even longer.* ***S071*** *Yes, pain might be a factor, but I just think that sometimes though "Is the pain real?" "Are you saying what you need to say just to get in there?" I guess it would be at the doctor's discretion.* ***SN242*** *It would be nice if we could say base it on need, on the pain that people are experiencing. My pain for my condition may be more or less than the next person, so it doesn't mean that my situation is any worse it's just that I'm experiencing more pain. It would be nice if there was a triage thing for people that are impacted the most. The worst conditions could go first but I don't know how you'd do that.* ***SN027*** *The fairest way is that it is first come, first serve. You go in order. There is a sequence to that whole thing and there is a method to that.* ***S2051*** *Nobody will ever notice that certain people are moving up the queue before other people and there's no way of telling that. I honestly believe that happens… I'm thinking that if somebody knows somebody in the system it sometimes helps moves things along.*

Div) Patient Confidence in the System

Confidence in the overall system varied from none at all to total confidence that everything possible was being done with most participants falling somewhere around the middle. There was consensus that patients' waiting situation in general would benefit from their stronger confidence in the system, which could be enhanced through ensuring ongoing contact with the surgeons and /or their office staff, having a set surgery date at surgical consult time, and having an understanding of the triaging system.

Table 16

System Topics	Exemplar Quote
Patient Confidence in the System	***S2054*** *That what happens…if someone needs a hip, you get bumped. How do you know if I'm being bumped? That is a big issue. I don't know what's happening. I have no confidence in the (public health) system right now.* ***S2059*** *Basically, unless I call in and say tell him that I'm on a verge of a mental breakdown which I don't want to lie about, but maybe that is what some guys are doing to get to the front of the queue. My biggest concern is that if there is this big of a waiting list, why isn't someone doing something about getting more surgery time? To me the public system is failing us.* ***S082*** *My mental outlook is that things could be a lot worse, you just believe in the system and that it will take care of you.* ***CN7*** *It (the system) is what it is, right? Everybody wants to go to the store and you go to the store and there is a line up. You have to wait in the line-up. That is the way it is. I can't blame the system. It is a pretty simple system you know, it is first come, first serve…I think it goes by severity as well. If somebody has a very bad case, they might say if we have a cancellation, we'll call you versus a guy that is not in as much pain.* ***SN051*** *I have confidence in the health care system I think in emergency and urgent situations. I think they do a pretty good job with regard to urgent matters. I have had some surgeries that have required immediate attention and I think that's been good. I think that's the best part. Yeah, I think if you are in a tough situation it's good, but I think if you are in an elective situation it's irritating.* ***SN057*** *All it is i a goal (timeline) that they strive for but if it doesn't fit in there, there isn't any consequence. Nobody is accountable for the fact that we want the emergency response time to be this, or the surgery wait time to be this or that. I know that there are times that are worse than others and*

	those goals are not being met. The problem is that we haven't been meeting these things (surgery timelines) off and on for a long time, which is why there isn't any consequence. ***SN125*** *Yes, I do have confidence in health care system. Again, it's my knowledge of how the system works and how it works well and how when it doesn't work well. I know that there is work being geared toward when it doesn't work well to improve things, so I do have confidence that the system does mostly work quite well but when it doesn't work well we do try to fix it. That's my internal knowledge.* ***SN130*** *Well, honestly aCATS is doing great work. I have a lot of confidence that the right people are having surgery at the right times.* ***SN131*** *We haven't totally eradicated waitlists and that would be really nice, but I do believe the patients that need the surgeries and the priority and triage scale that aCATS uses is really working. Most patients don't know this and they should.* ***SN135*** *I think that it is important to do research with patients. If for no other reason, whatsoever, I honestly believe we need to begin on a much more consistent level involve patients and the public in what we do, so that they have more confidence in what we do and they understand it better.* ***S661*** *I think generally it waiting for surgery is frustrating. For my surgery it isn't as serious as some other people but I've known a lot of people and it does affect people's confidence in the system. Quite often the ball got dropped and it (referral) didn't get made. There are massive holes.* ***SN297*** *I have to drive to Olds for surgery and have to have someone drive me there and back. I find that annoying when I have a hospital here in my hometown (Red Deer).* ***SN300*** *No, the first one (surgery) was to clean all the junk out of it and that is when they found out that it will have to be replaced, I'm not going to start the process (for knee replacement surgery). I'm tired of fooling around with the Red Deer hospital and doctors. I'll manage the pain and then when it gets bad enough I will start (the knee replacement surgery process). I just don't feel like going down the road and always being put off, put off (for surgery).* **SN313** Living in Red Deer makes it more difficult to get health services). Our elected government. (makes it more difficult to get health services). Well, Rachel Notley was here last month to announce that the Red Deer hospital was not getting any money period but she gave money for Calgary and Edmonton.

Discussion

The patients in this study were faced with differing wait times, medical conditions requiring surgery and knowledge of their surgery dates, yet many aspects of their experience across all eighteen participants were remarkably consistent. The first section of the results (problems encountered by participants) provided insight into what the patients perceived as the major concerns in their situation, and what they experienced as a result of these concerns. The second category (taking action and trying to manage) included patients' ideas on what could be done to improve their situation, and what they would be able to do with better supports from the system.

The Problem: "*generally waiting for surgery is frustrating*" (S661).

In accordance with the literature patients generally perceived that waiting impacted their health as they experienced, at some level, pain or discomfort, worsening of symptoms or the emergence of new symptoms they believed were related to the wait and anxiety and /or depression (Gillis, Gill et al., 2017; Johnson, Horwood & Gooberman, 2014; Conner-Spady, Johnston et al., 2007a; Sanmartin, Berthelot & McIntosh, 2007; Edwards, Boland et al., 2003). Many patients described the increased anxiety and depression noted in Mitchell's (2003) scoping literature review. They were also aware of the importance of timely surgical treatment and thus expressed a fear that surgery outcomes or the quality of after surgery recovery could be affected by the deterioration of their health during a lengthy waiting time.

As noted in the Results section, those patients with only an estimated surgical date appeared to have increased difficulty with waiting as they lived with the uncertainty of when the wait would end, but their experience of waiting was similar. Knowing their surgical date did not ameliorate the level of pain, perception of deteriorating health or level of anxiety experienced but there was hope as they could see the end in sight.

In general patients tended to accept the systemic problem of waiting as often frustrating and potentially harmful, but inevitable "*We are victims of the system*" (SN012). However their accounts represented active self management attempts during the period of waiting, as well as a "wish list" of things that patients believed might help them and others in the future.

Patients Taking (and Asking for) Action: "*telling me what to do while I wait and how long I might have to wait would have been good*" (SN381).

The patients in this study believed that they were responsible for staying as healthy and educated as possible prior to surgery, a finding supported by a recent Enhanced Recovery After Surgery (ERAS) study (Gillis, Gill et al., 2017). They believed that this would have been easier to achieve if they had more initial and ongoing support and information from the healthcare system. This desire to spend waiting time "getting ready for surgery" accords with recent work in the ERAS field , which outlines the benefits for patients (Gillis, Loiselle, Fiore et al., 2016). Our participants believed this would not only help them maintain health but mitigate the isolation from the system they experienced. Some of the patients in the study reached out for care outside the system by accessing and paying for chiropractors, counselors, acupuncturists and other related services as well as browsing the Internet. Once more they would have preferred system support by having their surgeons provide them with a list of reputable sites.

Participants with and without firm surgery dates, no matter how long or short the wait period, believed that their lives were on hold, a finding supported in the literature (Carr, Teucher & Casson, 2014; Carr, Teucher, Mann & Casson, 2009; Sjoling, Agren et al., 2004). Having one's life on hold caused problems at work and with finances as well as an inability to make plans and follow a normal life since many were hampered by pain and mobility issues. Lack of contact from the health care system and their healthcare providers, especially their surgeons and his or her staff, left them believing they were in limbo and engendered in some, especially those without a surgery date, feelings of anger and frustration at a "faceless system" outlined in the Sjoling, Agren et al. (2004) article. Those with no firm surgery date had more work related and financial problems. Unlike those with a surgery date they could not plan when they would need coverage at work, their finances, or who would be available to take them to and from hospital and look after their post surgery needs.

Participants had no knowledge or understanding of how they were triaged for surgery, a finding supported by in two articles reviewed (Conner-Spady, Johnston et al., 2007b; Conner-Spady, Sanmugasunderam et al., 2004). They were left to guess why they were waiting and based their guesses principally on media coverage or from other patients' experience. Providers told them they were in a queue but patients had no knowledge if they were taken in order of presentation or if there were other factors in their assigned wait times. This led to many wondering about the fairness of the wait system and often a subsequent lack of confidence in the system. One participant told us if he were an Edmonton Oiler, he would not be waiting. There were also questions about the varying wait times for the same surgery across different surgical centres and a few patients voiced the fear that they may be "getting bumped" by people who were "in the know".

Reflections on the "Origins of Health" while Waiting (Salutogenesis Theory)

The strategies and resources that patients used in the process of managing the stress while waiting provided a remarkable fit with Antonovsky's (1985, 1987) theory of *salutogenesis* – a theory that explains the origins of health, in contrast with studying the causes and origins of disease (*pathogenesis*). We discovered that many participants were able to use their resources and seek supports necessary to maintain reasonable health, as best they could while waiting for surgery. They were also able to articulate their ideas and frustrations on what resources were lacking that could help them maintain their health in better ways.

In particular, we were able to conceptualize three areas of participant's ideas that corresponded with the three components of Antonovsky's *Sense of Coherence (SOC)* – comprehensibility, manageability, and meaningfulness (Antonovsky, 1987). Sense of Coherence is defined as "a global orientation" that enables individuals to move toward health and withstand the stresses of life. This ability is as strong as the extent to which the individual feels confident that the world is understandable, manageable, and has meaning (Antonovsky, 1990, p. 7).

The three areas in which our research participants found both the best *opportunity* for action to maintain their health and the greatest *difficulty* coping without resources were as follows:

Knowledge (understanding). This correlates with Antonovsky's *comprehensibility* component of sense of coherence - the belief that one can understand and explain the situation. It was the need to know what to expect (when will the surgery happen and what exactly is at risk while waiting), and what can be done. Finding oneself in "a black hole" was perceived as damaging. Acquiring sufficient knowledge was helpful. In particular, health care providers can acknowledge the patients' active search for such knowledge and meet their need for thoughtful communication.

Support (managing). This correlates with *manageability*, the belief that one is able to find the means to manage and control the situation (how to take care of oneself while waiting, what might prevent the effects of the delay or expedite the date). The patients wanted to manage their health, prepare for the upcoming surgery, and increase their chances for better outcomes. They would like health care providers to contact them, follow up, and provide available tools for staying as healthy as possible.

Trust (making sense). This correlates with the *meaningfulness* component of the sense of coherence, in which the patient needs to believe that the situation makes sense, and one's efforts are "worthy of investment and engagement" (Antonovsky, 1990, p. 8). The questions about the causes of, and reasons for waiting, the meaning and fairness of triaging, and the need to fell confident in the system fit into this category. The patients want to remain confident and secure, have the right to stand up for themselves, and to trust that providers in the system do care.

Generally patients who, despite severe problems, score well on *The Sense of Coherency Scale* (Antonovsky, 1993) tend to be more hopeful and perceive themselves as having a greater sense of wellbeing than those with weaker scores. This may suggest that patients with weaker scores might need extra support (Soderberg, Lundman, & Norberg, 1997). Carr, Teucher & Casson (2017) found that patient experiences of time spent waiting for surgery varied in severity, indicating a complex relationship between greater perceived symptom severity and ability to tolerate waiting indicating some might benefit from having faster surgery.

Reflections on the Recruitment Process

As we noted in the methods section, recruitment for this project was much more difficult than PaCER's usual experience, with difficulties emerging at all stages of the research. The aCATS leads making first contact experienced difficulty and the researchers were unable to engage successfully patients' interest as well as they had in previous studies. There were more "no-shows" for focus groups and interviews than was normal with patients committing and then being unavailable and non responding to contact. The researchers have discussed this with their colleagues and academic advisors and have no explanation for this phenomenon.

Conclusion

It appears that waiting for elective surgery engenders common experiences across differing times spent waiting, five different surgical services, three AHS zones and having a firm or estimated surgery date. It is the intensity of experience that may differ according to length of waiting time and being assigned a firm or estimated surgery date. Participants identified perceived service gaps, especially with respect to ongoing contact and transparency of the triage system that they believe make waiting for surgery more difficult and may contribute to the level of confidence in the overall system.

Strengths and Limitations

This study was conducted through all phases of the research by patients who had experienced waiting for elective surgery. Recognition by participants that the researchers shared their experiences of having to wait for elective surgery 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 patient participants as co-design partners drove the direction of the research and they were an integral part of the analysis process (Marlett, Shklarov et al., 2014). We engaged with 18 patients waiting for elective surgery in three zones across Alberta, an average and sufficient sample for a qualitative research project and the data is authentic, thick and rich. Saturation was reached after the 12th COLLECT interview, but we decided to continue with our remaining 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 within other systems. While we attained diversity in age, gender, zone, education and service, all of our participants apart from one (Asian) were Caucasian.

Participants from different cultural, ethnic and socioeconomic groups may have different lived experiences and further research is recommended.

Recommendations

Waiting affects us in many ways: we experience waiting as frustrating, risky, and often harmful. We are trying to manage our situation by seeking more information, making sure that everything is possible is done to support us while we wait, and trying to do the right things to help ourselves. We are told that nothing can be done about having to wait, it is a systemic problem. We accept the waiting problem as inevitable and know that healthcare providers are generally doing their best, but we also believe that there are gaps or flaws in the current system that could be mended. We would like to have more support from our providers, more transparent information, reassurance, open communication and access to timely available treatments while we wait for elective surgery More precisely we suggest the following:

1. Provide a simple, easily understood explanation of the current triaging system for elective surgery.
2. Provide initial and ongoing support and information, including whom to contact if there are changes in their health status, to patients as they wait for elective surgery.
3. Provide check-ins on those waiting for elective surgery by staff on a consistent basis.
4. Attempt to increase the number of firm surgery dates by extending forward planning.
5. Consider exploring patient sense of coherence when triaging for elective surgery.
6. Continue to strive for equity across zones.

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