The Experience of Waiting for Help with Osteoarthritis

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Patients Matter: Engaging Patients as Collaborators
to Improve Osteoarthritis Care in Alberta

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Section 1: Introduction

This is a report on an internship project in Patient Engagement Research (PER) conducted as part of the *Patients Matter* grant awarded through the Canadian Foundation for Healthcare Improvement (CFHI) and their Patient Engagement Program. The report documents the experiences of five intern researchers working together in exploring and designing the project and its instruments, and engaging patients in understanding the waiting experience of patients with osteoarthritis (OA). The research titled *"What are patients' experiences of waiting for help with their osteoarthritis?"* was formalized with an ARECCI process used to write the ethics proposal.[1]

The general area of our research grew from the concerns of the team who wrote the initial training grant. The Alberta Bone and Joint Health Institute (ABJHI) had been working on a system-wide clinical pathway, and the scientists were concerned about the lack of patient data prior to surgery and about how to operationalize a realistic wait time strategy.

The issue of the experience of waiting for help with osteoarthritis developed from our class focus groups and narrative interviews conducted as in-class activities. The issue is widespread. According to Carr, Teucher, Mann and Casson (2009) publically funded health care systems have been trying to improve wait times, especially for surgery, for some time.

We began to realize that we could add to the existing research by exploring waiting for help from a clear patient perspective, for as Fogarty and Cronin (2008) note, while health care professionals have focused on "waiting lists" and "waiting times," they "have little

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[1] This research study (Ethics ID number 24144) is approved by the University of Calgary Conjoint Health Research Ethics Board, and has been reviewed by the Alberta Bone and Joint Strategic Clinical Network's research review committee.

understanding of what it means to wait for health care from a client perspective" (p.464). While not specifically addressing osteoarthritis waiting times, Suzanne K. Irvin (2001) discusses patient anxiety and emotional distress generated through uncertainty and loss of control in waiting for medical events to unfold. The writer's conclusion goes on to state that waiting is a stationary, yet dynamic, and unspecified time-frame phenomenon in which uncertainty is a manifested outcome. Fogerty and Cronin also suggest that clients experience uncertainty and powerlessness while anticipating a disease outcome and that waiting is commonplace in many areas of healthcare.

We approached our research on the premise that waiting could take a number of forms. People may wait for a specialist, wait for a diagnosis, for treatment, for information, for things to get better, or even for things to get worse. As persons living with OA, we were in a position to engage with our peers in discussions that would further expand on our collective understanding of the experience of waiting.

The project utilized the PER research method of *SET, COLLECT, REFLECT* as outlined by Marlett and Emes (2010). The unique framework of the team's research was our ability as fellow patients to engage our participants as peers. What initially started out as a research project to simply look at the waiting experience of clients in the process of getting help for their osteoarthritis, turned into a much more complex and meaningful search for information as we struggled to understand what waiting for help actually meant.

We hope that this report will be of interest to those who are hoping to engage patients in research, those hoping to understand how the science of health experience and patient engagement might bring new perspectives to health care planning, to patients interested in learning about patient engagement research and, perhaps most importantly, to patients and their families living a life of waiting to find help with OA.

Section 2: Literature Review

In this very brief literature review we set the context of our study as a new direction in osteoarthritis wait time research where the focus has been on waiting for surgery as the primary medical intervention. It is assumed that the patient will be "cured" once they have undergone a specified course of treatment. This implies that there is a linear clinical pathway from diagnosis, to specialist, to wait list, to surgery, to return to everyday life.

There is scant research on the concept of waiting specifically relating to osteoarthritis, a disease for which there is no cure, and which must essentially be managed over the span of an individual's lifetime. As such, specific interventions in linear progression are unlikely to adequately eliminate the pain and disability associated with the condition. Carr et al (2009) demonstrate that traditional definitions of wait times as a linear construct fail to take into account the complexity of patient waiting experience, "which may have multiple meanings – waiting that is experienced as rest, as interruption, as planning or as a completed and meaningful experience" (p.108).

Sjoling, Norbergh, Malker, and Asplund (2006) challenge the perceived practice that osteoarthritic patients are primarily "a hip or knee that needs to be taken care of" (p.12); rather "patients want to be seen as complex human beings, to be taken seriously and not to be seen as an object" (p.12). In fact, concept analysis confirms that waiting is a social phenomenon which constitutes a process whereby patients are active participants as they cope on an ongoing basis with their condition (Irvin, 2001; Fogarty & Cronin, 2008). Irvin, and Fogarty and Cronin challenge previous perceptions and definitions of waiting as merely an inactive state of being. It appears to be clear that we are approaching a major shift in wait time research, where we diverge from quantitative indicators and measurement tools of patient reported outcomes of satisfaction and introduce a science based on the actual lived experiences of patients (Parsons, Godfrey & Jester, 2008).

In the course of conducting our research we initially considered that we would be able to create a “patient perspective,” and soon discovered that even when we focused on a fairly tight definition of an engaged patient, we were faced with the stark reality that patients are both individual in their perceptions and influenced by the social groups to which they belong. Socioeconomic factors create disparities with respect to waiting for help, as outlined by Ackermam, Graves, Wicks, Bennell and Osborne (2005). Studies that reflect these disparities along a broad continuum of waiting that migrate outside of the scope of surgical intervention and wait times are not represented in the literature. We hope, along with our sister project researching post-surgery experiences of Punjabi speaking patients, to open the door to discussions about representation.

Section 3: Engagement Methods

We begin this section with an overview of the general methodology, move to the process of recruiting and working with participants, describe the SET research, the COLLECT narrative interviews and the REFLECT stage.

Patient Engagement Research Methodology

The general method consists of three phases as represented below.

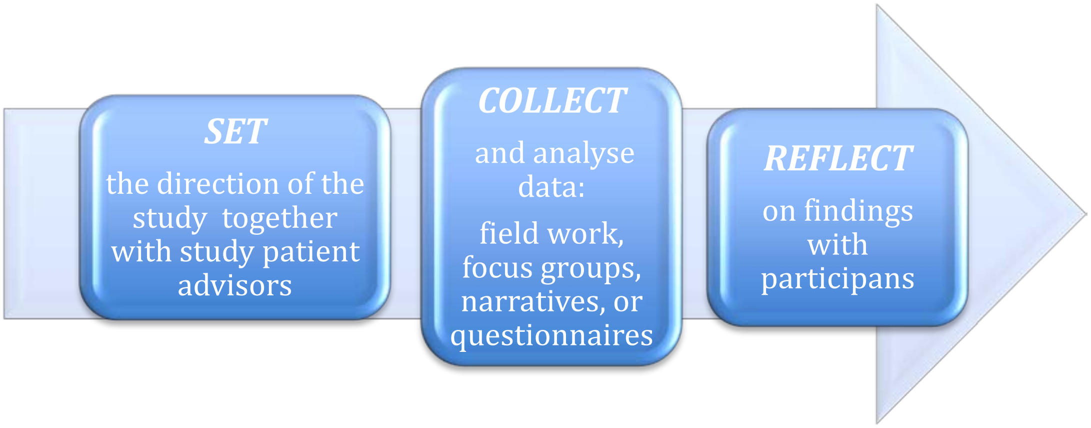

Figure 1. PER Research Methodology.

1. ***SET:*** This opening procedure, generally a focus group, invites representative patients and other relevant participants to become advisors and help *SET* the stage for the study by refining the particular protocols (recruitment, locations, alliances), questions and data collection.

2. ***COLLECT:*** Particular techniques of data collection and analysis depend on the specifics of research questions and purposes of each given study.

3. ***REFLECT:*** At this stage, participants from the initial *SET* focus group (item 1) review findings and analysis with the PER team and suggest knowledge utilization and recommendations for further research. This stage completes the circle of PER procedures and prepares the data to be shared with the relevant health system.

SET and REFLECT focus groups are the hallmarks of the PER method, serving to ensure a *meaningful patient involvement* and *contextual validity.*

Our Process Overview

We conducted an initial SET focus group to get feedback on the idea of waiting for help with OA. We decided that we would follow the SET focus group with narrative interviews because we wanted more depth of understanding and we saw the value of the story as the unit of analysis. The feedback from the SET focus group assisted in adapting the narrative interview to include more encompassing concepts of waiting as part of a chronic condition that has no "cure." The results, analysis, and stories from the narrative interviews were then fed back to a final REFLECT focus group for their input and those findings are reported in section four of this report. The findings from each activity prepared us for the next stage of research.

Recruitment and Participants

Participants were recruited from personal and professional contacts, people attending the Calgary Community Forum of the Arthritis Society, and by placing posters at The Arthritis Society as well as in downtown grocery stores. We anticipated that we would recruit 10 to 12 participants for SET and REFLECT focus groups and 10 to 15 patients for narrative interviews. We were able to recruit 20 people in total who were all OA patients. Seven people attended each of the focus groups, and we did 13 narrative interviews. Three people who participated in the first focus group also participated in the second focus group, and four who took part in the narrative interviews participated in the second focus group.

When we started our research we felt reasonably certain we would be able to recruit patients from a variety of backgrounds. However, as we looked around the horseshoe seating arrangement in our SET focus group (arranged to reduce power dynamics and place researchers directly among participants as equal peers in the research), we realized this was not the case. The group was composed of well-informed, highly resourceful women, with good problem-solving and discussion-making skills who represented patients with a home, income and resources. Some came with health-related and medical articles, lists of doctors, medications, and health facility names and-addresses. We became more aware of our need to recruit "others" – more men, and people from varying age groups, cultures, and socio-economic backgrounds, which we partially accomplished in our narrative interviews and REFLECT focus group. Our recruiting led to an overall participant group of 5 men and 15 women: 1 in their 30s, 1 in 40s, 3 in 50s, 9 in 60s, 5 in 70s, and 1 in her 80s.

In order to assure participants' anonymity their names have not been used, and information that could be used to identify any individual has been removed. In this report each participant quote was assigned a code. Focus group participant quotes were documented from the audiotapes and process notes. Relevant quotes from the narrative interviews were organized according to the key elements of waiting for help that arose from the study. Quotes were coded as either FG (focus group) or NI (narrative interview) followed by the quote number: for example, FG1 followed by FG2, and NI1 followed by NI2. Thus there is no way to link the quote with any individual.

One of the patients interviewed, Spencer (a pseudonym), is in a marginalized, low-income sub-culture of our general society. He has no permanent address, living in homeless shelters, temporary housing programs or on the street. He lacks stability and often has no income at all, yet he shares most of the same experiences and competencies as other participants. Sadly, where things differ for Spencer is in the response he gets when needing help for osteoarthritis. Even though Spencer is a reasonable representative of a homeless individual in our city, by looks, one cannot tell he is homeless.

We were concerned and sometimes derailed as we struggled with social justice issues facing low income patients attempting to find help with their osteoarthritis. To overcome these difficulties, we will show both likenesses and differences in Spencer's experiences with waiting for help. We see Spencer as a participant representing an important voice in our research and will include this one individual voice throughout our report as a touchstone. We contextualized our study within the boundaries of engaged, resourced patients, but have also chosen to include Spencer in our analysis as his experience helps to define the boundaries to the phenomenon.

SET Focus Group

As patients with OA we had already identified our researchable issue as *the experience of waiting for help with osteoarthritis.* We brought this issue to the first focus group for further exploration and development. Our participants reinforced the relevance of this issue and while there was some talk about waiting for surgery and for various medical appointments, participants focused on how waiting impacted their day-to-day living. They did not see waiting as an event with a start and stop time, or a holding place in a wait list, or awaiting a date. Participants spoke about coping, learning medical jargon, managing their health over time, and seeking help. Our understanding of the issue was broadened as we listened to their frustrations with a system that doesn't work smoothly and their eternal hope that things will get better. We used flip charts to document participants' experiences of waiting for help and we used these, along with process notes, to refine the focus of our narrative interviews.

Our SET focus group participants became a spontaneous mental and emotional support to each other. Some spoke aloud more than others, but upon parting each acknowledged, either through nods of agreement or direct mention that they "felt heard by people [research team] who know what waiting for help for osteoarthritis is about" (FG35). We, as researchers, came to understand first-hand the impact of being peers when the participants felt comfortable in sharing their information.

COLLECT: The Narrative Interviews

In order to gain a more in-depth understanding of the experience of waiting for help we used the narrative interview protocol we learned in our training and developed by Marlett and Emes (2010). In this approach the story becomes the unit of analysis. The protocol maximizes engagement while maintaining a focus on the topic. Each of our narrative interviews involved two researchers from our five-member team: one researcher conducted the interview, while the other researcher dealt with distractions, observed body language, managed the recorder and took notes.

As we progressed through the interviews, we began to pick up on nearly universal, related phrases: “I'm not in bad enough shape, my doctor says,” “it's not [body parts most affected by OA] bad enough yet,” “why do I have to wait until irreversible damage occurs.” We wait to be seen by the right kind of doctor who can administer the right kind of tests, and arrange a referral to the most appropriate specialist. This waiting is confounded by pain, hope, frustration, fear, and confusion. We are told we are “not bad enough,” “too heavy/fat,” “too young,” and sometimes “too old,” to be considered a right fit for some treatments. Most of us are trying hard to lose weight, to fit in with doctor schedules, follow-up visits, and medical testing: in fact, we are doing whatever we have to do in despite of knowing there is no guarantee that we will succeed. We heard about strategies patients use to get around system barriers in order to get the help they need. We heard that when one “wait time” ends, another begins. A person can be part of many “wait times” without actually getting any serious medical attention only to start waiting for symptoms to get worse which ultimately leads to the next waiting experience.

Researchers listened to the interviews they conducted and constructed individual participant’s stories of waiting for help: as per the narrative interview protocol, these individual stories became the unit of analysis. This was done using Marlett and Emes's (2010) story structure: title, context, plot, outcomes, consequences, and lessons.

The 46 stories from all participants were compiled into one analysis grid and from there we came to consensus on the key scripts of waiting for help with osteoarthritis. This was followed by an iterative process leading to a mind map of 12 key experiences that we then took to our REFLECT focus group. These key experiences related to: getting a diagnosis; burden and support, worry and loss; frustration; taking charge and managing; and living through the waiting for things to get worse.

REFLECT Focus Group

The purpose of this focus group was to establish a collective patient voice on the issue of waiting for help by sharing our findings, collaborating on personal relevance, and considering future directions. Participants offered their personal views on which of the key waiting experiences were most relevant to them and they discussed what the system could do to improve their waiting experiences.

The patients in this focus group were very committed to participating in the final stage of our study: several were having a severe pain day, and as the day progressed we learned about Calgary's impending flood. The participants came ready to work and to contribute to *their* research. As the day wore on, their exhaustion was clear but the power of the group intensified: they were intent on seeing it through.

During the REFLECT focus group we used flip charts to document participants individual points and group reflections. We used these, along with process notes, to inform our findings which follow.

In honour of the experiences we shared and our belief that the findings belong to both researchers and participants, we have chosen to present the analysis in the first person plural. Here "we" stands for researchers and participants as one voice. We have separated out Spencer's experience as it offers a glimpse into an alternative experience that we believe is an important touchstone to developing a more in-depth understanding of waiting for help.

Section 4: Discussion of Findings

In analyzing the data from our SET focus group, narrative interviews, and REFLECT focus group, we began to see a journey unfolding before us: a journey requiring great exertion and passage through many gates. In effect, we are on a quest for help with our OA.

We came to this study because we wanted to know more about dealing with osteoarthritis. We wanted to know how to better manage our OA on a day-to-day basis. Some of us were on a quest for joint replacement surgery. In many ways surgery had become the "magic bullet" for dealing with our pain and immobility. We had become conditioned to the idea that surgery is "the gold standard" of treatment: new joints as the solution to our pain and immobility.

As we anticipated, we learned a great deal about what waiting for help means to people with osteoarthritis. It can mean waiting to be heard; waiting to be believed; waiting for things to get better; waiting for things to get worse; waiting for a referral; and waiting for surgery.

At first glance the quest for help looks quite straightforward. However, we often find this a daunting task. There are locked gates along the way which may or may not have gate keepers. At times we find we are at the wrong gate and have to back track. Finding the key to get through the gate or past the gatekeeper becomes a challenge.

> One participant kept going back to her doctor as she knew something wasn't right and she needed help: as her symptoms worsened she went back more and more frequently. At one visit her doctor told her that it was people like her who were putting stress on the healthcare system. That day she left the doctor's office, went back to work and burst into tears, thinking "Dear god, someone's got to help me." NI1

This section of our report describes our quest in seeking help for our osteoarthritis. The quest is organized into these stages: Getting Medical Attention; Managing; Dealing with the Vicious Cycle; Living a Life On-hold; Getting through the Surgical Gate (Figure 2); and Reflecting on the Quest for Help.

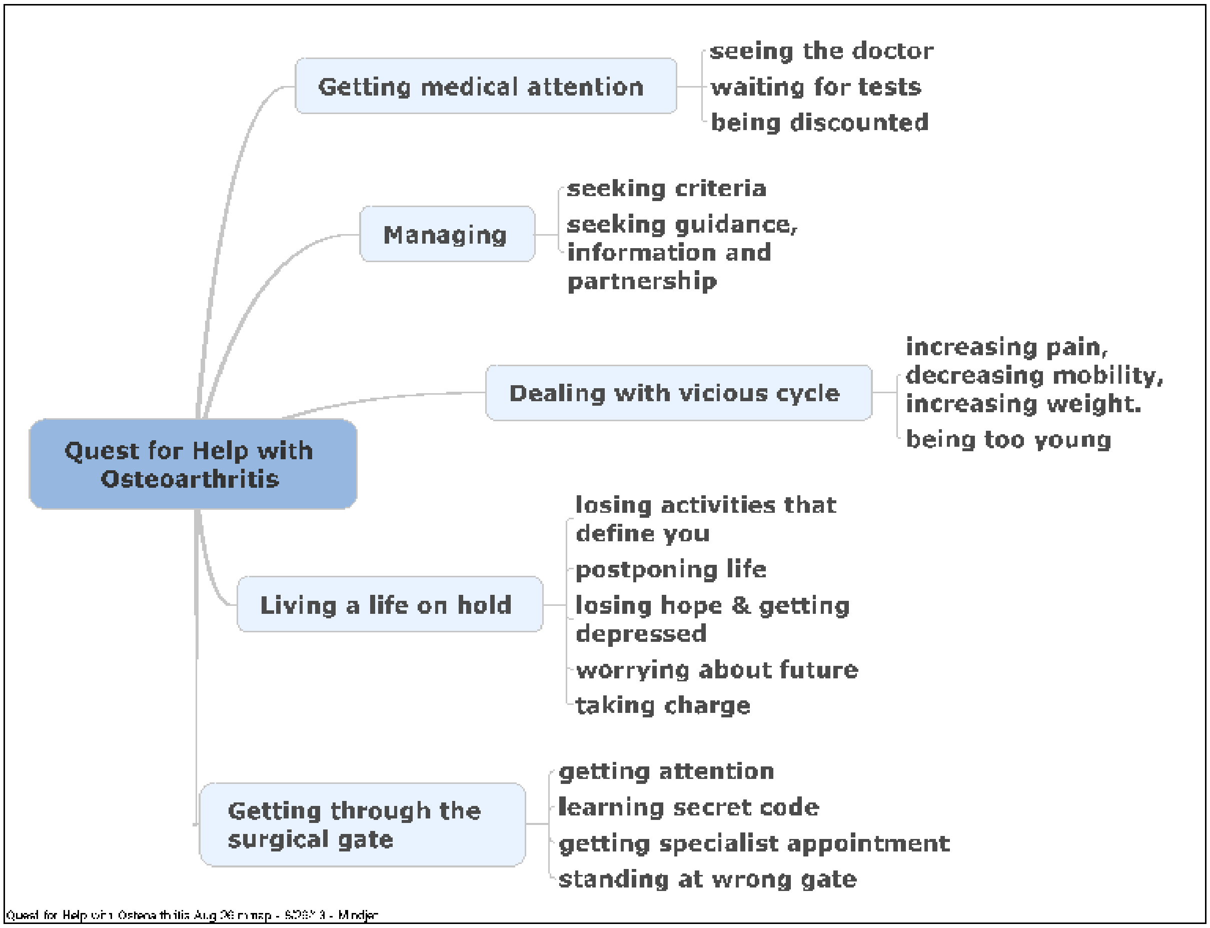

Figure 2. Our Quest for Help with Osteoarthritis.

Getting Attention

Seeing the doctor. A joint begins to ache; it feels weak, perhaps swells and then becomes painful. Initially we rest the joint, apply ice, wrap it with a tensor, and take a pain pill. As the pain continues and worsens we seek medical attention. This is the first gate on our journey. For most of us this gate swings open: we get into see our primary care physician quite easily. Others have to work harder to open this gate, finding a clinic or perhaps even going to an Emergency Unit. For some this gate is locked:

> Spencer is stuck in a low-income subculture of our society. He is considered homeless and lives in shelters. Some days he is unable to manage his own care much less get himself to his doctor's office. His life is often in chaos. He doesn't have a car and doesn't have money to pay for a cab or use public transportation. NI 2

This suggests inequities in accessing the healthcare system. According to Ackerman et al (2005), studies in the US and the UK show that people on social assistance are less likely to be on waiting lists because of their financial situation, their resources and their health beliefs. Giovanni Gasparini (1995) refers to an underlying power issue whereby someone with more power is able to avoid waiting, as opposed to someone with less power.

Waiting for tests. Our primary care physicians usually send us for diagnostic testing: an x-ray and perhaps an MRI. Sometimes we discover the doctor's office has forgotten to forward the referral. Other times we find ourselves on a long MRI wait list and are told that if we want to get by this gate we can go a private clinic.

> One participant who waited a long time for an MRI wondered if maybe he "doesn't cry wolf loud enough." Six months after seeing his doctor and having an x-ray he discovered his MRI referral had not left the doctor's office. At that point he was told that if he wanted it done quickly he could pay for an MRI at a private clinic. He found this objectionable and felt this is an example of a 2-tier medical system. He realized he should have been more persistent,

> calling more often about his appointment. He wonders if he would have had his MRI sooner had he done this. NI 22

Once we get to the specialist some of us learn that an MRI was an unnecessary test.

After we are diagnosed with OA primary care physicians take on a gate keeping role. Physicians seem reluctant, or in one case unable, to refer us to specialists or other services.

> One participant with RA and recently diagnosed OA requested a referral to an arthritis program she knew about. She was astonished when her specialist informed her that was not possible as the specialist didn't have access to that program. NI 28

We are left feeling there is not much that can be done to help us manage our OA.

There may be some truth in Fogarty and Cronin's (2008) claim that being kept waiting for healthcare is a way to ration and prioritize limited services. However, physicians aren't necessarily happy about playing the gate keeping role.

> Out of frustration one of our participant went back to her primary care physician to see if she couldn't speed things up a bit. Her physician told her that beyond making a referral there was nothing more she could do: "That's just the way the system is." NI 29

Being discounted. Sometimes our concerns are discounted, ignored, or dismissed as part of aging. We wonder why our symptoms aren't being taken seriously. We are told pain comes with age so we just need to "get over it" and "live with it."

> A 38-year-old mother of four with early onset of OA recounts her doctor telling her she would continue to have pain and that she should take some pain pills and decrease her activity level. In her words, she was being told "to get over it." NI 39
>
> "We are told to just suck it up and live with it!" FG 4
>
> A 55-year-old man with more than one type of arthritis described his frustration at not being taken seriously by his doctor. He felt he was continually being brushed off and at one point wondered: "Am I not bleeding sufficiently enough here?" NI 21
>
> Even though Spencer goes to great lengths to be sure he's clean, well-dressed, and informed for his medical appointments, he finds that once his true situation is known he does not get

> the help he needs. Medical personnel do not realize that what they prescribe for him to do is not always possible. For example, he can't rest when he's in pain as he must leave the shelter for the day. NI 45

As our quest for help continues we soon realize that we aren't likely to get much help until our arthritis gets "bad enough." But just how bad is bad enough is unclear. We know it has something to do with pain and immobility, but beyond that we're not sure. As a result we are at a loss about what to report and how to act. We have reached a large keyless gate.

Managing

Seeking criteria. The issue of criteria for taking action was raised in our SET focus group and it became an even stronger message in our REFLECT focus group. Participants wondered under what circumstances they should go back to their doctor: "When is it bad enough to report?" (FG 36). They also wanted to know what criteria are used for deciding if they needed surgery or other treatments.

> A 68-year-old lady with what she called mild OA stated: "I don't feel I'm in dire straits: should I report it or not? There are others worse than me." FG 21

We are acutely aware of being perceived as a burden to the healthcare system. "We don't want to report too much too early … we don't go to the doctor intending to be a burden … we try to cope the best we can" (FG 16). Another person in the SET focus group felt badly about making so many trips to the doctor and emergency department. Even though the system made her feel guilty about this, she found it was the only way to get attention (FG 15).

Seeking guidance, information, and partnership. We really don't expect our primary care physicians to cure our OA or make all the hurt go away. As one person noted, "It's not that we sit back and don't want to help ourselves; we want to do the right thing but we don't know what path is best" (NI 18). We just want physicians to tell us what we should report and when, as well as what to expect from the healthcare system. We also need them to tell us what has been proven to work best (e.g., physiotherapy, exercise, and pain management) and to work in partnership with us so we make good choices as we live with OA on a day-to-day basis. Often we heard this is not the case: "it's experimentation" (FG 23).

In retrospect, the idea of experimentation was rather surprising given that we are a group of fairly articulate people with reasonable resources, and an inclination to access the services we need. There could be a number of reasons for this. It may be the healthcare system hasn't met our needs. Or perhaps we are experimenting with new things because our OA is changing and things that worked in the past no longer do.

This idea about the need for information is born out in the literature. In Carr et al's (2009) systematic literature review the authors report that patients want to know where they are on the wait list, how the list is managed and how they can contact those managing the list. In Sjoling et al's (2006) nurse-led focus group research, patients said they need better information on when their surgery will occur so they can plan their lives. They also want someone in the system to stay in contact with them. In these studies patients wanted to know about effective pain management and exercise programs; what services they should access such as physiotherapy and support groups; and where to get reliable information. The patients in Parsons et al's (2009) study of the lived experience of end-stage OA also needed more information, support and guidance. Those who knew people who had gone through the surgery felt they had an advantage over patients who did not.

The Vicious Cycle

Pain, mobility, weight and age. For those of us who are waiting for joint replacement we soon come to realize that in addition to pain and immobility there are two other factors that keep the gate to surgery shut: our age and our weight. We can't be too young or too much overweight.

> A 68-year-old woman who had been suffering increased pain and immobility for 13 years saw an orthopedic surgeon in 2005 and again in 2010. Both times she was told she was not having enough pain and was too young for knee replacement surgery. Two years later she got a referral to another surgeon. She recounted, "this was the most awful appointment in my life." She was "gob-smacked" by his attitude. He gave her a long list of reasons why she shouldn't have surgery: she was too young, too overweight, and the wait list for knee surgery was over a year long. He followed this with the question: "do you want to be on the list or not?" NI 30
>
> Another woman in her mid-sixties with multiple health problems including osteoarthritis has been told repeatedly that she isn't bad enough to have knee surgery. Her doctor told her that because she seems to be keeping mobile she is slipping down the list for replacement surgery. NI 16

We find ourselves in a vicious cycle: as we wait for our pain and mobility to get bad enough the years slip by, our bodies get older, and we develop other health problems. As the pain increases, our mobility decreases, making it harder to control our weight, and as a result we become less active, which in turn leads to more pain and more weight gain. "It's hard to lose weight when you can't walk" (NI 37). By the time we are eligible for joint replacement surgery we have moved from being *young-old* to *old-old*. When we finally get to surgery we are not in very good shape to make a good recovery, certainly not the recovery we would have made had we been younger.

> While you wait you "just manage" and you "accept deteriorating mobility and life" and as a result you become a poor candidate for surgery. FG 9

We found the issue of not being old enough particularly frustrating. As one participant commented: "One can't do much about being too young…" (NI 21). We hope that in the future age becomes less of a factor in deciding when we are ready for new joints. This would go some distance in getting us out of the vicious cycle. According to the National Institute of Arthritis and Musculoskeletal and Skin Diseases (n.d.), joint replacements were traditionally done on older people because they were less hard on artificial joints than younger people, but thanks to new technologies, artificial joints are lasting longer and are better able to withstand stress and strain.

Spencer also finds himself in a vicious cycle. Even though his joint pain leaves him at risk for injury he must leave the shelter during the day. He returns at night in more pain where the noise in the shelter leaves him sleep deprived. Shelter residents and staff do not understand his pain and he is seen as a whiner and a complainer. With further deterioration his mental, emotional and physical health continues to decline. Spencer believes the only way he will get the help he needs is if he falls apart completely.

Living a Life On-hold

Losing the activities that define you. While enduring this vicious cycle we find we have to put our lives on hold, “Life stopped” (FG 22). One participant described leaving a job she loved and going on disability as “totally devastating” … “I lost a lot of my life” (NI 39). Another said, “You lose the activities that define you … that give you meaning” (NI 40).

Postponing life. Putting our lives on hold has some serious consequences. Participants in Sjoling, Agren, Olofsson, Hellzen and Asplund’s (2004) study on the lived experience of waiting for knee or hip surgery felt as if they were “in a no-man’s land” (p.541) where their lives were on hold leading to stigmatization, isolation, and depression. They felt the healthcare system stopped them from living a normal life and they found it hard to cope with the uncertainty of when they would get their surgery. They felt like they were facing “a faceless enemy, the system” (p.539).

This sentiment was echoed by two of our participants: “the system has the heart of a stone” (NI 38) and “(it's) a non-caring system, the government mainly … so many steps and not enough people. Every time you’re referred to a specialist someone is making more money” (NI 34).

> One participant said he would have to postpone going south for the winter because he wouldn’t want to be away should he get finally get an appointment with the specialist. However, staying in Canada will not be good for his health: in Arizona he golfs every day, his pain is less, and he returns in better shape than when he left. If he winters in Canada he stays indoors as he is afraid of slipping on the ice which leads to more pain and weight gain. He felt it was unfair for the system to expect him to put his life on hold. NI 23

In a study by Parsons et al (2009) participants awaiting joint replacement surgery for their OA were in a similar situation: they postponed activities such as home renovations and family visits as they were not sure when they would be called for surgery. They felt as if they had no control over their lives.

Losing hope and getting depressed. The unending quest for help begins to take its toll, we become frustrated and we begin to lose hope. We keep hoping things will get better, but they don’t. With the loss of hope comes depression: participants in our REFLECT focus group spoke quite openly about this. They spoke of the fatigue that comes with the constant up and down nature of OA, and the chronic pain that leads to depression. One participant described it as “a loss of psychic energy” (FG 25). According to Hawker et al (2011) there is a well-established link between OA and depression.

Worrying about the future. As we wait for things to get bad enough we begin to realize the future isn’t going to be as we envisioned, for example, perhaps we won’t be able to take on a new work role, or travel in our retirement. We worry about what life will really be like after going through so much physical and emotional pain (FG 26), and what will it be like when the symptoms get even worse? (FG 27).

Spencer is 55 and he also worries what his future. He is losing what is left of his working years and is 10 years away from receiving retirement benefits. He also worries about the immediate future as he has no money, appropriate shelter, or medical help.

Through all of this we strive to maintain hope.

> "Some days I have great hope and some days I don't." FG 30
>
> "I know I'm going to hear things I don't want to hear, but you need to put the next step forward and hope." FG 31
>
> "If hope is shattered, what then?" FG 32

Taking charge. We realize we need to take charge and manage our pain and immobility so we seek help that will give us hope. We exercise when the pain allows, go to physiotherapists, go on diets, or whatever else we think will work. Managing our pain becomes a major daily focus.

> "I fight it, I will do what I want and then put up with the pain to get over it. What the heck." NI3
>
> One woman said that in order to have a good quality of life she takes as much pain medication as she needs to get the comfort she needs. "I am an example of better living through chemicals." FG 1

Getting through the Surgical Gate

Getting attention. As we wait for surgery we devise ways to manipulate a healthcare system that is not working for us. "You get creative in how to get attention" (NI 17).

> One woman waited a year and a half to see an orthopedic surgeon for knee surgery and during that time her hip began to cause problems. Instead of going back to her doctor for another referral she brought this up with the surgeon as she was wondering if maybe that should be looked after first. This annoyed the surgeon to the extent that he refused to look after the knee or the hip. NI 40
>
> Another lady was so desperate for help that her friend asked her own doctor if she could give up her appointment to this lady. NI 41

Learning the secret code. Then just as we are about to give up on the quest for surgery we learn that some answers to doctors' routine questions are more effective than others. "You learn the secret code, it's learned from others, and you give the right answer to get action" (FG 28). The routine questions are: Can you walk a block? Can you do a flight of stairs? Does the pain wake you at night? Rather than answering these questions with "yes" or "no" we need to answer in more detail: for example, "yes I can walk a block but not without my walking sticks"; "yes I can climb the stairs but I do it sideways, one step at a time, holding onto the railing"; "I do have pain at night and the only way I can handle it is to get up every two hours and move around" (FG 37). Those who have provided this kind of detail say it helped their doctor understand the severity of their symptoms which facilitated a timelier surgical referral.

Getting a specialist appointment. With our referral in place, can surgery be far behind? Another gate looms. We find that the wait time for getting an appointment is long. Once again miscommunication can make that time even longer. Once again we are on hold.

> One lady waited two years for her specialist appointment, during which time she tried to live as normal a life as possible even though many activities would leave her in pain for days. When she arrived for her appointment she was told she didn't have one: "I just wanted out of there… I didn't have time to argue." She got an appointment 1 year later. FG 4
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> One of the researchers called her doctor's office 2 months after the referral was sent to see if they had heard of a date for her appointment with the orthopedic surgeon only to be told no, but that she could call his clinic and ask to talk to one particular person who could likely tell her the date. She did this and got in on a cancellation that week! "Who knows how long it would have been if I had not called?" NI 24

One of Sjoling et al's (2004) study participants spoke of making frequent phone calls. She persisted in phoning the clinic every day even though she got very frustrated when she was left on-hold or shunted off to someone else. She began to feel they were misunderstanding her intentions.

Standing at the wrong gate. Finally we get to see the orthopedic surgeon, who says "yes," your joint needs replacing and "yes," I will do your surgery. You are directed to contact the surgery scheduler for your date. For some this step in the quest goes quickly: "I was totally surprised when after all this waiting, I saw the surgeon and in a matter of 45 minutes had everything I needed to prep for surgery including a surgical date in 3 months! There is hope in the system" (FG 11). Others find themselves at the wrong gate:

> One participant with debilitating shoulder osteoarthritis was referred by his doctor to a sports medicine doctor who in turn referred him to a surgeon: this was in October. In December he was notified that his appointment date was in February. At that appointment the surgeon agreed that he needed a new shoulder but he was no longer doing that type of surgery. They had put him in the wrong wait line. This participant wrote a letter to the doctors outlining what had happened where he "basically said, you guys are unreal." He felt like a pawn, and asked them "what would WestJet do?" In his letter he indicated that he expected to be seen by the right surgeon the next clinic day and to be put in the surgical wait queue as if the first surgeon was the right surgeon. The new surgeon said he was embarrassed and disappointed in the way the system had handled the participant, but there was nothing he could do about it. Our participant waited another three months to see the right surgeon. When he finally got to the right surgeon he was told there were 22 people in line ahead of him and they were only doing 2 shoulder surgeries a month, and that basically, the only thing he could do was to "shut up and get back in line." "So you need to grin and bear it." NI 26

Time passes, and eventually our quest for surgery is over and our operation is scheduled. For most of us our surgery and recovery go well with many returning to our former lives. However, due to the chronic nature of osteoarthritis our quest is likely not at an end.

Section 5: Reflections on the Quest for Help

In this section we use the metaphor of the quest for getting help with osteoarthritis and the challenges that define this quest. We consider this quest from the perspective of the majority "we" in this study, as well as from the minority voice of Spencer. We also reflect on areas for future Patient Engagement Research.

Our quest for help is an arduous journey filled with many gates and gate keepers. For most of us the first gate (getting attention from the doctor) was easy to maneuver. The next set of gates is hard to locate: diagnostic tests and their referral gatekeepers are marked by mis-directions, referrals not being processed and long line-ups. Once a diagnosis of OA is confirmed primary care physicians take on an unwelcome gatekeeper role that thwarts some of our efforts to get the care we need. We sometimes leave the doctor's office feeling discounted and ignored, with our pain and disability ascribed to "getting old."

As our quest continues we quickly come to realize that we aren't likely to get much help with our OA until it is "bad enough" – a concept we can't seem to define: a large keyless gate stands before us. We don't know what and when we should be reporting to the doctor and we worry about being labeled a burden to the system. We try our best to cope, but without guidance, information, and a patient-doctor partner relationship we experiment with strategies that might or might not work. We then find ourselves in a vicious cycle that leaves us in less than optimal shape for surgery: more pain leads to less mobility and more weight gain, which in turns leads to less activity, more pain, and more weight gain. It is hard for us to see a way out of this cycle when one of the criteria for surgery is to be older.

As we wait for things to get worse we put our lives on hold, withdrawing from meaningful activities many of which make the cycle even more vicious: we lose control over our lives, we lose hope, become depressed, and we worry what the future holds. We do everything we can think of to take charge of our lives, but this is difficult when we don't know what comes next. If the healthcare system is not working for us we devise creative and sometimes desperate means to get by the gates and get the attention we need.

Through Spencer we are given a glimpse into the quest for help with osteoarthritis for those who are marginalized. Spencer faces the same issues as the rest of us: dealing with pain and immobility; maneuvering the medical system; and managing his condition. However, as a homeless person he faces challenges unknown to the rest of us. His unstable living condition and lack of money and transportation make it difficult to get through the primary care gate. While he tries to make himself an acceptable candidate for treatment he leaves his doctors' appointments feeling neglected, invisible, and even unworthy of help. Further, shelter living is not conducive to managing his OA pain as he gets little rest and he can't spend the day in the shelter. His vicious cycle goes beyond issues of increasing age, pain, mobility and weight. For him it's a cycle of survival as he copes with deteriorating health, poverty, and homelessness. He feels that the only way he will get any help at all is if he falls apart completely. He sees his future as one of poverty, and even death.

Given the chronic nature of osteoarthritis we know this is not our last quest and we will use what we have learned here as we deal with our OA and other health problems that may arise. We hope that in the future there will be more certainty about what to expect and how to act from the healthcare system, fewer and easier to manage gates as well as opportunities for peer support and exchange of information and experiences.

This study brought to light other potentially worthwhile issues for study from a patient engagement perspective. The issue of gates and gatekeepers appeared early in our study and was pervasive throughout. Further patient engagement research that explores the gates and gatekeepers patients encounter in the health care experience and how they get around them is warranted. It would also be useful to study patients' experiences of peer support related to experimenting with self-management strategies. Both such studies would shed light on what goes on behind the scenes as patients manage their health and the system. The resulting information would be of interest to patients, their families, and those who are in charge of the health care system.

This study barely scratched the surface of health experiences of patients from more diverse backgrounds and communities. However, the glimpse we were given into the experience of getting help from one homeless person with osteoarthritis has shown us more research is needed to better understand the homeless and other communities such as new immigrants, aboriginal, or LGBT. The PER approach, patients doing research with fellow-patients, is one way to bring the voices of these more marginalized citizens to the forefront of the health care dialogue.

Section 6: Our Journey as PER Learners

In this last section we discuss what each of us has brought to this experience.

Colin

Working as a part of a team is never an easy process at the best of times. The process of our particular team was to reach consensus on issues or concerns related to the project and not to vote on a concern before going forward. This was a difficult task at times as it is next to impossible for consensus building to occur when each member was a trained professional in their own right with preconceived principles and practices. In most cases, the team was able to rectify project related issues and when this was not possible, we called in the project management team of Nancy, Svetlana or Mary to assist us in a go forward solution building process. All in all, I feel our team worked quite well together.

Of most import to me, however, were the unexpected emotions that surfaced between the research team and the involved focus group participants. My expectations were that we would have a straight forward sharing of ideas back and forth in a safe environment and there would be no need for sharing emotions on behalf of any of us. This was mostly true with the first focus group where we were working on sharing ideas to develop the narrative interview process. However, with the second focus group, a couple of the participants became quite emotionally engaged in expressing the day to day trauma of waiting for help with OA and the seemingly endless conclusion that led day in and day out to the experience of unbearable pain, depression and anxiety. One particular incident brought me close to tears when one of the researchers, to get the attention of one of the participants, put her hand lightly on the person's shoulder, at which point the individual surprisingly yelped out in pain and recoiled from the touch. Another incident involved one of the participants, after hearing a lot of discussion about the effects of depression and anxiety, came to the conclusion that this was a problem for him that would now get some attention by a professional.

Sylvia

I came to Patient Engagement Research out of a sense of curiosity upon reading an invitation to those with osteoarthritis to learn about PER. Once into the classes I was amazed to find how much the journey of other patient/learners mirrored mine. The exercise to determine what issues members of the class have with their osteoarthritis saw us quickly move into the 3 research groups. Several of us had concerns with the experience of waiting for help with our OA and we decided to research that.

My story of waiting for help (which soon became defined as knee replacement surgery) spanned a period of 6 years during which I joined a ladies exercise class and went every weekday morning for half an hour for 5 years. I also went to a physiotherapist regularly for acupuncture, exercise, heat and cold therapy just to keep moving. I saw a massage therapist regularly as well, feeling very fortunate that I could afford these. As the pain worsened I took stronger anti-inflammatory and pain medications. My family physician counseled me to lose weight and keep moving, indicating that my knee was not “bad enough” for surgery. Until I “answered his questions correctly” as pointed out by my physio, he did not refer me for surgery.

I find the *SET, COLLECT, REFLECT* process of patient engagement research very powerful with narrative interviews giving voice to the true concerns of patients. The stories we heard in the focus groups with other patients and in the narrative interviews were remarkably similar and I felt quite engaged with them. By getting our stories out, there is a possibility to see some small transformation of the system that will make this process of waiting for help with osteoarthritis better for all.

Jean

As a patient I came to this project with an early diagnosis of osteoarthritis that was causing giving me quite severe night pain in my left leg. I was struggling to find out what I should do about it as standard pain medication and physiotherapy didn’t give me much relief. I also realized this was likely just the beginning of my dealing with this chronic disease. As a reasonably healthy 68-year-old I worried how OA was going to affect my life and I wanted to know what I could do to keep myself as active, pain free, and healthy as possible.

I also came to this project with a working knowledge of the research methods used in PER however early in the course on I realized that my experience as a professional doing research was not the same as a patient doing research. This realization came about not only from my course work, but also from my sitting on the Bone and Joint Strategic Clinical Network (BJSCN) Core Committee. In my encounters with nursing peers I found myself saying “of course nurses engage with patients about their issues and concerns, that is what nursing is all about… but this (PER) is very different than that.” Even though health professionals do qualitative research with patients and truly believe they bring the voice of the patient forward, they do it from the perspective of developing knowledge professionals can directly use when providing care to patients. This is not the same as patients engaging with other patients about their issues, and carrying out research that tells other patients, the pubic and health professionals about issues from their perspective.

PER research does not replace professional research: professionals do research to find out how to best influence the lives of patients they work with. They take that knowledge and use it with individual patients appropriately: what I know as the art of nursing. PER research supplements those findings by bringing credible research to professionals about issues generated by patients who develop knowledge that supplements what professionals do. That is one way PER method brings a voice to patients.

There is an idea that keeps coming to mind about how the PER method can bring a patient voice that is of use to the system, particularly in dealing with chronic conditions. The system strives to put in place a range of services that help patients, and then they let patients know about these through referrals, pamphlets etc. In our focus groups we heard about interventions patients find most helpful and I wonder if finding out what those are could help the system transform its services.

PER’s unique contribution is that it brings the collective voice of patients forward. Through the *SET, COLLECT, REFLECT* process in-depth knowledge of patients’ experiences are gathered and shared with others. This goes beyond individual patient voices and satisfaction surveys.

There are two issues related to getting patients' voices heard. The first is the challenge of engaging a wide range of patient voices. For the most part the participants in our study were articulate, educated people of reasonable means and financial stability. We were able to engage only one participant of limited means and stability even though one of our research team came from that background. This limitation means an important patient voice is missing from the health care system dialogue.

The second challenge in getting the patient voice heard relates to getting the stakeholders on board. On more than one occasion I have witnessed professionals and leaders voice their support of patient engagement only to find their later actions do not reflect that support. The idea of truly meaningful engagement with patients has yet to be fully understood by all: patients and the public as well as those in the health care system.

Cheryl

I gravitated towards this research project for several reasons. As a young adult patient with osteoarthritis and related comorbidities, I had personally experienced years of frustration to get accurate diagnoses and validation that the symptoms I presented were indeed real, physiological indicators of osteoarthritis. These experiences influenced my choices to embark on academic and professional career paths which would serve to educate and support individuals with bone and conditions. While I had the opportunity to hear hundreds of stories and experiences over several years, I was unable to make sense of and translate these voices into a meaningful format which would serve to represent patients as change agents in the context of impactful policy formation and decision making.

The research methodology as developed by Marlett and Emes provided an essential missing link to mesh patient experiential knowings with a rigorous academic process which could then serve as a vehicle to effectively transfer the findings to inform decisions in the health care arena.

Throughout the process, my own beliefs and experiences have undergone transformation as I have shared in others' stories. They provided an incredible depth, illustrating the common experiences as well as individual variations. I am privileged to have been a part of this important work. Our findings suggest that we have touched the tip of the iceberg of patient experience related to osteoarthritis. The feedback on our project by participants has been overwhelmingly positive, in that we were able to provide a safe, trustful environment in which patients could share their stories, emotions, fears and triumphs.

Tracy Ray

I am a 40-something recovering addict (sober 9 years), formerly homeless, now a community advocate providing information on homelessness and poverty in Calgary. I am also an AISH recipient and a mature student at the university level studying Radical Humanities and Liberal Arts. My place in society is demarcated by how communities, societies, educators, authorities and media label addicts and formerly homeless individuals. My interest is in how those who live with mental illness and disabilities and within certain income brackets are viewed. Although my place is not outlined in stone, I have to step up at every opportunity to assert that I am not "just" an AISH recipient. I'm a philosopher too. I am not "just" a recovering addict and formerly homeless person. I am a mentor, educator and social justice advocate.

I have to make noise and expend a lot of energy not to sink into the AISH, homeless, addict-related slots that are assigned to me by convenient definitions. I want people to know I am not so easy to classify and understand as belonging to one or more of these slots.

I notice power dynamics that others often miss and am acutely aware of body language and body placement in various surroundings. I learned to pay attention to these details when I was homeless because being aware of these details kept me and others safe on the streets and in shelters. This means that I picked up on income cues, status and power cues during all of our research activities.

As participants shared their experiences I heard few comments related to low income and little talk about financial woes. This is a contrast to what I hear in my advocacy work where many homeless folk mention social workers, AISH, and Independent Living Support workers, Employment Insurance documents: their world is one where the lack of financial support is a constant. I concluded as I observed our first Focus Group participants that most were of middle- to upper-income level.

Status or lack of it plays a part in the experience of waiting for help with OA and whether those waiting do or do not receive information, help, services and responses from the medical community. I also noticed what I thought might be a gender issue when I acted as an interviewer.

Two of us acted as interviewers with one older man: my partner was male and acting as the lead interviewer while I was to act as recorder. We experienced difficulty getting full answers to our questions. When I checked the digital recording I heard that the man being interviewed responded more fully and with greater ease when my male co-researcher spoke to him directly than when I asked questions or made comments. Although I'd like to believe people are all the same with the same rights and responsibilities and access to medical care, this project has shown me just how much our beliefs, biases, social views of others affect us when we do research.

My one narrative interview with a homeless man who is waiting for help with his severe OA showed me that he was stuck in the low-income, no-income subculture of our society. He lives in shelters and is considered homeless and is not getting his needs met to be seen and treated as a human being. Low status or no status, low income and being marginalized prevent him from being seen by medical personnel. As a researcher it felt at times that I was asked to leave status whether low or otherwise out of our discussions and I felt that my words were being sanitized at times particularly in discussion of this participant but to bring visibility and respect to this one participant I have to bring details about his homelessness and marginalization to light. Otherwise he remains invisible which works against the very principle of our intent to bring patient experience to light. One percent of our population in Calgary is marginalized in the ways I have identified and less than that one per cent will have OA but we may never reach or find those waiting for help if we don't give their experience a voice in this research. What I have learned on my journey is that we need research on the specific problems of waiting for help with OA among the homeless and the poor in Calgary.

References

Alberta Innovates Health Solutions. (n. d.). *ARECCI Ethics Decision-Support Tools for Projects.* Retrieved from Alberta Innovates Health Solutions website http://www.aihealthsolutions.ca/arecci/areccitools.php

Ackerman, Il, Graves, S., Wicks, I., Bennell, K., & Osborne, R. (2005). Severely compromised quality of life in women and those of lower socioeconomic status waiting for joint replacement surgery. *Arthritis & Rheumatism,* 53(5), 653-658.

Carr, T., Teucher, U., Mann, J., & Casson, A. (2009). Waiting for surgery from the patient perspective. *Psychology Research and Behaviour Management,* 2,107-119.

Fogarty, C. & Cronin, P. (2008). Waiting for healthcare: A concept analysis. *Journal of Advanced Nursing,* 61(4), 463-471.

Gasparini, G. (1995). On waiting. *Time & Society*, 4, 29 - 45.

Hawker, G., Gignac, M., Badley, E., Davis, A., French, M., Li, Y., Perruccio, A., Power, J., Sale, J., & Lou, W. (2011). A longitudinal study to explain the pain-depression link in older adults with osteoarthritis. *Arthritis Care and Research, 63*(10), 1381-1380.

Irvin, S. (2001). Waiting: Concept Analysis. *Nursing Diagnosis* 12(4), Oct-Dec:128-136.

Marlett, N. & Emes, C. (2010). *Grey Matters: A guide to collaborative research for seniors.* Calgary: University of Calgary Press.

National Institute of Arthritis and Musculoskeletal and Skin Diseases. (n.d.). *Questions and answers about hip replacement.* Retrieved August 7, 2013 from http://www.niams.nih.gov/Health_Info/Hip_Replacement/Default.asp

Parsons, G., Godfrey, H., & Jester, R.F. (2009). Living with severe osteoarthritis while awaiting hip and knee joint replacement surgery. *Musculoskeletal Care,* 7(2), 121-135.

Sjoling, M., Norbergh, K.G., Malker, H., & Asplund, K. (2006). What information do patients waiting for and undergoing arthroplasty surgery want?: Their side of the story. *Journal of Orthopaedic Nursing,* 10, 5-14.

Sjoling, M., Agren, Y., Olofsson, N., Hellzen, O., & Asplund, K. (2005). Waiting for surgery: Living a life on hold – a continuous struggle against a faceless system. *International Journal of Nursing Studies,* 42, 539-547.