

EXPLORING HOW PATIENTS AWAIT SCHEDULED SURGERY:  
IMPLICATIONS FOR QUALITY OF LIFE

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By

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## **ABSTRACT**

In this thesis, I explored the relationship between patient experience of wait time for consultation and scheduled surgery, type of illness (orthopaedic or cardiac), and descriptions of time using qualitative methodology. Thirty two patients awaiting orthopaedic or cardiac surgery were recruited by surgeons in Saskatoon, Saskatchewan during the period of September 2009 to November 2010. Those patients awaiting orthopaedic surgery were interviewed when the decision to treat was made and again at the midpoint of their waiting period. Cardiac surgery patients were interviewed after their angiography and consent to surgery, and again the day prior to surgery. Patients were asked about their perceptions of time while waiting, maximum acceptable wait time for consultation and surgery, and the effects of waiting. Interpretative phenomenology (1) was the method and data were analysed using interpretative phenomenological analysis.

Participant suffering, the meaningfulness given to the experience, and the agency participants felt they had over the waiting period determined the lived duration of time experience. Participants considered pain, mobility restriction, disease progression and lethality of condition to be the primary determinants of wait time maximums. Waiting effects included restriction, uncertainty, resignation, coping with waiting, and opportunity. Few subtle differences between groups emerged indicating other variables may be more relevant to the quality of waiting experience. Participant suggestions for improving experience consisted of managing patient conditions and navigating the system. The findings suggest uncertainty in illness impacts the quality of wait time experience. The study denotes the experience of waiting for scheduled surgery is complex and not necessarily a linear relationship between greater symptom severity and less tolerance for wait time.

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## **DEDICATION**

For my mom, who hates to wait.

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## 1 Introduction

This research on patients' experiences of wait time was inspired in part by my friend, Bill. Bill, who is in his early 70s, and I have had a regular lunch date for the last 15 years, and our conversations often include discussions of health and illness. A few years ago, Bill needed total knee replacement on each knee. After consultation with a surgeon, he was told the wait time for each surgery could be up to 18 months, making the total waiting period three years. For Bill, this wait was too long. He felt by the time he waited and recovered from the procedures he would be compromising otherwise healthy years of his life. He did what few people are able to do – as a dual citizen of Canada and the US, he went to the Mayo Clinic for each procedure and arranged to have them six months apart. Bill sent the summary of his experience in this email to me:

I began working with a trainer when my family physician referred me to an orthopaedic surgeon [in Saskatchewan, *my note*] and I was told that there would be a nine month or so wait to get in to see him. I worked with the trainer 3X per week and paid approximately \$720 a month. During this time I also began my weight loss. By the time I got in to see the orthopaedic surgeon he said that I was "bone on bone" but since I wasn't using either a walker or cane, I would go on the longer waiting list, probably a year or a year and a half. That's when I went to the Mayo Clinic. I phoned Mayo, got an appointment with an orthopaedic surgeon in three weeks. The surgeon, when I saw him, was able to book me within another three weeks. Because U.S. Medicare covered most of the cost, my cost for the surgery, not including travel and accommodations, was around \$3,800 per knee. The Saskatchewan Government adamantly refused to reimburse me for the \$3,800 per knee because I could get the surgery in Saskatchewan. At the time I went to the Mayo Clinic, I could not walk two blocks without having to stop and rest at least four times. My trainer focused on building the muscles around my knee and legs. Paying the trainer was a good investment because the muscle strengthening enhanced my recovery. I continued with the training after both operations.<sup>1</sup>

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<sup>1</sup> Bill provided consent for me to describe his experience and use his words from this email.

In my perspective, Bill did not fit the *profile* of someone waiting for surgery. Once he knew he would have surgery and then decided he would go to the Mayo Clinic, he took the opportunity to ready himself physically and mentally. He hired a personal trainer, he lost weight, and he researched the procedure and recovery. He seemed to ‘take charge’ of his condition and his wait time. To me, he did not appear to be ‘waiting’ in the passive sense that the word ‘wait’ implies. But, I thought, he must be an exception. He had special circumstances. For others, waiting is likely what it is commonly conceptualized to be – a linear construct where patients become more distressed the longer they wait.

My impression of Bill’s waiting experience prompted several questions. Was it his level of suffering that determined his actions or his actions that shaped his suffering? He seemed to take charge of his condition and maintain meaningful activities despite his illness. In the present research, I explored the relationship between patient experience of wait time for consultation and scheduled surgery, type of illness, and descriptions of time, using qualitative methodology. This type of analysis enabled a rich and close examination of patients’ waiting experiences and allowed me to place my friend Bill’s wait time experience in context.

## 1.1 DEFINING WAIT TIME FOR SURGERY

Wait times for health services in general, and for surgery in particular, have been widely publicized as a growing concern for publicly funded health care systems. Wait times may occur throughout the course of health service delivery and tend to vary depending on patient condition and supply and demand of services. Theoretically, a roster of waiting patients, or wait list, will accrue in any health care system when the overall demand for a service, such as surgery, exceeds the supply (2). However, wait lists have been acknowledged as complex phenomena influenced

by patient, diagnostic, physician, hospital, government, and societal factors (3). Considerable efforts have been made to understand and improve the management of wait lists for health care services in various health care systems (2-6).

While no standardized definition exists of wait time, several wait times are acknowledged in the period leading up to procedures such as general surgery, hip and knee replacement and cataract surgery (7). These times are assessed quantitatively and counted as days or months between points in time. Generally, in the wait time literature, the period between the decision to treat and the procedure is considered the wait time (8). However, from the patient perspective total wait time (7), or the time between when a patient first experiences symptoms, seeks care and finally receives treatment, may be the most salient.

## 1.2 STUDY RATIONALE

Whether the wait for health services is a few minutes for a blood test or weeks to months for elective (scheduled) surgery, waiting is commonly portrayed as irritating, frustrating and a source of great uncertainty (9). For patients awaiting surgery for potentially life threatening conditions such as heart disease, wait times may reveal existential concerns about fear of mortality and a degree of urgency. In addition to the nature of illness, patient characteristics and sense of time may influence the experience of waiting. Moreover, protracted wait time may have multiple meanings—waiting that is experienced as rest, as interruption, as planning, or as a completed and meaningful experience (10). How patients experience time while they wait may be affected by these potential meanings.

The complexity of wait time is poorly understood and has been explored only to a limited extent (9-11). Experiences of waiting in general may be perceived as complex, subjective, and

culturally influenced (10). The connections between type of illness, waiting experience and sense of time remain relatively unexplored. In particular, the experience of time for patients who wait is unknown, yet the limited literature suggests patients' time experience is inextricably linked to their quality of life (12,13,14). Instead, most research concentrates on the maximum amount of time patients tolerate waiting and the quantitatively measured health related quality of life while waiting. In order for the phenomenon of wait time to be more fully understood, a qualitative examination that addresses these gaps in the literature could lead to improved patient care. Moreover, a qualitative study will allow patients to communicate their wait time experiences with depth and in detail (15). If what waiting means to patients is assessed using qualitative methods, the complexity of wait time experience may be revealed. Understanding the experiences of patients is fundamental to responsive and compassionate delivery of patient-centered care.

### 1.3 RESEARCH OBJECTIVES

The purpose of this study was to use qualitative methods to explore the experiences of patients awaiting scheduled surgery. In particular, this study aimed to uncover three aspects of the experiences of patients awaiting scheduled surgery: a) the experience of time while waiting for consultation and surgery, b) the perception of maximum acceptable wait time for the patient's consultation or surgery and other similar procedures, and c) the patient's experience of the effects of waiting for consultation and surgery.

In order to achieve these objectives, two interviews were conducted with patients who had awaited consultation and scheduled surgery. Patients were selected based on three surgical conditions: hip or knee replacement surgery, shoulder surgery, or cardiac surgery. Selecting

participants from these three groups allowed comparisons to be made between relatively longer wait times (for those participants in the orthopaedic groups) and relatively brief wait times (for those participants in the cardiac surgery group). An interpretative phenomenological approach was used regarding the research method and data analysis. The ultimate goal of the study was to go beyond basic describing and interpreting of patient experiences to offer possibilities for the enhancement of patient care.

#### 1.4 MY BACKGROUND AND INFLUENCES

My experience is primarily as a quantitative researcher. This interdisciplinary health science degree introduced me to graduate training in qualitative methods. However, this dissertation was my first foray into a qualitative style of writing and in some sections the reader may notice my tendency towards the use of a more positivistic voice. This may be most notable in the literature review as a portion of this chapter was published in a quantitatively based journal. Although I was influenced by my quantitative experience, I endeavoured to take a critical realist approach to this research (16). In embracing a critical realist stance, I will acknowledge that experiences exist independently of my interpretation, yet my interpretation impinges on the creation of knowledge from these experiences. Critical realists call these concepts “ontological realism” and “epistemological relativism”, respectively (17 p582). To apply these ideas to the present research, my position is that the experiences of my participants are ‘real’ and hold meaning for them, and my interpretation of those experiences (in other words, the knowledge I derive from their experiences) is laden in my own views and experiences.

My own views and experiences have multidisciplinary influences. My primary lens is a psychological one, grounded in two psychology degrees and fifteen years as a psychology

instructor. In this way, I am keenly interested in individuals and their experiences. As a result of many years experience as a health science researcher, from coordinating psychiatric clinical trials to interviewing patients in critical care medicine and gastroenterology to public health surveys and health services program evaluation, I am comfortable in a health sciences setting. I also embrace a systems approach via training I received in health promotion and the determinants of health. These influences allowed me to be open to a wide variety of ideas from philosophy, psychology, psychiatry, nursing, and sociology. My goal is to apply these influences to a health science context to better appreciate patient experiences of wait time.

This research is also informed by my personal influences. I began this work as I turned 40 having lived in Saskatchewan my entire life. I grew up in a very small town and have now lived in Saskatoon for nearly 25 years. I have vivid memories of transitioning from small town girl to the ‘big city’, and therefore I appreciate what it may be like to navigate the health care system from that vantage point. Though I have never waited for the types of surgery in this study or for surgery in general, some family members have undergone these procedures. In this way, I have had vicarious waiting experiences – the wait time for others’ recovery.

## **2 Literature Review**

There are two main areas of literature that are most relevant to this study. The first area is the patient perspective on waiting for surgery. Research related to the patient perspective on waiting for scheduled surgery has examined three main topics: 1) maximum tolerance, 2) quality of life, and 3) nature of the waiting experience. This literature is predominantly quantitative though some qualitative studies of the patient perspective have been conducted. I gathered articles connected with these topics and co-authored a literature review in 2009. The following section on waiting for surgery from the patient perspective reflects extracts from that peer reviewed article. Additional research published subsequent to August 2009 is summarized in a subsequent section.

The second relevant area of literature examines a certain aspect of the patient perspective of wait time, in particular, patients' experiences of waiting. The specific focus of this review relates to the patient experience of time while waiting for healthcare. The literature on the experience of time has philosophical origins, though the health and social sciences have applied these ideas to the experience of patients. In compiling sources from philosophy, psychiatry, nursing, sociology, and psychology, I proposed a conceptual framework for understanding the experience of time while patients wait for care. Beginning with the concept that waiting often elicits an awareness of time and embodiment through suffering and discontent, I argued the typical wait time experience varies in terms of duration, meaningfulness, and agency according to patient choices as they engage with suffering. Such choices may be heavily influenced by both personal characteristics as well as structural and cultural influences. I developed this conceptual framework into a manuscript and submitted it for publication with my two supervisors as co-

authors. The section on time while waiting for healthcare is a close approximation to that manuscript.

## 2.1 WAITING FOR SURGERY FROM THE PATIENT PERSPECTIVE

### 2.1.1 Sources of wait time literature

The wait time literature has emerged from two main sources: 1) agency and government reports and 2) academic studies. In general, the gathering of wait time data on benchmarks and best practices, complete with policy recommendations, has comprised reports from government and other agencies (2,5-11,18-21). This literature connects relevant clinical data to establish such benchmarks and best practices, without a specific focus on the patient perspective of the wait time experience. For example, the benchmark for scheduled cases of coronary artery bypass grafting (CABG) has been determined by the Canadian Cardiovascular Society (CCS) Access to Care Working Group (5). Following a review of the literature and existing clinical practice guidelines, the Working Group surveyed cardiovascular centres and developed a consensus opinion regarding wait times. According to this consensus, the benchmark for scheduled CABG is within six weeks (5).

A similar process for establishing benchmarks has occurred with scheduled hip and knee replacement surgery. The National Standards Committee of the Canadian Orthopaedic Association recommends that a patient, regardless of acuity, should not wait longer than six months for surgery (3). Moreover, the Western Canada Waiting List Project (WCWL) identified maximal acceptable wait times (MAWT) for hip and knee replacement surgery using a validated priority criteria screening tool (7). If WCWL standards are applied, the least urgent (ie, scheduled) hip and knee replacement surgery should occur within five months.

The academic literature has centered more on the development of clinically derived priority criteria systems and evaluation of those systems (4,18-37). General categories have been developed to broadly describe emergent, urgent, and elective (ie, scheduled) surgery or procedures. The aim of this research has been to establish standardized and reliable methods of determining fair and equitable access to health care services.

A considerable amount of the work on priority criteria systems originated in New Zealand with the development of clinical priority assessment criteria (CPAC) to book patients for scheduled procedures (26,27). When New Zealand restructured its health system in 1992, a project was designed to standardize sets of criteria to measure the presumed gains from scheduled surgical procedures. Professional advisory groups created priority standards for cataract surgery, CABG, hip and knee replacement, cholecystectomy, and tympanostomy tubes for otitis media with effusion (chronic middle ear inflammation). Both clinical and social factors were considered when establishing priority criteria. Priority criteria were intended to help reduce surgical waiting lists and establish booking systems.

Similar to the New Zealand projects, the WCWL has derived priority criteria for several types of scheduled surgery, procedures and services (22,32). The WCWL, a federally funded partnership of 19 organizations, operates under the principle that patients with the most urgent conditions should have first priority (37). Urgency is defined as the clinical severity of the condition (ie, the extent of suffering), activity limitation, and risk of premature death (37). This definition also integrates the natural history of the condition and the expected benefits of treatment. The WCWL maintains priority and urgency may be interchangeable concepts, though priority criteria could also include social factors, such as patient lifestyle and demographics.

Although the WCWL has developed criteria systems for some procedures, the extent to which these have been implemented as part of routine practice and studied in correlation with patient outcomes is limited.

### 2.1.2 Purpose of the literature review

Waiting for surgery from the patient perspective is one area of inquiry that has received relatively little emphasis in the wait list literature. The aim of the present review is to describe the research that has been conducted from the standpoint of patients awaiting scheduled surgery. Studies that investigated physical and psychological aspects of the patient experience of waiting were reviewed.

In order to gather relevant studies regarding the patient perspective of wait time for scheduled surgery, studies were originally screened using the following broad criteria: 1) English language, and 2) participants as adult patients waiting for scheduled surgery. Studies of surgery with ambiguous waits such as transplantation surgery were omitted. Cancer surgery was also not considered as surgery may be required for diagnosis and staging in addition to definitive management. Surgery can play a role at each time. Articles regarding wait times for emergency procedures were also excluded, as the focus was to understand patient experience of waiting for surgery. Furthermore, papers were not included that examined wait list cost-effectiveness or focused on rationing surgical resources or reducing wait times or wait lists, as this literature tends to measure patient demographics as opposed to patient viewpoint. Both qualitative and quantitative studies were considered, therefore, additional statistical analysis of the findings from each study was not performed.

The majority of studies used a cross-sectional (n=15; 56%) or prospective cohort design (n=9; 33%). The remaining three studies applied a retrospective cohort design. For most studies, wait time was defined as the length of time between the decision to treat or booking of surgery and the procedure. Data were gathered using face to face and telephone interviews, questionnaires, and surveys. The articles which examined health related quality of life used physiological assessments such as the Harris Hip Score, the Western Ontario McMaster Osteoarthritis index, Euroqol (EQ-5D) or visual analogue scales.

The research on the patient perspective of waiting for scheduled surgery generally had three objectives: to establish maximum acceptable wait time (MAWT) from the patient point of view, to assess health related quality of life (HRQOL) in relation to length of time on the wait list, and to explore the nature of the wait time experience from the patient standpoint. These three themes are presented in the following sections.

#### *2.1.2.1 Patient perspective of acceptability of wait time length*

The 11 studies investigating patient perspective of the length of wait times are presented in Table 2.2. (All tables from section 2.1 appear at the end of the chapter). The WCWL Project had several reports of patient views on the length of an acceptable wait for scheduled cataract (38, 39) and joint replacement (40-42) surgery. What the patient perceived as the MAWT was commonly measured through the question: “In your judgment, what should be the appropriate maximum waiting time for you or a person like yourself?” MAWT has also been calculated by presenting patients with a hypothetical choice between length of wait and risk of post-operative mortality (43) in order to indirectly assess attitudes towards waiting. When patients choose a shorter wait (eg, 3 months versus 6 months) with the trade-off of a higher risk of mortality (eg, 5% versus 1%), they demonstrate a greater aversion to waiting.

In a prospective cohort study, patients awaiting cataract surgery were satisfied with their wait time when their MAWT was shorter than the actual wait compared with patients who had longer waits than their MAWT (39). A comparable study measured patient and physician perspectives on MAWT for different levels of urgency according to a visual analogue scale (VAS) and Visual Function Assessment (38). The average physician-rated MAWT was 15.1 weeks, compared to patient ratings of 9.9 weeks. From the patient perspective, MAWT for the most urgent category was four weeks. Lower MAWT was predicted by male sex and higher VAS urgency.

A multi-centre international study (44) of patients awaiting cataract surgery gathered pre- and post-operative interview data on socio-demographics, visual and health characteristics, anticipated wait time, and opinions about personal wait time. Length of wait was divided into “too long” versus “reasonable” or “too short”. Similar to the WCWL studies, lower tolerance for waiting was positively correlated with greater self-reported visual difficulties. Patients from all centers reported accepting waits of three months or less and considered a wait time of six months or more to be too long. No relationship was found between the socio-demographics and visual acuity of the patients and their acceptance of waiting. These authors also concluded patients appear to accept wait times that are longer than those recognized as reasonable by specialists, however, subsequent studies that compared patient and physician perspectives of MAWT for cataract surgery indicate patients have lower tolerance for waiting than times identified by specialists (38).

The relationship between symptom severity and MAWT for patients awaiting orthopaedic surgery has been demonstrated in several studies (38,40,45). When MAWT was assessed in

patients awaiting hip or knee replacement surgery, MAWT ratings were related to patient pain, loss of mobility, time needed to prepare, and severity at consultation (40). In a study of patient and surgeon perspectives on wait times for hip or knee arthroplasty, (41) shorter patient MAWT was determined by greater urgency as measured by a visual analogue scale, shorter anticipated wait time, and older age. In related research, (42) patients who were awaiting hip or knee arthroplasty or had undergone one of these procedures in the past year were sent a questionnaire to gauge their willingness to change surgeons to secure a shorter wait time. The majority (63%) were unlikely to consider such a change. Those who were more likely to consider changing surgeons were male, possessed high school education or greater, and had already undergone surgery. Preference for a particular surgeon prior to referral, better HRQOL, perception of acceptable wait time to see the surgeon, and perceived fairness of treatment predicted decreased likelihood of changing surgeons for a shorter wait time.

In another study utilizing a retrospective cohort design, (46) a random sample of patients who had received knee replacement surgery during a five year period in the mid to late 1980s received a survey about their wait times. The survey collected data on the acceptability of wait time for surgical consultation and the timing of surgery. While over 80% of respondents felt their wait time for consultation and surgery were acceptable, those patients who described their wait as not acceptable waited significantly longer on average than patients who found the wait acceptable (34.3 weeks versus 13.2 weeks). Patient perception of the acceptability of the wait time was not associated with satisfaction with surgical outcomes. A similar study (47) with patients who had undergone hip replacement, back surgery or arthroscopic knee surgery measured retrospective perceptions of acceptance of wait time. Again, patients who found their wait time acceptable had considerably shorter median wait times than patients reporting their

wait time as unacceptable or too long (hip replacement: 4.9 months versus 6.7 months; back surgery: 1.6 months versus 4.4 months; arthroscopic knee surgery: 1.6 months versus 2.5 months). The length of wait time predicted the acceptability of waiting for each of the patient groups. For patients in the back surgery group a change in the scheduled surgery date and discontent with the surgery outcome was associated with lower acceptance of wait time. Patients who had undergone arthroscopic knee surgery were more likely to report the wait time as too long when they did not have the option to influence the surgery date.

To compare actual wait times and patient perceptions of the acceptability of wait times for initial orthopedic consultation and surgery in rural versus urban areas of Ontario, Canada, a survey was sent to patients who had undergone hip or knee arthroplasty (48). Urban patients waited longer than rural patients for initial consultation; however there was no difference in wait times for surgery between the groups. The perception of the length of wait for consultation was longer than the actual wait time. For surgery, perceived length of wait corresponded to actual wait time. Approximately half of the patients (56% of urban and 44% of rural) were unhappy with their wait time or found the wait unacceptable. Fifty-four per cent of urban patients compared to 38% of rural patients reported their wait for surgery contributed to deterioration in their health status. These reports of acceptability are considerably lower than in an earlier study, (46) which could be related to overall increases in wait times.

Using the hypothetical choice assessment of conditional MAWT, the majority (57%) of patients awaiting hip or knee replacement surgery in a cross-sectional study (43) chose a six-month wait with a 1% mortality risk. Those patients with a lower tolerance for waiting reported a shorter wait time from the decision to treat than those with a higher wait time tolerance.

Preferences for shorter wait times were also associated with lower subjective utility scores, a self-rating of functional status.

Former patients receiving one of three types of general surgery (varicose veins, inguinal hernia, and gallstones) offered their assessment of maximally acceptable wait times based on vignettes of patients with various levels of physical, psychological, social and work impairment (49). Severity of condition, in particular degree of physical symptoms and impairment to work, affected judgments of the MAWT. Former patient views of MAWT were similar to physician, surgeon and layperson perspectives.

#### *2.1.2.2 Patient health related quality of life awaiting scheduled surgery*

Health related quality of life (HRQOL) was typically assessed using quality of life instruments such as the Assessment of Quality of Life (AQOL), Euroqol (EU-5D) and Medical Outcomes Studies 36-item Short Form (SF-36) or functional status measurements such as the Western Ontario McMaster (WOMAC) Osteoarthritis Index and Harris Hip Scale. Six studies examined the HRQOL of patients undergoing joint replacement surgery (45,50-54) and one study considered the impact of wait time on quality of life for patients undergoing coronary artery bypass surgery (55) (see Table 2.3). HRQOL in these studies was measured at various points in patient wait time: at the decision to treat, (50-52,54) at six month (51,54) and two year (49) intervals, immediately (55) or two weeks (52) prior to surgery, and at six weeks (53) and six months (53,55) post-operatively.

Patients placed on wait lists for hip or knee replacement surgery reported high psychological distress and poorer HRQOL than the population norm (50). This was especially the case for female patients and patients from lower socio-economic groups. Cohort studies that

followed patients on wait lists for orthopaedic surgery have found the physical and HRQOL impacts of waiting are substantive (51,52,54). Longer waits correlate with physical decline, (52) and shorter waits are associated with greater mobility and increased HRQOL (54). A wait time of six months or longer predicted poorer HRQOL outcomes (51) for patients undergoing joint replacement surgery.

Interviews with patients waiting for hip or knee replacement surgery were conducted preoperatively and postoperatively to assess the impact of long wait times on quality of life (53). In this study, the level of pain was the main determinant of quality of life. Patients also expressed several other concerns regarding wait time quality of life including: mobility, loss of dignity, effects on family life, being alone, financial effects, and impacts on leisure activity.

One study of patients waiting for hip or knee replacement included patients undergoing prostatectomy (45). When the three patient groups were compared to national levels of HRQOL as measured by the SF-36, all patient groups scored significantly lower on every dimension. Patients awaiting hip or knee replacement had particularly low SF-36 scores on emotional and social functioning. As symptom severity increased for each patient group, quality of life decreased.

One study was found that assessed HRQOL among patients undergoing CABG (55). Similar to patients waiting for orthopaedic surgery, patients with heart disease awaiting surgery reported negative impacts on HRQOL as wait time increases. The impact of waiting on patients undergoing CABG was assessed using the SF-36 at decision to treat and immediately prior to surgery (55). The critical point for these patients appeared at the 3 month period. For patients who waited longer than 97 days for surgery, physical functioning, vitality, social functioning and

general health were significantly lower than for patients who waited 97 days or less. Longer waits were also associated with greater incidence of postoperative adverse events and decreased likelihood of return to work.

### *2.1.2.3 Patient experience awaiting scheduled surgery*

The patient experience of waiting for scheduled surgery has been examined using qualitative (56-61) and quantitative methods (45,62) (see Table 2.4). Four studies explored the experience of patients awaiting various types of orthopaedic surgery (45,56,61,62) and five studies examined the experiences of patients undergoing coronary artery bypass surgery (57-60,63).

In reviewing the research of the patient experience of waiting for joint replacement surgery, two studies (56,61), used a qualitative approach to investigate the experience of ‘lived bodies’ and ‘lived experience’ related to wait time. The notions of ‘lived’ body and experience come from the qualitative tradition of phenomenology, where patients encounter themselves and situations through their bodies which have intelligence to relate their personal concerns and understanding of the situation (56,61). Twelve patients scheduled for hip or knee replacement surgery were interviewed and reported the experience of their bodies as deteriorating, frightened and mortal prior to surgery (56). Patients anticipated they would become more able-bodied through surgery. Another study of 18 patients and their lived experience while waiting for hip or knee replacement surgery (61) revealed one paradigm case and six themes. The paradigm case embodied the patient reality of a life in “no man’s land”, where uncertainty and loss of dignity prevailed. The commonality in all cases was waiting to return to a more normal life. The first theme, pain restricting normal activities, was a common predicament for participants in this study. The second theme, a life on hold—a continuous struggle against a faceless system, was

related to long wait times. Most respondents had been on the wait list for more than a year, and many had attempted, without success to find out when their surgery was scheduled. The consequences of long waits were also related to the third theme: living an undignified, meaningless life due to pain and disability. The respondents reported feelings of stigmatization, isolation, and depression. For the fourth theme, caring needs met, participants recognized the importance of established trusting relationships with care providers. In the fifth theme, some respondents reported the ability to preserve a sense of living a full life. For these respondents pain, disability, and uncertainty did not impinge on everyday life. The final theme related to having a sense of underlying support from family and friends. Support varied from assistance with practical tasks to provision of emotional encouragement. The authors (61) determined respondents who had the ability to manifest meaning in their life could more easily accept wait times and wait for their turn for surgery. When the system failed to affirm the caring needs of some respondents, they experienced a struggle against a faceless enemy, “the system”.

These themes (61) intersect with what is understood about chronic illness and the experience of waiting (9). The interruption and uncertainty of these patients awaiting orthopaedic surgery could be characterized as “lost time” and “a loss of control over time” (9). Charmaz (9) describes this time as “locked into a protracted limbo”. Similarly, the paradigm case from this study embodies “no man’s land” (61) where uncertainty prevails.

A correlational study of patients waiting for orthopaedic and general surgery measured anxiety and health anxiety, depression and coping to determine which constructs would predict concern about wait time (62). A greater proportion of patients reported concern about waiting than concern about the surgery itself. Eighty-five percent of respondents were moderately or very

concerned about the waiting. Patient concern about the wait for surgery was moderately related to depression and health anxiety. Interestingly, length of wait time did not predict patient concern about waiting, which could suggest the nature rather than the duration of the wait is what is important to patients. When participants were asked what could assist them while they were waiting, two general themes emerged: support related to the wait list and provision of other services. Participants wanted information about their position on the list, a timeframe for their surgery, and more information about how the wait list was managed, including more contact with those administering the list. Other essential services reported by participants included support groups, pain management, tailored exercise programs, therapies, and further information about their condition and expectations of surgery.

In addition to measuring HRQOL and acceptable wait time, (45) patients waiting for prostatectomy, hip or knee joint replacement responded to a question about the length of wait time. Participants expressed anger towards public agencies and reported difficulties planning holidays. Some participants had experienced problems with the administrative systems. There was a lack of understanding of the waiting list process, and a further lack of communication from the hospital regarding patient position on the list and possible length of wait time. At the same time, there was reluctance by some participants to complain about the length of waiting or present themselves as a 'nuisance'.

Research describing the patient experience of waiting for CABG (57-60) has gathered accounts of patient anxiety, uncertainty, and symptom distress. An additional study assessed the opinions and concerns of patients regarding wait time (63). The main issue expressed by the sample of 100 patients was that the wait was stressful. Sixty-four percent disclosed moderate to

severe anxiety, and 16% said they were angry due to delays. Younger patients and those still working reported economic hardships as a result of postponements. A large minority of patients (41%) were entirely satisfied with the support received from the institution. However, 47% had complaints regarding communication about wait times. These complaints often stemmed from lack of clarity about wait time and urgency ranking. As a result, patients experienced longer than anticipated delays, a lack of awareness of whether wait time began at initial consultation or after diagnostic investigations, and unclear booking dates. Despite the availability of educational material regarding surgery, only 55% of patients received the educational package prior to their admission for surgery.

In two studies (59,60) the waiting experience of 70 patients on the wait list for CABG was analyzed using a qualitative and quantitative approach. Three interviews occurred at two to four weeks, six months and 12 months from referral for surgery. Forty-nine patients completed the second interview, and 28 were interviewed at the third interval. Data were analyzed using thematic content analysis and three central themes with six secondary and interrelated themes were identified. The three central themes were uncertainty, chest pain and anxiety. Patients felt they did not receive enough information about their wait for surgery, which meant they felt they could not plan for the future. Uncertainty was high in the initial interview, subsided at the six month interval, and peaked again when patients were followed up at one year. The second central theme, chest pain, was a major difficulty in daily lives of patients due to restricted physical activity, inhibited lifestyle and the reminder of their heart problems and the wait for surgery. These concerns about pain dissipated over time as pain management skills improved. The third central theme, anxiety, was a predominant issue; patients were anxious about their heart problem and the impending surgery. At the initial interview, patients were more concerned

about their diagnosis and not surviving the wait time, while at the one year follow up, apprehension was related to the surgery itself. When anxiety was measured quantitatively (60) in the same sample of patients using the State Trait Anxiety Inventory, anxiety scores were high at all three stages of data collection. State and trait anxiety was significantly related to increased reports of angina.

The phenomena of uncertainty, anxiety, and symptom distress have been investigated among 25 patients awaiting CABG (57,58). Content analysis of interview data noted the following categories: taking actions to manage coronary symptoms while waiting, “getting my life back” through physical and psychosocial improvements, and “getting it over with” or using cognitive and behavioural strategies to cope with impending surgery (57). Forty-two patients completed a questionnaire which measured uncertainty, anxiety, symptom frequency and related distress, and physical and social limitation (58). Actual or perceived wait time had no significant relationship to any other construct, including functional status. Symptom distress, on the other hand, was significantly associated with both anxiety and uncertainty. However, in some cases uncertainty was not perceived as a threatening experience, but rather as an opportunity once surgery was completed.

#### *2.1.2.4 Recent literature on patient perspective of wait time for scheduled surgery*

Since the initial review in August 2009, three studies have been published related to the patient perspective of waiting for scheduled surgery (see Table 2.5). Two (64,65) examined patient tolerance of or satisfaction with waiting and one (66) investigated the relationship between wait time and quality of life.

In the most recent study of the conditions that affect patients' wait time tolerance (MAWT) for cataract surgery (64) the findings were similar to prior investigations (38,39,44). Lower tolerance was associated with greater self-reported vision difficulties, rather than clinically measured acuity. Those patients with greater acceptance of wait time tended to have higher education and the ability to work. Longer MAWT was also predicted by family members living at home (partner or children). In contrast to an earlier study, (38) these researchers found male patients to be more likely to accept longer waits, a finding possibly explained by male patients' better subjective vision ratings than female patients in the sample.

The determinants of wait time satisfaction were assessed among two groups of patients, one waiting for hip and knee replacement surgery and another group of postoperative patients (65). Measures of perceived ideal waiting time, MAWT, expected waiting time, fairness and satisfaction were gathered to test the disconfirmation model – the notion that satisfaction decreases as a function of the discrepancy between expectations and perceived performance. Results for both patient groups were consistent with the disconfirmation model. That is, waiting and post-surgery patients reported less satisfaction when wait times were longer than expected and more satisfaction when wait times were shorter than expected. Similar results were found regarding perceived fairness and satisfaction; dissatisfaction was associated with a perception of being treated unfairly. These findings complemented a study of cataract surgery (39) where shorter actual wait time increased satisfaction among patients who waited longer. The authors concluded improved communication regarding realistic wait times would bolster patient satisfaction with waiting.

The relationship between wait time for hip replacement surgery and pain and function after surgery was examined to understand the clinical effects of longer time on the waiting list (66). The study also considered the factors that affected wait time duration in the absence of prioritization criteria. Patients completed the WOMAC, designed to assess pain, stiffness and physical function, and the SF-36, a health related quality of life measure preoperatively and 6 months after surgery. Factors that affected wait time duration were better physical and social function (longer wait times) and greater pain, stiffness and functional severity (shorter wait times). At 6 months post surgery, functional capacity was significantly diminished among patients whose wait time for surgery exceeded 6 months, a finding that fits with previous studies (51,54). These results indicate that a failure to implement prioritization criteria can impact patient functional capacity after surgery.

### 2.1.3 Summary and conclusions

The literature examining the patient perspective of waiting for scheduled surgery can be summarized into three categories. First, the existing research has investigated the patient perception of MAWT. Generally, patients are less likely to report longer wait times as acceptable. This is particularly true for patients with more severe symptoms or impairment (38,40,43,44,64). The second focus has been to assess the relationship between length of wait and HRQOL. This relationship tends to depend on surgery type and severity at time of booking. For example, patients report wait times for joint replacement surgery of six months or longer as having a negative impact on HRQOL (51,54,66). Patients awaiting CABG experience significantly reduced quality of life when wait times exceed three months (55). Third, researchers have attempted to understand the nature of the waiting experience from the patient standpoint. These studies are predominately qualitative and describe the waiting experience as

stressful and anxiety provoking (57-60,63). Some patients express anger and frustration about wait times (45,59) and report communication issues with the system (45,53,62). Interestingly, the experience of waiting is not uniformly negative in this research. Studies indicate some patients view the uncertainty during waiting as an opportunity to consider surgery as a second chance (58) and are able to live full lives despite pain and disability (61).

The studies of the nature of the patient experience awaiting joint replacement and CABG illustrate some common concerns among participants. Both patient groups tend to cite a measure of uncertainty in the waiting period prior to surgery. This theme is especially prevalent among patients awaiting CABG where existential concerns about mortality risk are emphasized. While each patient group reports positive aspects to the waiting experience, a recurring theme in most studies was lack of information and communication during the wait period. In one study, the “system” was viewed as a faceless “enemy” (61).

#### *2.1.3.1 Limitations*

The limitations of this review are influenced by the characteristics of the original references. Some studies using a cross-sectional or retrospective cohort design asked patients who were no longer on the waiting list for their MAWT opinions, their perceptions of HRQOL, and/or their wait time experiences. It is likely patient perspectives of waiting are influenced by the specific time in the waiting process. Asking patients postoperatively about their wait time may reveal substantially different perceptions. For example, when two groups of patients before and after joint replacement surgery were surveyed, being in the postoperative surgery group predicted the likelihood to change surgeons to achieve a shorter wait time (42).

Although this review provides a description of the current state of the literature on the patient perspective of waiting for scheduled surgery, several questions remain. Opportunities exist to further explore patient conceptions of time, waiting, and coping with the preoperative period. Given the multiple experiences of wait time as a fount of opportunity and meaning or as a source of uncertainty and despair, additional studies of patient perspectives on waiting could examine conceptions of “life on hold” versus “waiting as opportunity”. Such investigations could invoke systematic change to support patients during the waiting period.

Only four studies (53,59,61,65) made specific clinical and/or policy recommendations based on their findings. Given the significance of wait times for patients, service providers, and the health system, translating research findings into practical solutions to assist patients during their wait period is essential. Until the wait time of patients is more fully understood, evaluation research on interventions designed to improve wait time will be limited.

## 2.2 TIME WHILE WAITING

The question and study of time is one of the oldest in philosophical debate. In the 4<sup>th</sup> century, St. Augustine recognized the compelling and perplexing nature of time experience with his famous quote: (72) “What then is time? Provided that no one asks me, I know. If I want to explain it to an inquirer, I do not know” (p230). St. Augustine devoted an entire chapter of his autobiographical confessions (Book XI) to the exploration of the experience of time. In his ‘conversation’ with God, he mused on the creation of heaven, earth and time. Most relevant to this discussion, he maintained time is the distension of the mind. In doing so, he distinguished between quantitative or chronological time and subjective or experienced time, a demarcation that is acknowledged to this day with varying degrees of complexity.

Improvements in healthcare have influenced both quality and quantity of human life. Generally, this provision of a 'better' and longer lifespan (ie, more time) has been embraced to the extent that it has become an expectation. At the same time, the acquisition of longer life appears to have coincided with a culture of less patience and greater time urgency. In many ways, cultural influences on perceptions of time have enslaved us in a hyper- awareness of time (67). Hoffman (67) argues the relationship with time in Western culture tends to be steeped in ambiguity and complexity. For example, time has been commoditized to the extent that it must never be 'lost' or 'wasted'. Yet, time may also be deliberately 'killed' when its passage is eagerly awaited. Accordingly, there appears to be little patience for waiting for the healthcare that has made 'bonus' time possible. Indeed, the intolerance of wait times in the healthcare system has mounted and has become a persistent challenge for governments and administrators and prime fodder for media. Whether waiting for a few minutes for a blood test or weeks to months for scheduled surgery, the widely held assumption is the experience of wait time will vary from mild irritation to great anxiety.

Current evidence lends some support to wait time experience as synonymous with frustration and irritation (68). The majority of studies in this area have linked wait time tolerance with symptom severity and quality of life outcomes. For example, when symptoms or functional impairment are severe, patients tend to perceive longer wait times as less acceptable, and health related quality of life appears to decline with greater waiting duration (68). Other research on the nature of the waiting experience indicates wait time is potentially meaningful for some patients. Waiting can provide opportunity for the assessment of priorities and allow a 'full life' despite pain and disability (13,61). Nevertheless, a resounding theme in many studies of the patient

perspective is wait time often elicits uncertainty and anxiety and suspends aspects of 'normal' role function (68).

The general wait time literature conceptualizes time in an objective and linear sense – the longer patients wait, the poorer their outcomes. Surprisingly, what has received little attention is the experience of 'lived time' while waiting from the perspective of the patient. Lived time could be described as "what it is like to live time". (69,p203). In particular, the role that lived time or the phenomenological experience of time plays in the lives of patients awaiting healthcare has not been explored. The limited literature on illness and the experience of time (9,12-14) suggests that an understanding of patient lived time experience may enhance patient care. For instance, Zhou, (14) who studied lived time experiences among people in China with HIV/AIDS, states time as lived "is an indispensable dimension of human experience and a distinct form of illness experience" (323). Zhou's work further identified patient lived time experience that went beyond time as having a linear directional flow. Specifically, when participants were diagnosed with HIV, their perception of their future was altered. In their view, the diagnosis of HIV disrupted particular plans and goals, making re-evaluation of these pursuits necessary. As participants were able to comprehend time where their priorities were reassessed, they restored a sense of control over their lives despite the prognosis for their condition.

Similar to patients diagnosed with HIV, researchers (13) found patients diagnosed with cancer re-evaluated their remaining life experience. Time for these patients was no longer defined by the clock and calendar, instead they reported becoming "stingy" with their time and setting priorities in favour of their own lives versus the needs of others (p620). According to

these authors, understanding the efforts by cancer survivors to maintain control over their temporal lives will ensure greater insight into patient concerns and improve patient care.

Given the paucity of knowledge regarding the lived time experience of patients awaiting healthcare and the importance of the experience of time, uncovering a method to understand the patient experience of wait time is essential to enhance patient care. Such a method may inform clinicians and administrators regarding the patient perspective and could allow shifts in both practice and policy toward better patient centred care. If, as Eva Hoffman (67) asserts: “time is to the mind as air is to the lungs” (p63), then a greater understanding of how patients experience time while they wait will assist clinicians to provide more responsive and compassionate treatment. In the following sections, the complexity of wait time experience from patients’ perspectives is explored.

In order to understand the conditions whereby waiting becomes tantamount to suffering, the wait time experience must be contextualized. By suffering I mean pain or distress, not primarily in the physical sense, but in terms of mental or psychological suffering. At the same time, I suspect that intense mental and physical suffering are inextricably linked. How the patient experiences time while waiting will influence the level of suffering he or she will endure. In this section, the limited literature on the experience of time and research on the patient perspective of waiting will be linked to create the context for the lived wait time experience. The lived wait time context, by definition, is imbued in social and cultural influences. While discussion of lived wait time focuses on patient experiences, the patient cannot be separated from the social and cultural context in which he or she waits.

First, two states of lived time experience: ‘implicit’ versus ‘explicit’ temporality (71) will be distinguished. These states will guide discussion of three specific concepts from the lived time literature as each is applied to the wait time experience. Wait time duration, meaningfulness of the experience, and anxiety and uncertainty are highlighted in the existing wait time research, (Anxiety and uncertainty may be diminished by increased agency, the sense of control over one’s life and in this particular situation one’s time). Therefore, it is reasonable to incorporate the particular ideas of lived duration, meaningfulness, and temporal agency into the conceptual framework. By integrating these three ideas into a continuum of experience and implementing the overarching concept of ‘implicit’ (unconscious) versus ‘explicit’ (conscious) temporality, the lived time experience of waiting for help with a health problem will be elucidated (see Table 2.1 for the framework summary). This framework will explain how wait time for some patients is fraught with suffering while others may wait with relative equanimity.

Table 2.1 Conceptual Framework of Experience of Lived Time While Waiting

<b>Implicit temporality</b>	<b>Explicit temporality</b>
Accelerated duration	Protracted duration
Meaningfulness	Lack of meaningfulness
Agency/certainty	Lack of agency/certainty

### 2.2.1 Lived time and lived wait time

The subjective experience of time bears little resemblance with time’s portrayal as a singular, independent and linear dimension to be tallied and quantified. Much of the contemporary research on time has been dominated by experimental studies of psychophysical time perception, memory and attention, and neuropharmacology (73). While clocks and

calendars provide the standardization necessary to coordinate daily events, phenomenal time or 'lived time' has distinct qualitative features. Perhaps the most important feature of subjective time pertains to the degree that we are aware or conscious of temporal experience. The notion that lived time consists in distinct states of either implicit or explicit temporality (71) will aid understanding of lived wait time experience. In particular, time while waiting can be experienced consciously, where its passage is apparent, or unconsciously, where its passage is indiscernible.

In a philosophical paper, Thomas Fuchs (71) describes the distinction between unconscious (implicit) and conscious (explicit) temporality in order to better explain the time disturbances experienced in psychiatric illness. Specifically, Fuchs proposes the parallel structure of embodiment and temporality to illustrate how our awareness or lack of awareness of our bodies is coupled with our conscious perception of time. As we become aware of our bodies through the experience of physical or psychological suffering, we inevitably become aware of time. Conversely, when our bodies are well we are more likely to experience temporality implicitly. For Fuchs, time remains implicit as we continue to be immersed in the 'busy-ness' of life and remain unaffected by suffering. Implicit temporality does not imply we are unaware of other aspects of the experience; it means that when we reflect on a particular experience we observe that time passed unnoticed.

When time is experienced explicitly, temporality is said to exist in two specific conditions (71). The first condition of explicit temporality is when a gap appears between need and satisfaction of that need. This situation creates a "temporality of awaiting" (p195), a mindful experience of the passage of time with regard to an anticipated future. To apply this condition to waiting for healthcare, this first condition of explicit temporality may manifest as a patient

awaits a reprieve from symptoms. In Fuchs' second condition of explicit temporality, a conscious break emerges between the present and the 'lost' past. Time may be experienced in the explicit state of 'no more' as the present moves on from the past. Fuchs describes this state as the temporality of missing or mourning. To apply this condition to patients awaiting healthcare, they might become more conscious of time when they compare their current state to a former healthier state. Fuchs argues the experience of time becomes explicit as the split widens between the present and the irrevocable past. This means patients are likely to become more aware of time when their state of health continues to deteriorate the longer they wait. Both conditions of explicit temporality, awaiting a future reprieve from symptoms and mourning past health, may often converge with experiences of displeasure or suffering (71).

Applying these conditions of explicit temporality, wait time could be viewed as an intersection where suffering is likely to implicate both temporality and embodiment. Patients, in a conscious awareness of time, await the relief of suffering and a restoration of health. That is, suffering and discontent while waiting elicits time consciousness. It is within this consciousness of time that patients are likely to be aware of and experience aspects of time duration, meaningfulness and temporal agency as related to their wait time. Lived duration is the patient's perception of the length of wait time; the meaningfulness of wait time indicates the value the patient ascribes to the experience; and agency describes how much control the patient feels he or she has during wait time.

### 2.2.2 Lived duration

A fundamental human quality is the ability to experience time's passage—that is, to comprehend the duration of time. In the context of waiting for healthcare, it may be assumed that

our need to be relieved of suffering makes the passage of time a seemingly long and protracted experience. However, Flaherty (74), a sociologist, contends the concept of waiting, in general, is problematic because we *know* we will wait. For Flaherty, the waiting experience exists within personal and social conditions. Particularly, the extremity of circumstances, emotional concerns, cognitive involvement, and stimulus complexity contribute to the experience of duration (74). These conditions can pack “standard units of temporality with a *density of experience* that far surpasses their normal volume of sensations” (p95). This leads to so-called moments of time to be over- or under-loaded with experience. According to Flaherty, the perception of protracted duration occurs in both situations—when objective moments of time seem, subjectively, either ‘full’ or ‘empty’.

When we wait for healthcare, objective moments of time may be either ‘full’ of uncertainty and anxiety or ‘empty’ as a result of boredom and role upheaval. Uncertainty, a cognitive state which can lead to the affective condition of anxiety, could be ameliorated by enhanced agency – the patient’s ability to engage in regular activities despite illness. As sociologist Charmaz (9) noted in her study of patients with chronic disease, engaging in a struggle against illness seems to quicken the experience of time, while passively absorbing the sick role may slow time down. When the future is dreaded and shrouded in uncertainty waiting may become a barrier to the recommencement of one’s former self (9). That is, waiting can render the self ‘on hold’ and may affect the experience of lived duration.

This experience of time’s seemingly arrested duration was also acknowledged in a phenomenological study of 13 individuals with non-malignant chronic pain (75). These individuals perceived their world, including time, through the ‘filter’ of their pain. Thomas

reports, “In the agony of the moment, they experienced a stopping of time as if the moment would never end” (p94). These participants reported a paradoxical relationship to time where the moment, a relatively short duration in ‘clock’ or objective time, was experienced as lengthy and heavy. For these participants, the concept of a frozen ‘moment’ represented a possible lifetime of suffering.

In addition to physical pain, emotional states such as anticipation, uncertainty and anxiety often characterize waiting for healthcare (11). Such states could add to the protracted experience of lived duration. For patients with anxiety and uncertainty, waiting may feel like “a sentence unwillingly served” (74 p57), interminably and painfully slow. Alternatively, anticipation of positive outcomes for some patients could make waiting periods ‘fly by’. In fact, a study using interviews with patients awaiting diagnostic services at the Mayo Clinic found patients rarely complained about waiting (11). In the words of one patient: “Waiting? That’s not the right word. I’m wondering, anticipating, most of all hoping” (11 p157). Time passed quickly when a positive result was expected.

The experience of lived duration while waiting for healthcare seems to depend on physical symptoms and emotional states such as anticipation, uncertainty and anxiety. Pain, uncertainty and anxiety prolong time. Boredom and disturbances in ability to engage in daily activities also play a role in lengthening lived duration. Anticipation of (or hope for) freedom from suffering and the relief of uncertainty influence how time is perceived during this period. When a patient hopes for or anticipates positive outcomes, time likely passes more quickly. Waiting for answers to medical questions and for the amelioration of symptoms has an impact on the patient experience lived duration.

Because considerable attention has been given to wait time and the quantitative measurement of duration (68), it is important to recognize that ‘lived duration’ has qualitative elements. These qualitative features of lived duration may be explained using the implicit versus explicit temporality construct. Explicit temporality, which is likely to be concomitant with greater suffering and distress, including anxiety and uncertainty, within a waiting period, will coincide with a protracted experience of time. Implicit temporality, on the other hand, tends to correspond with a healthier state (or with an ability to adapt to suffering) and an accelerated experience of the passage of time. Consequently, patient ability to transcend suffering and distress may determine how duration is ‘lived’.

This leads to the question: what influences a patient’s ability to overcome the distress of waiting? In the following sections, the concepts of temporal meaningfulness and temporal agency are presented as a possible answer to this question. That is, the meaning patients assign to their time and the control or agency they assert over their time impacts their ability to endure distress and suffering.

### 2.2.3 Meaningfulness of temporal experience

The meaningfulness of temporal experience has been contemplated by various philosophers, psychologists and sociologists. Specific sources can be employed to understand the relationship between the meaningfulness of temporal experience and patient suffering and distress (10,76). These sources suggest the meaningfulness associated with the experience of time may be an important determinant of patient suffering and distress. Psychologist Carl Hale (76) offers detailed and creative descriptions of subjective time experiences and aims to provide a standard of what he refers to as temporal authenticity. In outlining several dimensions of

authentic and inauthentic time experiences, Hale characterizes temporal authenticity as attention to inner subjective time, a complete immersion in and concentration on immediate experience, and an ability to have a meaningful relationship with past and future. Using Hale's definition, the potential for wait time to be a meaningful experience could be determined by the patient's choice to manifest meaning while waiting and to avoid inauthentic time dimensions.

According to Hale (76), in inauthentic time dimensions we are not living fully in the present. We are only 'spending time', running away from the possible meaning of the moment into the fallacious daydream of past and future (76). Using literary themes, Hale specifies various examples of inauthentic temporality where time can be experienced at a frenzied pace or consumed by meaningless activity. Hale describes fast-paced, ceaseless and often meaningless activity as *Faustian* time, and time wasted or squandered time as *Distracted* time. Authentic time dimensions, on the other hand, include *Promethean* time and *Icarus* time. During *Promethean* time we are engaged in creative self-expression and the pure joy of the moment. *Icarus* time, the opposite of *Distracted* time, is a transient time experience where we feel positive and productive in relation to time (76). Patients might experience the Promethean dimension when they are focused on positive aspects of the present and the Icarus dimension when they perceive an optimistic future.

In the context of my study, a particular dimension that may personify wait time experience is *Sisyphus* time (76). Sisyphus, the mythical Greek king who was sentenced by the gods to roll a rock up a mountain in perpetuity, exemplifies the experience of time as we suffer from personal crisis, adversity, or loss. Similar to the experience of Sisyphus, wait time could seemingly consist of endless suffering where the past and present lose meaning, each moment is abysmal and the

future is indefinite. Hale argues confrontation with that type of suffering will elicit the recognition of mortality and can have two potential outcomes. The *Sisyphus* time dimension is said to either foster openness and empathy (in terms of authenticity) or self-absorption and cynicism (in terms of inauthenticity). Whether patients suffer the ‘drone’ of *Sisyphus* time could depend on their ability to explore alternative and meaningful time experiences.

The idea that wait time offers a range of possibilities including meaningfulness was echoed by Gasparini (10) who regards waiting experience (also referred to as ‘interstitial time’) as influenced by various role expectations. Such expectations are said to evoke temporal aspects of action which can lead to waiting. In the context of healthcare, for example, we might expect to be contacted with results from a medical test after a certain passage of time. In the meantime, we wait. For Gasparini, at worst, waiting can be experienced as ‘time wasted’, and at best, be seen as a completed and meaningful experience. Time while waiting can comprise substitute meanings such as rest, reading, etc. According to Gasparini, those who wait are confronted by the choice to either minimize and avoid waiting or accept wait time. In a situation where waiting is unavoidable, acceptance means acknowledgement of a person’s loss of control over time and his or her relative place in the queue. In this instance, a patient would enter the medical testing centre, take a number, and patiently await his or her turn.

For Gasparini (10), the meaningfulness of wait time is contingent upon the cultural norms, values and beliefs that social actors attach to their life experiences. While in many cultures waiting is often depicted as frustration and distress, other perspectives on wait time embody hope and fulfilment. When serious illness involves a long course of treatment and protracted wait

times, patients may be more likely to accept waiting. In this situation where waiting is unavoidable, wait time might be experienced as meaningful in itself (10).

The experience of wait time may be tantamount to Hale's description of the *Sisyphus* time dimension. Certainly, patients who await treatment are challenged by crisis or adversity and may be faced with loss of ability or mortality. This suggests wait time can be either temporally meaningful, where time is experienced implicitly as growth and self-actualization, or without temporal meaning, where we may wallow in prolonged periods of suffering with explicit temporality. In other words, patients who are able to find or maintain meaning in their lives while waiting for healthcare are more likely to remain functioning 'in time' (71). Patients without temporal meaningfulness may experience the suffering associated with an explicit awareness of time's passage.

#### 2.2.4 Temporal agency

The final piece of the conceptual framework is the notion of temporal agency. The concept of agency is a rich and complex construct with a long history of investigation. Although agency has various definitions (eg, self-determination, self-will, choice, intentionality, freedom, sense of control), for the purpose of this exploration, I will concentrate on sources that intentionally marry the concepts of agency and temporality (77-79). Essentially, these authors agree time is not experienced reflexively. Each views agency as embedded in time perspectives and all assert that as agentic social actors, we exercise control regarding how we experience time.

One facet of temporal experience of the social actor includes a projective element or 'projectivity' regarding the future (77). That is, actors will 'try on' future scenarios in an attempt to hypothesize their consequences. Flaherty (78) would include this action as an aspect of 'time

work', the "intrapersonal and interpersonal effort directed toward provoking or preventing various temporal experiences" (12). Similarly, Hiltin and Elder (79) describe the 'time horizon' where the social actor will focus on "a particular zone of temporal space" (p171) in response to various social exigencies. Thus, the 'time work' of patients awaiting healthcare as projecting ambiguous outcomes while entrenched in a future time orientation.

Particular to the projectivity of the waiting experience is a spectrum of ambiguity. Often, ambiguity and uncertainty brings anxiety. Patient agency may be a determinant of the quality of the waiting experience, in the sense that patients who control how and when they wait keep the probability of anxiety at bay. Yet, patients, by definition, could be viewed as having little agency when it comes to the wait time to receive healthcare. Flaherty (78) would argue to the contrary, that is, "there can be no unadulterated determinism when temporal experience is at issue" (p141). In other words, in Flaherty's view people always have agency over their experience of time; temporal experience is not determined by outside forces. Flaherty says we either attend or do not attend to events in our lives and thereby shape the duration, frequency, sequence, timing and allocation of these events. It is the force of our selective attention that allows us to shape our temporal experience (78).

Applying this notion of temporal agency to wait time experience suggests waiting typically orientates patients to an uncertain future 'time horizon'. This time horizon varies in degree of uncertainty depending upon the conscious acknowledgement of temporal agency. For those with a great amount of uncertainty about the impending aspect of healthcare, time will be experienced explicitly. Those with less uncertainty are more apt to experience implicit time. The goal of

healthcare providers could become indentifying patients with high levels of uncertainty and supporting them to attend to agentic aspects of their temporal lives.

#### 2.2.5 Caveats for conceptual framework

This initial attempt to elucidate the lived wait time experience of patients awaiting healthcare will require further development. Although a framework has been presented that may provide the background for empirical consideration of lived wait time experience, a number of caveats should be recognized. One cautionary note when interpreting the framework is Table 2.1 implies a bifurcation of wait time experience. From the table, it might be assumed that wait time is experienced as either implicit or explicit or that temporality can be accelerated/protracted, meaningfulness/lacking meaning, and certain/uncertain. It is not the intention to suggest the complexity and subjectivity of wait time experience can be reduced to dualistic typologies. Instead, it is probable that patient experience may vacillate between the extremes and is likely to change during the course of any waiting period. Equally likely is certain temporal experiences vary according to the specific aspect of care the patient awaits. Awaiting a diagnostic test result to reveal a potentially lethal disease would be expected to evoke a different temporal experience than waiting for a routine procedure with low lethality. Consequently, these categories should be viewed as fluid rather than static representations of patient experience.

While the framework proposes particular conceptual categories for lived wait time experience, further investigation is required into personal and structural influences on the temporality of waiting. It is suspected that such influences as gender, age, cohort, and culture are also important facets of lived wait time experience and should be considered in employing this framework. For example, the ‘time culture’ in which the patient resides undoubtedly has a

powerful impact on wait time experience (67). That is, in societies where waiting of any kind is not easily tolerated (ie, more emblematic of Western culture), wait time for healthcare might also be experienced as wasted, meaningless time.

A further caveat relates to the display and discussion of the conceptual categories. For ease of presentation, these concepts were portrayed as distinct and seemingly standalone categories. However, an empirical test of the framework may reveal each concept is interrelated and connected in important ways. A particular instance may occur where protracted temporality can coincide with a meaningful wait time experience, or temporal agency might be found to dictate many features of the quality and quantity of waiting. Indeed, lived duration may be epiphenomenal to the other two concepts, with meaningfulness and agency inexorably interconnected. Nevertheless, the application of these categories do provide a unique conception of the lived wait time experience of patients and offer myriad possibilities for future research and clinical interventions.

#### 2.2.6 Conceptual framework conclusion

Within the context of implicit and explicit temporality, the notions of lived duration, meaningfulness of temporal experience, and temporal agency can provide a framework for understanding the patient experience of wait time for healthcare. This conceptual framework suggests wait time for healthcare often consists of protracted duration, especially when patients are preoccupied with emotions like anxiety. Similarly, level of patient suffering determines whether time will be experienced explicitly and protractedly. The possibility of temporal meaningfulness in the waiting period may depend upon the patient's ability to maintain or

manifest meaningful experiences despite suffering. Like all social actors, patients have the potential to shape the temporal experience of waiting to minimize uncertainty.

Wait times are commonly assumed to be negative experiences; however, the present conceptualization of the wait time experience for healthcare implies the lived wait time experience may not be unequivocally detrimental and is subject to greater complexity than conventional opinion dictates. It further suggests some patients may use wait time to generate meaning in their lives. If wait time is recognized as subjective experience, rather than as uniform quantitative duration, opportunities arise to examine the relationship between patient characteristics, social conditions and wait time experience. Indeed, the essential feature of the waiting experience may not be quantitative duration at all, but the qualitative experience of that duration. While waiting, patients may have the capacity to manifest meaning and transcend suffering.

This conceptual framework adds to the body of knowledge on the patient experience of wait time, which up to this point has been limited to quantitative studies of waiting tolerance and quality of life impacts. Knowing that within conditions of implicit or explicit temporality, wait time consists of lived duration, the potential for meaningfulness, and temporal agency may lead to greater understanding of the patient experience of waiting. As this experience is better understood, more appropriate support can be provided to patients while they wait.

### 2.3 THE PRESENT RESEARCH

These two areas of literature, the empirical research regarding the patient perspective on waiting for scheduled surgery (including perspectives of maximum acceptable wait time and the

nature of waiting experiences) and the proposed conceptual framework on the experience of time while waiting for healthcare, provide the foundation for the present study.

Further investigation into the conditions that influence patient experience of waiting for scheduled surgery is required. Very few studies have examined the complexity and subjectivity of wait time. The connections between illness type, waiting experience, patient characteristics and experience of time are explored in the present study using qualitative methods.

Table 2.2 Patient Perception of Acceptability of Wait Time

Study No.	Surgery type	N	Design (Location)	Method	Main Findings
38	Cataract	213	Cross-sectional (British Columbia, Canada)	Patient perspective of MAWT, <sup>a</sup> VAS <sup>b</sup> urgency, and Visual Function Assessment assessed via mailed questionnaires	Physician-rated MAWT was significantly longer than patient-rated MAWT. Sex and visual acuity in nonsurgery eye significantly predicted patient MAWT
39	Cataract	166	Prospective cohort (British Columbia, Canada)	Assessed satisfaction, MAWT, urgency, visual function, visual acuity, and HRQOL using mailed questionnaires before and 8-10 weeks after surgery	Patients whose actual wait time was shorter than MAWT had greater odds of being satisfied than those who waited longer
40	THA, <sup>c</sup> TKA <sup>d</sup>	432	Cross-sectional (Saskatchewan, Canada)	Questionnaire	MAWT ratings based on pain, loss of mobility, time needed to prepare, severity at consultation
41	THA, TKA	233	Cross-sectional (Alberta, Canada)	Physician ratings of urgency, MAWT; patient ratings of urgency, MAWT, WOMAC <sup>e</sup>	Urgency influenced both patient and surgeon MAWT. Older patients reported shorter MAWT

Study No.	Surgery type	N	Design (Location)	Method	Main Findings
42	THA, TKA	611	Cross-sectional (Saskatchewan, Canada)	Questionnaire	63% of patients were unlikely to change surgeons to shorten wait. Male sex, high school or more, and postsurgery group predicted likelihood to change surgeon.
43	THA, TKA	148	Cross-sectional (Ontario, Canada)	Measures of symptom severity (WOMAC); subjective burden of arthritis, choices between wait time and risk to generate MAWT	57% chose 6 month wait with 1% mortality risk. MAWT ranged from 1-26 months, with median of 7 months. Those with lower tolerance for waiting reported lower utility scores and shorter times since decision to treat had been made
44	Cataract	550	Prospective cohort (Manitoba, Canada; Denmark; and Barcelona, Spain)	Telephone interviews identified anticipated waiting time, opinions about personal waiting time, and visual and health characteristics	Patients in all three sites were accepting of waits of 3 months or <, and considered waits > 6 months to be excessive. Low tolerance for waiting was associated with greater self-reported difficulty with vision. Acceptance of waiting was not associated with clinical visual acuity measures or socio-demographic characteristics
46	TKA	127	Retrospective cohort (Ontario, Canada)	Survey mail out with telephone follow up	Median wait times for initial consultation and for TKA were 4.0 and 9.5 weeks, respectively. Waiting times did not change significantly over the 5-year study period. Majority of patients considered their wait time acceptable

Study No.	Surgery type	N	Design (Location)	Method	Main Findings
47	THA, back surgery, knee arthroscopy	1336	Retrospective cohort (Sweden)	Questionnaire 3 months post-operative	Length of wait predicted patient acceptance of wait time. SES <sup>f</sup> variables and hospital type were not related to perceptions of time on wait list. For arthroscopic knee surgery group lack of influence over surgery date was related to perception of wait time as too long or unacceptable
48	THA, TKA	260	Cross-sectional (Ontario, Canada)	Mailed survey: length of wait, acceptability of wait, effect of wait on health, what acceptable wait would be	50% were unhappy with wait for surgery or found wait unacceptable. No difference between groups in acceptability of wait. 38% rural and 54% urban thought surgical wait contributed to health deterioration
49	General surgery, varicose veins, inguinal hernia, gallstones	257	Cross-sectional (Netherlands)	Mailed survey: vignettes describing physical, psychological, social and work impairments	Physical symptoms and impairment at work influenced MAWT judgments. Former patients' views were similar to physician, surgeon and laypersons

<sup>a</sup>Maximum Acceptable Wait Time; <sup>b</sup>Visual Analogue Scale; <sup>c</sup>Total hip arthroplasty; <sup>d</sup>Total knee arthroplasty; <sup>e</sup> Western Ontario McMaster Osteoarthritis index; <sup>f</sup>Socio-economic status

Table 2.3 Patient Health Related Quality of Life While Waiting for Scheduled Surgery

Study	Surgery type	N	Design (Location)	Method	Main Findings
45	THA, <sup>a</sup> TKA; <sup>b</sup> prostatectomy	124	Cross-sectional (New Zealand)	Interviews: HRQOL, <sup>c</sup> condition- specific severity, acceptability of wait time	Those with more severe symptoms wanted surgery sooner. Waiting represented burden re: unrelieved symptoms and poor HRQOL. Other issues related to wait list and health system: anger, lack of understanding, difficulties planning, administrative failures, reluctance to complain
50	THA, TKA	214	Cross-sectional (Australia)	Questionnaire	Poorer HRQOL than population norm, high psychological distress; especially among women and lower SES <sup>d</sup> groups
51	THA	127	Prospective cohort (Ontario, Canada)	WOMAC <sup>e</sup> at decision to treat and 6 month intervals	Waiting > 6 mos significantly increased pain and physical disability
52	THA	167	Retrospective cohort (UK)	Physical assessment when booked for surgery compared to 2 weeks prior to surgery	Immediate preoperative Harris score decreased significantly compared to initial score. Length of time on the waiting list correlated with decreased score
53	THA, TKA	33	Prospective cohort (UK)	Interviews pre and post-operative	Wait for some had been as long as 5 years. Some sought private treatment. Quality of life for all was affected by pain. Other main considerations: mobility, loss of dignity, effects on family life, being alone, financial effects, leisure activity. Patients wanted information from hospital about admission time. Improved communication among partners

Study	Surgery type	N	Design (Location)	Method	Main Findings
					was needed
54	THA	99	Prospective cohort  (Ontario, Canada)	Questionnairebaseline and every 6 months: HRQOL, WOMAC, Harris Hip Scale, State-Trait Anxiety Inventory	Longer waits relative to shorter waits were not related to poorer postoperative outcomes. Waits > 6 months were associated with decline. Shorter wait time meant greater mobility and increase in HRQOL
55	CABG	266	Prospective cohort  (Quebec, Canada)	Measures of quality of life, incidence of chest pain, frequency of symptoms, and rates of complications	Immediately prior to surgery, patients waiting longer (>97 days) had significantly reduced physical functioning, vitality, social functioning and general health. 6 months after surgery, longer waits were related to reduced physical functioning, physical role, vitality, mental health and general health. Incidence of postoperative adverse events was significantly greater and increased likelihood of not returning to work

<sup>a</sup>Total hip arthroplasty; <sup>b</sup>Total knee arthroplasty; <sup>c</sup>Health related quality of life; <sup>d</sup>Socio-economic status; <sup>e</sup>Western Ontario McMaster Osteoarthritis index

Table 2.4 Patient Experiences While Waiting for Scheduled Surgery

Study	Surgery type	N/ Valid N	Design (Location)	Method	Main Findings
45	THA, <sup>a</sup> TKA; <sup>b</sup> prostatectomy	124; 178	Cross-sectional (New Zealand)	Interviews: HRQOL, <sup>c</sup> condition-specific severity, acceptability of wait time	Those with more severe symptoms wanted surgery sooner. Waiting represented burden re: unrelieved symptoms and poor HRQOL. Other issues related to wait list and health system: anger, lack of understanding, difficulties planning, administrative failures, reluctance to complain
56	THA, TKA	12	Qualitative longitudinal  (Sweden)	Qualitative interviews on 5 occasions	Preoperative themes: a deteriorating body anticipates becoming able-bodied through surgery; a frightened and mortal body
57	CABG <sup>d</sup>	25	Qualitative cross-sectional  (Manitoba, Canada)	Qualitative telephone interviews	Content analysis: 1) taking responsibility, 2) getting my life back, 3) getting it over with. Patients were limited by impact of symptoms, were aware of their bodies and actions exacerbating or relieving symptoms. Anxiety influenced by family, or other stories about surgery. Lengthy waits create significant psychological disturbances

Study	Surgery type	N/ Valid N	Design (Location)	Method	Main Findings
58	CABG	42;25	Cross-sectional  (Manitoba, Canada)	Qualitative telephone interviews, quantitative questionnaires	Interviews suggested positive views of uncertainty— may be experienced as danger and opportunity simultaneously. No statistically significant relationship between study variables and waiting time; but a nonsignificant trend toward deterioration of psychologic and physical condition with longer waits—may have clinical significance
59	CABG	70	Prospective cohort  (UK)	3 qualitative interviews and self-administration of State-Trait Anxiety Inventory (STAI) during waiting period	STAI scores were high at each time. Anxiety was significantly related to increased angina
60	CABG	70	Prospective cohort  (UK)	3 qualitative interviews during waiting period	3 central themes - uncertainty, chest pain, anxiety; 6 secondary themes - powerlessness, dissatisfaction with treatment, anger/frustration, physical incapacity, reduced self-esteem, altered family and social relationships
61	THA, TKA	18	Cross-sectional  (Sweden)	Interviews 1 week post- operative (TKA); Interviews while waiting for THA	Paradigm case: waiting to return to a normal life. 6 themes: pain restricting life activities, life on hold— continuous struggle against faceless system, living undignified, meaningless life due to pain/disability, caring needs met, living a full life—in spite of pain, disability, uncertainty, living in a supportive world

Study	Surgery type	N/ Valid N	Design (Location)	Method	Main Findings
62	THA, TKA, shoulder, spinal, general	39	Cross-sectional (Saskatchewan, Canada)	Questionnaire administered in face to face interview: Short- Form McGill Pain Questionnaire (MPQ), Pain Disability Index, Anxiety about Waiting and Surgery, Short Health Anxiety Inventory, Anxiety Sensitivity Index, Hospital Anxiety and Depression Scale, Coping with Health Injuries and Problems Scale	21% were anxious, 10% were depressed, 34% had elevated health anxiety, 37% had elevated anxiety sensitivity. Concern with waiting was related to the 2 pain measures and health anxiety. Anxiety about surgery was related to the other two anxiety measures and MPQ. Emotional preoccupation coping was related to both pain and anxiety measures. Patient suggestions: more information on position on wait list/how wait list was managed, timeframe for surgery, more contact with those in charge; additional services: support groups, pain management, exercise programs, massage/physiotherapy, more information on condition and what to expect from procedure
63	CABG	100	Cross-sectional (Nova Scotia, Canada)	Questionnaire and structured interviews	84 % complained wait was stressful; 64% noted at least moderate anxiety; 16% expressed anger over delay; only 4% thought queuing according to medical need was unfair; 15%, mostly younger and blue collar working patients, noted economic hardship due to delayed surgery; 41% were satisfied with existing institutional supports

<sup>a</sup>Total hip arthroplasty; <sup>b</sup>Total knee arthroplasty; <sup>c</sup>Health related quality of life; <sup>d</sup>Coronary artery bypass grafting surgery

Table 2.5 Recent literature on patient perspective of wait time for scheduled surgery

Study No.	Surgery type	N	Design (Location)	Method	Main Findings
64	Cataract	256	Cross-sectional (Austria)	Questionnaire	Lower waiting tolerance associated with visual impairment, ability to work, and ability to live independently. Better educated patients, patients with family support at home, and men were more accepting of longer wait times
65	THA <sup>a</sup> , TKA <sup>b</sup>	1240	Cross-sectional (Saskatchewan, Canada)	Mailed questionnaire to waiting and postoperative groups: Expectation, perceived wait time and satisfaction	Waiting satisfaction was related to fulfillment of expectations about waiting and a perception of fairness
66	THA	527	Cross-sectional (Spain)	SF-36 and WOMAC <sup>c</sup> questionnaires while on wait list and 6 months post-operative	Determination of wait time by pain and degree of function. QoL <sup>d</sup> and SES <sup>e</sup> not included in prioritization and should be. Patients with better physical function, physical role and social function wait longer. Functional capacity decreases if wait time is >6 months

<sup>a</sup>Total hip arthroplasty; <sup>b</sup>Total knee arthroplasty; <sup>c</sup>Western Ontario McMaster Osteoarthritis index <sup>d</sup>Health related quality of life; <sup>e</sup>Socio-economic status

### 3 Method

#### 3.1 METHODOLOGICAL APPROACH

In this study I aimed to uncover three aspects of the experiences of patients awaiting scheduled surgery: a) the experience of time while waiting for consultation and surgery, b) the perception of maximum acceptable wait time for the patient's consultation or surgery and other similar procedures, and c) the patient's experience of the effects of waiting for consultation and surgery. The first area, lived time, was a concept that had not been examined in the waiting for surgery literature. The second area, perceptions of maximum acceptable wait times, had been investigated in several settings using primarily quantitative methods. The third area of interest, patients' experiences of the effects of waiting for surgery, had been explored using both quantitative and qualitative methods.

Because the primary intent of this study was to understand the quality, rather than the quantity, of the experiences of patients awaiting scheduled surgery, I decided a qualitative methodology, specifically a phenomenological approach to the method and data analysis, would be the best way to reach my research objectives. Since I was interested in participants' lived experience of wait time, in general, and lived time experience while waiting, in particular, phenomenological inquiry could address these meanings from the perspectives of participants (80). In the following sections, I briefly outline the key concepts of phenomenology as a philosophy and consider the primary manifestations of phenomenology as a research method. Then, I expound on the specific phenomenological approach of this study, that is, interpretative phenomenology as discussed by Smith and his colleagues. The concomitant analytic technique,

Interpretative Phenomenological Analysis (IPA) is discussed in section 3.6 where I describe how I analysed my data.

### 3.1.1 Phenomenology as Philosophy and Method

Contemporary phenomenology has many schools and encompasses several paradigms (81). The philosophical foundations of phenomenology are grounded in the 20<sup>th</sup> century European philosophy of Husserl and Heidegger (82). Husserl is accepted as the founder of the phenomenology movement; Heidegger, a student of Husserl, made significant departures and contributions from Husserl's beginnings. Phenomenological inquiry has evolved according to the works of these two philosophers in unique, yet related, perspectives: descriptive (Husserlian) and interpretative (Heideggerian) (82,83). Phenomenology, as a philosophical tradition, began with Husserl's assumption that people can only know what they experience by attending to perceptions and meanings that awaken their conscious awareness (82). People understand phenomena through intentional concentration on sensory experience. That experience is then interpreted, described and explicated, and the result embodies the meaning of the experience (83,84). Experience, for Husserl, provided the most important source of scientific knowledge, and he was ultimately concerned with the epistemological value of experience. In this way, Husserl's philosophy is descriptive, with his goal to arrive at an essential understanding of human experience (81).

To achieve this goal, Husserl introduced the concept of bracketing – holding aside one's preconceptions regarding a phenomenon – in order to attain the genuine sense of the 'thing' itself (85). The act of bracketing enables a phenomenon to 'speak for itself' rather than be coloured by pre-existing theories and assumptions about it. On this point, Heidegger made an important

demarcation from his teacher, and in doing so, is described as the second intellectual pillar of phenomenology (85). Heidegger believed understanding lived experience necessitated interpretation. In this way, 'bracketing,' as Husserl understood it, was neither possible nor desirable.

Instead, Heidegger focused on the ontological aspects of phenomenology rather than the epistemological. The core of his philosophy was to study 'Being-in-the-world' (the hyphens represent Heidegger's belief that there was no separation between human beings and their world) (81). For Heidegger, our relationship with the world was engaged, overlapping and shared – intersubjective (1). Such intersubjectivity enables us to make sense of and communicate with each other.

Phenomenology from Heidegger's perspective was a hermeneutic enterprise (1). That is, interpretation does not and cannot occur without presupposition. We always bring our prior experiences, assumptions and preconceptions to any encounter; we cannot avoid viewing any stimulus without being influenced by our prior experience. This idea was developed further by Gadamer, a student of Heidegger, who argued meanings can never be complete because acts of interpretations are ceaseless 'dialogues' between the interpreter and the interpreted (86). In this sense, bracketing as Husserl understood it, could only be partially achieved (1).

While Husserl and Heidegger cast the philosophical foundation of phenomenology, several researchers have developed these origins into a methodological basis for empirical work. Some expand upon Husserl's ideas (87), whereas others are more inclined to follow Heidegger's approach (88). Regardless of philosophical differences, phenomenological researchers share

interest in the study of the lived experiences of participants. In particular, researchers using a phenomenological approach seek to understand the meanings of 'things' to individuals (89).

Given the philosophical origins of phenomenology, phenomenological researchers have attempted to answer research questions which are situated in human meaning and experience (90). Therefore, in designing a phenomenological study, a typical research question might be: what is the meaning of a phenomenon? The participants in such a study are those who are living/experiencing the phenomenon, and examples of data gathering methods would be in-depth conversations or written anecdotes of personal experiences (90). In general, phenomenological data analytic strategies comprise reading of transcribed or existing texts and reflection by the researcher on those texts. The process of writing and rewriting permits the researcher to convey the contextual substance of the lived experience (15).

### 3.1.2 Interpretative Phenomenology

Grounded in an interpretative phenomenological perspective, Smith and colleagues (1,91) propose a theory, method and analytical technique for qualitative research. Developed specifically within psychology, the goal of the approach is to understand how participants themselves make sense of their experiences. In other words, this interpretative phenomenology analysis (IPA) is theoretically and methodologically based in the examination of the meanings that these experiences hold for the participants (92). IPA evolved as an analytical technique from the desire of psychological researchers to depict qualitative experience within the mainstream of psychology (1). Its theoretical basis lies within the three fields of phenomenology (experience), hermeneutics (interpretation) and idiography (particularity) (1,94). The intent of this approach is not to produce an 'objective' record of the event or experience, but to explore an individual's

personal perception or account of events or experiences while accounting for the researcher's preconceptions (1,94).

There is an underlying assumption in IPA that analysis of any phenomenon is bound by two conditions – the ability of participants to articulate their thoughts and experiences and the researcher's own ideas and preconceptions (93). The researcher never gains direct or complete access to the phenomenon. Instead, the interpretations of the participants' experiences are influenced by the researcher's capacity for reflection and analysis of the participants' experiences and his or her own preconceptions regarding the phenomenon. The researcher in IPA, as in qualitative research in general, is the primary research tool (90). Thus, interpretative activity is shaped by both the participants' articulation of the phenomenon and researchers' explanation of the participants' meaning of the phenomenon (1). In IPA, the researcher tries to make sense of the participants who are trying to make sense of what they are experiencing, a so-called "double hermeneutic" (1). Smith and colleagues (1) refer to "first-order" meaning-making by participants and "second-order" sense-making by the researcher (p36), resulting in a dynamic and iterative process of interpretation. Ultimately, a central feature of IPA is the discovery of meaning. Meaning is the focus, and the IPA purpose is to elucidate the content and complexity of those meanings rather than take some measure of frequency (1,91-93).

Of the many variations of the phenomenological method, I chose IPA for this study for several reasons. Using IPA could unveil a detailed portrait of how patients experience wait time, within the context of my interpretations as the researcher. I was comfortable with IPA as its beginnings are in psychology, my 'discipline of origin'. Several IPA studies with a health science focus have been published (92). In other words, the use of the approach is well

documented in the literature. As a relative newcomer to qualitative methods, I was encouraged by the availability of a comprehensive text (1) on IPA. This text has a detailed description of the theoretical underpinnings of IPA, contains the explicit stages involved in IPA research, and cites several examples of 'how to' conduct data analysis and write an IPA study. I was first exposed to the IPA approach through my graduate course in qualitative methodology, and I gained experience with the perspective during course assignments. How I applied IPA in my analysis is described in section 3.5.

It is important to note that I believe my interpretation of the experiences of the participants in this study remain inextricably linked to my own presuppositions, regardless of my efforts to limit them. I endeavoured to follow the interpretative phenomenological school as outlined by Smith (1). Moreover, I recognize that my interactions with participants likely had some bearing on how they interpreted their waiting experience. As Gadamer proposed, meanings represent a dialogue between the interpreter (myself) and the interpreted (participants), this work, from a philosophical standpoint, approximates how participants made sense of their experiences of wait time.

## 3.2 PARTICIPANTS

Patients were eligible for the study if they were seen by specific orthopaedic or cardiac surgeons during the fall, winter or spring of 2009-10. Through my supervisor, I gained the cooperation of five particular surgeons, three orthopaedic and two cardiovascular to assist with recruitment. I chose to recruit patients waiting for hip or knee replacement surgery, shoulder surgery and cardiac surgery because wait times for these types of surgery ranged from weeks (cardiac surgery – coronary artery bypass grafting surgery or valve replacement surgery) to

months (hip or knee replacement surgery and shoulder surgery). This would allow me to compare wait time experiences of participants who would experience a range of wait times in terms of chronologic time. Also, cardiac surgery and hip and knee replacement surgery represent two of the priority areas for the study of wait times in Canada. The only exclusion criterion from participation was presence of cognitive deficit, such as dementia. Of the patients referred by surgeons to the study, eight declined participation – four awaiting cardiac surgery, two awaiting hip replacement surgery, and two awaiting shoulder surgery.

### 3.3 MATERIALS

Data were collected using two semi-structured interview guides that asked participants questions in five general areas. The questions in both interview guides were similar, with a few exceptions. In the first interview (see Appendix A), I asked participants basic demographic questions: age, residence, marital status, ethnic/cultural group, highest level of schooling, and present employment status. The second section comprised general questions regarding the participant's presenting health condition. The second interview guide (see Appendix B) asked only about changes in any demographics or in the presenting health condition. The third set of questions in both guides was intended to explore the participant's current experience of time while waiting and compare that experience with similar wait time experiences. The fourth section of questions assessed maximum acceptable wait time as it related to the participant's condition and then asked participants to assess MAWT for the two other surgical groups. The final questions related to the effects of waiting where participants were asked to discuss the impacts waiting had on various aspects of their lives, including their thoughts about the future.

Both interviews concluded with the invitation for participants to add anything further about their wait time experience.

The purpose of the interview guide questions was to allow participants to have the opportunity to share their lived experiences while waiting for surgery. Questions were designed with the goal to have participants convey the meaning of their waiting experiences. To this end, the interview guide questions were developed in a series of drafts. A partial template was adapted from my supervisor's Cancer and Aging study. I used his title page and formatting for the question responses and coding of participants' identity. The initial draft of the interview questions was produced as part of an assignment in my clinical research methods course. Subsequent drafts were generated in several discussions with my supervisor. Once the interview guide was finalized, it was pre-tested with a convenience sample of two former patients, one who had cardiac surgery and the other who had knee replacement surgery. This preliminary test of the interview guide enabled me to become comfortable with the question format prior to participant recruitment.

A third attempt was made to gather data between interviews in the form of a diary (see Appendix C). At the first interview, participants were offered the option to take a small coil bound diary with them to track their thoughts, feelings, and experiences of their wait time for a two week duration while waiting for surgery and return it at the second interview.

A final source of data comprised my field notes. In keeping with the reflective nature of a phenomenological study, I found it necessary to have a disciplined approach when considering my interactions with participants. After each interview, I reflected on my contact with the participant and noted my observations. In some cases, I recorded key issues from the interview

(eg, a participant's specific concern about waiting; a metaphor used to describe time experience). These notes also provided the opportunity to document non-verbal aspects of our interactions, such as, my perception of the demeanour or attitude of the participant. If the participant appeared introverted, for instance, I would make a remark to guard against 'over talking' him or her. These notes proved to be an invaluable tool in helping me continue to 'know' the participants from one interview to the next. They also documented my initial impressions of the interviews to compare with the written transcripts. By the time the real work of the analysis began, my notes allowed me to still 'visualize' each of my participants.

### 3.4 PROCEDURE

The research proposal including the consent form (see Appendix D) was submitted for ethical review and approved by the University of Saskatchewan Advisory Committee on Ethics in Behavioural Science Research prior to the commencement of the study (see Appendix E). Since participant recruitment and data gathering occurred at Saskatoon Health Region sites (primarily Royal University Hospital, RUH), operational approval for the study was also obtained from the Saskatoon Health Region.

Recruitment began in September of 2009 and the final interview took place the end of November 2010. Five surgeons, three orthopaedic and two cardiac surgeons, agreed to assist with patient recruitment. Patients were told about the study at visits with their surgeons. The surgeons contacted me with names of those patients who expressed interest in participation. The orthopaedic surgeons told eligible patients about the study, and if patients expressed interest, the surgeon then contacted me with their name and phone number. In some cases, the potential participant was being seen in the orthopaedic outpatient clinic, and I could obtain his or her

consent and conduct the interview on the same day. In other cases, and for the majority of the participants who were awaiting cardiac surgery, informed consent was read and explained prior to the first interview via telephone and the consent form was signed when I met the participant in person at the second interview. Initial consent was obtained by the cardiac surgery secretary when she booked the patients for surgery. She informed potential participants about the study and if the patients were interested, she passed their contact information to me.

The goal was to complete two in-person and/or telephone interviews with each participant. Those patients awaiting scheduled hip or knee replacement surgery or shoulder surgery were interviewed usually within a week of when the decision to treat was made (ie, the patient’s appointment with the specialist) and again at the midpoint of their waiting period. Generally, participants from the cardiac surgery group were interviewed within a week of their angiography and consent to surgery and again the day prior to surgery. See Table 3.1 for a description of the wait times between the two interviews for participants awaiting the three surgery types.

Table 3.1 Surgery Wait Times In Days Between Interviews By Surgery Type

<b>Surgery Type</b>	<b>Minimum-Maximum</b>	<b>Mode</b>	<b>Median</b>	<b>Mean</b>
Cardiac	3-60	7	6.5	15.1
Hip/knee replacement	41-218	91	105.5	108
Shoulder	70-147	103	101	106.8

Table 3.1 is a reflection of the number of days between participant interviews and a proximate measure of how long participants were waiting for surgery. For participants awaiting cardiac surgery, there was typically one week between their notification of a surgery date and

completing the first interview and the second interview which invariably took place the day before surgery at their preoperative assessment. One participant awaiting cardiac surgery had asked for her surgery date to be postponed past the holiday season, and therefore, the interval between her interviews was much longer. Second interviews for participants in the two orthopaedic groups usually took place about 90 days after they knew they would be having surgery. In the group awaiting hip or knee replacement surgery, notable exceptions to these typical intervals were one participant awaiting hip replacement surgery who requested an earlier interview due to the holiday season (41 days) and one participant who asked to be put on the list a year and a half in advance (218 days). The intervals between interviews for the group awaiting shoulder surgery were similar except for the minimum (70 days) and maximum (147 days). In these cases participants requested interviews at certain times to accommodate holidays.

Efforts were made to have at least one in-person interview with each participant. For four participants awaiting orthopaedic surgery (two awaiting hip or knee replacement surgery and two awaiting shoulder surgery) only telephone interviews were conducted. I was able to meet and consent three of these participants in the outpatient clinic, but they were unable to stay for an in-person interview at that time. I did not meet the remaining rural male participant who was awaiting shoulder surgery; he mailed his consent prior to the telephone interviews. Table 3.2 describes the interview setting for participants from each surgery group.

Table 3.2 Interview Setting by Surgery Type and Time of Interview

Surgery Type	Time of Interview	Interview Setting			
		RUH <sup>a</sup>	POAU <sup>b</sup>	Telephone	Home <sup>c</sup>
Cardiac	1 <sup>st</sup>	1	-	9	-
	2 <sup>nd</sup>	2	8	-	-
Hip/knee replacement	1 <sup>st</sup>	9	-	2	-
	2 <sup>nd</sup>	5	-	5	1
Shoulder	1 <sup>st</sup>	8	-	2	1
	2 <sup>nd</sup>	5	-	6	-

<sup>a</sup>my office space at RUH; <sup>b</sup>the preoperative assessment unit – relevant only for participants in the cardiac group; <sup>c</sup>I conducted interviews in the homes of two participants – one who lived in Regina, so I would have the opportunity to do an in-person interview, and one with an elderly participant during the winter months

As Table 3.2 indicates, 40 of the 64 interviews were involved in-person contact with the participant. While telephone interviews were the less preferred mode of data collection, they did provide better opportunities for participation from patients outside of Saskatoon and patients who were said they were too busy to come to the hospital to be interviewed. As compensation to those who did attend interviews at the hospital, \$10 was offered to cover parking costs.

At the beginning of each interview, I reminded participants that I was most interested in their individual experiences of wait time and that there could be no ‘wrong’ answers to my questions. All interviews were audiotaped. The duration of the interviews ranged from 15 minutes to 1 hour and 15 minutes. The (second) interviews with the participants awaiting cardiac surgery that occurred in the preoperative assessment unit tended to be the shorter interviews. The majority of all interviews lasted between 30 and 45 minutes. All second interviews were

generally shorter than the first interview because the interview guide contained fewer questions. For example, only potential changes in demographics and participants' conditions were probed in the second interview as opposed to the first interview where more comprehensive data were collected.

In terms of the procedure for the diary data collection, only two diaries were returned at the second interview. For most participants in the group awaiting cardiac surgery, the wait time between the first and second interviews was less than two weeks. Therefore, this method of data collection was not feasible, and no diaries were distributed. Also, participants who completed their first interview via telephone frequently declined interest in completing the diary. Of the six participants who agreed to complete the diary, only two female participants, one awaiting shoulder surgery and one awaiting hip replacement surgery, returned their diaries. These data were compared to the transcript data for each participant for commonalities and differences. The diary data was a close reiteration of the transcript data for these participants. The diary had been offered as an optional component of participation in the study. Presenting this aspect of data collection as an option may have diminished participants' interest in completing a diary.

As data were collected, interview transcription was ongoing. For the first six interviews, I transcribed the interviews to get a better sense of how the interview process was unfolding (eg, did I need to make adjustments to my interviewing style; did my written notes during the interview match what I heard in the audiotape). Thus, transcribing the initial interviews involved a form of interpretation on my part. The remaining interviews were transcribed by two experienced medical secretaries. Each was instructed to conduct verbatim translation of the interviews, including pauses, laughter and other background noises. The interview transcripts

were formatted according to each speaker and periodic time notes were made to ease content review. Transcription is part of the interpretative process and reflects the co-construction of the interview experience between the interviewer and interviewee (95). Moreover, this interpretative process was influenced by the standard medical interview format provided by my transcribers. I reviewed each transcript for completeness and accuracy.

### 3.5 DATA ANALYSIS

In keeping with the interpretative phenomenological method of the study, Interpretative Phenomenological Analysis (IPA) was used to analyse the transcript data. The process for data analysis was derived from the six step description of IPA. These steps include: 1) reading and re-reading the transcript 2) taking initial notes 3) developing initial themes 4) searching for connections among emergent themes 5) moving to the next case 6) looking for patterns across cases. A typical IPA study (1,92) has a smaller sample size in order to encourage idiographic analysis. While some IPA research has used larger numbers of participants or transcripts (92), most researchers tend towards smaller sample sizes. Therefore, I approached the analysis in a compartmentalized manner (see Table 3.3). Not only did this compartmentalized approach make the analysis of 64 transcripts more manageable, it also made intergroup comparisons more easily apparent. Thus, the IPA steps were adapted to suit the nature of the study (three distinct groups, 32 participants, interviewed on two separate occasions, 64 transcripts).

After all the individual transcripts were read and general notes were made on prevailing meanings within each interview (Table 3.3 – Analysis A; IPA steps 1 and 2), separate subsections of the interviews were analyzed according to interview time and patient group (Table 3.3 – Analyses B, C, D). Initial themes were developed for each participant in each section of the

interview (IPA step 3), and then connections were made within each participant’s transcript (IPA step 4) and between participants within the patient group (IPA steps 5 and 6). All first interview transcripts and second interview transcripts were evaluated together (Table 3.3 – Analyses E, F). Essentially, each of Analyses B, C and D outlined in Table 3.3 reflect three individual analyses: participant experience of time while waiting, participant perspective of maximum acceptable wait time and effects of waiting.

Table 3.3 Overview of Analyses of the Transcript Data

<b>Analysis</b>	<b>Description of Participant Transcripts</b>	<b>Number of Participants</b>	<b>Number of Interview Transcripts</b>
A	All Participants at both Interview times	32	64
B	Total Participants awaiting Hip/Knee surgery at both Interview times	11	22
C	Total Participants awaiting Shoulder surgery at both Interview times	11	22
D	Total Participants awaiting Cardiac surgery at both IV times	10	20
E	All Groups at Time 1	32	32
F	All Groups at Time 2	32	32

In order to describe the analysis in a more specific way, I will explain how a particular analysis, participant experience of waiting effects, was accomplished in greater detail. Since I housed all my data in NVivo, a computer software program designed to assist with qualitative analysis, I created transcript portions from sections of the interview (ie, nodes) related to participant descriptions of their experiences of the effects of waiting. In the first interview, participants were asked to share what their wait time had been like while waiting to see the

specialist, and when necessary, they were further prompted to describe specific impacts, if any, on day to day activities, mobility, pain, effects on family and social life. Similarly, in the second interview, participants shared their perspectives on the effects of waiting since being placed on the waiting list. From these responses NVivo was used to gather the three patient groups into the two interview times and create six separate nodes. Once these nodes were aggregated, hard copies were printed, the combined transcript sections were read, and initial noting was made. The formation of these nodes encouraged analysis of what was distinct about the individual (ie, the idiographic influence of IPA) and permitted a more direct examination of the commonalities within and across the participant groups at each interview period. NVivo has a note making function, however, I found it beneficial to make notes by hand and then re-enter them into the computer. That way I could keep stages of the analyses in folders to refer back to or print as needed. While other researchers may find NVivo's functions very helpful for analysis, I found NVivo put distance between me and the data. Paper format was a better way for me to view extracts from all three groups, make notes and highlight similarities and differences. Moreover, I had used a paper based format in past qualitative analysis of community based survey data. I kept a data analysis log of important decisions.

When transitioning from the initial noting step (2) to the development of emergent themes (step 3), I sought more concise representations of my notes. For example, the original notation: 'he advises other people not to be in a hurry as it makes you old quick' became the emergent theme 'carries on while waiting'. Once these themes were developed for each participant, I searched for connections among the emergent themes (step 4) for the participants awaiting hip or knee replacement surgery, and then I moved on to the transcripts of the participants from the other two groups and followed the same procedure. In some instances, emergent themes were

imminently obvious due to the consistency with which they appeared, such as ‘restriction related to waiting.’ Other themes represented a polarization, for example, waiting experience could be ‘uncertain’ for some and ‘certain’ for other participants. Once emergent themes had been identified within each of the participant groups, I moved on to steps 5 and 6 which allowed me to see commonalities and differences. In other words, I identified recurrent or dominant themes among the sample. Through this process, ‘carries on while waiting’ and other similar themes became the dominant theme of ‘resignation’. For the duration of the analysis and writing of the results, I maintained a journal of my reflections and observations of the process. This served as a further audit trail to my field notes.

### 3.5.1 Reporting the Results

The findings are organized in a series of subtitled sections that outline the themes and interpretations in detail. The quotations are verbatim from participant interview transcripts. In some quotations, notation is used (see Table 3.4).

Table 3.4 Transcript Notation for Quoting Participant Extracts

<b>Notation</b>	<b>Description of Transcript Notation</b>
...	Significant pause by participant
[ ]	Material omitted
[ <i>wait time</i> ]	Context added by researcher

Separate files were created with participant quotes that were particularly representative of each component of the dominant themes. Where possible, efforts were made to select illustrative quotes from each patient group and both interview times. In some cases, a particular theme did

not appear in all groups at both times. These commonalities and differences are noted in the next chapter.

IPA studies typically do not endeavour to quantify meanings of participant experiences (1,92,94,96). In accordance with the theory and method of the IPA approach, themes are reported using terms like “some” or “many”. As the principles of interpretative phenomenological analysis recognize, the findings are inextricably tied to the researcher’s perspectives, ideas, attitudes, and experiences. Wherever possible these perspectives are identified and acknowledged.

### 3.5.2 Validity and quality of the study

Smith and his colleagues refer to specific criteria for assessing the validity and quality of an IPA study and focus on four overarching principles (1). These principles, which are borrowed from Yardley (97), entail: a) sensitivity to context, b) commitment and rigour, c) transparency and coherence, and d) impact and importance. These concepts are important to qualitative research in general, and I will discuss how these principles are reflected in the present study.

#### 3.5.2.1 *Sensitivity to context*

Context can refer to the study’s socio-cultural milieu, the related literature and the empirical data. In this study, efforts were made to be sensitive to the background of the participants by collecting and considering demographic information. The literature review situated the ‘problem’ of waiting in a wider theoretical and social context. In demonstrating sensitivity to the empirical data, I have endeavoured to support my arguments directly with verbatim extracts from the participants. Also, by being aware of the context of my participants, I was better able to understand what shaped their waiting experiences. I had the opportunity to get

to know the context of participants by interviewing them twice. In other words, I could get to know more about their lives in addition to their presenting health concern and their waiting experiences. For example, one male participant awaiting shoulder surgery described in each interview how his experience mirrored the opinion of host of a local radio station. I determined that his experience was influenced by the context in which he was situated. In this sense, I exercised reflexivity regarding the participants in my study.

#### *3.5.2.2 Commitment and rigour*

Commitment can be demonstrated by the skills of the researcher during data collection, while rigour is illustrated by the overall thoroughness of the study. I was fortunate that I had considerable experience with patient interviewing and felt I was able to establish rapport with participants. Moreover, I followed media reports of wait times and attended a national conference on waiting in healthcare. In other words, I was immersed in my research topic. In terms of the study's rigour, the appropriateness of the sample, the quality of the data, and the completeness of analysis are considered. My sample did comprise patients who were experiencing the phenomenon of waiting, and I was able to complete two interviews with each participant. The setting of the second interviews with most participants awaiting cardiac surgery was not ideal – the postoperative assessment unit and its many distractions is perhaps not the best place to conduct a phenomenological interview. These interviews tended to be briefer than other in person or telephone interviews. Regarding the completeness of the analysis, at least one extract from each participant was provided as an illustration for a theme. Efforts were made to maintain the idiographic aspects of IPA while using the technique to discover intergroup differences.

### *3.5.2.3 Transparency and coherence*

The stages of the research process are described in the previous sections. Transparency refers to the degree of clarity of this description. Coherence of the study applies to how the theory and method fit together and how the findings answer the research question. Essentially, as an IPA study, this inquiry should illustrate my attempts as a researcher to make sense of my participants' experience. In addition, I reflected on my abilities and shortcomings as a researcher. For example, I noted in my research journal a particular experience with one participant where my personal beliefs on an unrelated topic contrasted radically with a view raised by the participant. The topic was raised at the end of the interview by the participant and I recognized I struggled to keep my own view to myself. At the participant's second interview, I noted I was more reserved than I had been our first meeting. Again, at end of the second interview, the participant raised the same topic. The topic was not in any way related to any of our discussion of the participant's wait time experience. At this time, due to my discomfort, I changed the direction of the conversation, thanked the participant for participating, and hurriedly showed the participant out of the interview room. While doing the analysis, I was reminded of these unpleasant encounters with this participant and I struggled with including the participant's experiences. I realized I was influenced by our contrasting views on this outside issue. Nevertheless, in keeping with IPA's need for inclusion of experiences, I did incorporate this participant in the reporting phase. Noting these experiences assisted in my understanding of my own perspective as a researcher and helped me to reflect on my own views as an individual.

### *3.5.2.4 Impact and importance*

In my attempt to impact how waiting is understood, I reflected on how to best present these findings to policy makers, practitioners and patients. Thus, the final test of validity lies with the

ultimate question: why should we care? Will this study make a contribution to the theoretical understanding of waiting? Does this research have practical application for policy makers, practitioners and patients? Such questions have implications for how the findings are influenced by their audience. These questions are deliberated in the following chapters.

## 4 Results

### 4.1 STUDY SAMPLE

In total, 32 patients completed both interviews and were included in the analysis. While 40 patients had completed the first interview, eight participants did not complete the second interview for the following reasons: four patients, three awaiting cardiac surgery and one awaiting knee replacement surgery, had surgery before they could be interviewed for the second time; two participants who were awaiting hip or knee replacement surgery withdrew from the waiting list; one participant awaiting cardiac surgery postponed surgery past the end of the study period; and one participant awaiting hip replacement surgery was lost due to follow-up. These participants were not included in the study as only partial data were available.

Table 4.1 describes the background characteristics of the participants who completed both interviews. As the table indicates, most participants were married or were living as married. The majority of participants lived in one of the two main urban areas in the province (Saskatoon or Regina) or in a rural part of the province. If participants lived in a nonurban area, as defined by residence in a place of population less than 5,000, they were considered to be rural residents. Small urban centres were identified as having population between 5,000 and 100,000. These population parameters were adapted from Statistics Canada definitions (98). There was a difference in highest level of education between males and females in the sample, with more females having greater than high school education than males. Almost half of the participants were retired, compared to less than half of the participants holding full-time employment status. The number of participants of retirement age (ie, 65 or older) was highest in the group awaiting cardiac surgery (n=8), whereas the group of participants awaiting shoulder surgery had only one

participant who was retired. The aim of recruitment was to enrol 10 participants in each of the three surgical groups, with roughly equal numbers of male and female participants. The sample size of the study is discussed in greater detail in the data analysis section.

Table 4.1 Background Characteristics of Participants

	<b>Men, n = 16</b>	<b>Women, n = 16</b>
<b>Age</b>		
Median	59.5	62.5
Minimum-maximum	43-81	43-89
<b>Marital Status</b>		
Married, or living as married	13	10
Divorced	2	2
Widowed	1	4
<b>Residence</b>		
Urban	9	6
Small urban	-	4
Rural	7	6
<b>Highest level of education</b>		
Some high school or less	4	3
Graduated high school	7	2
Some trade/vocational/technical training	4	2
Certificate or diploma below Bachelor's level	1	4
Some university	-	2
Bachelor's level or above	-	3

	<b>Men, n = 16</b>	<b>Women, n = 16</b>
<b>Employment status</b>		
Employed full-time	5	2
Employed part-time	-	2
Self-employed	3	1
Retired	6	9
Other (eg, disability, unemployed)	2	2
<b>Type of surgery</b>		
Cardiac	6	4
Hip/Knee	4	7
Shoulder	6	5

Participants were also asked their ethnicity or cultural group. The responses to this question were uniform for the entire sample. That is, all participants indicated they were “not a visible minority”. The median age for the entire sample was 60 years. Median age among participants awaiting cardiac surgery was 68 years and age range was 43-81. The group awaiting hip or knee replacement surgery had a median age of 62.5 years and their ages ranged from 56-89. The participants awaiting shoulder surgery tended to be younger with median age of 54.5 years and a range between 43 and 71. Table 4.2 assigns pseudonyms to each participant and contains participant approximate age and sex by surgery type.

Table 4.2 Pseudonym, Sex and Approximate Age of Participants by Surgery Type

<b>Participant Pseudonym (sex)</b>	<b>Cardiac</b>	<b>Hip/Knee</b>	<b>Shoulder</b>
Lee (m)	Early 40s		
Paul (m)	Early 60s		
Shelley (f)	Mid 60s		
Arnold (m)	Late 60s		
Alice (f)	Late 60s		
Brian (m)	Late 60s		
Diane (f)	Early 70s		
Hillary (f)	Late 70s		
Rolland (m)	Late 70s		
Samuel (m)	Early 80s		
Nora (f)		Mid 50s	
Jack (m)		Late 50s	
Lionel (m)		Late 50s	
Joan (f)		Late 50s	
Candice (f)		Early 60s	
Mary (f)		Early 60s	
Myron (m)		Mid 60s	
Beatrice (f)		Early 70s	
Lorraine (f)		Mid 70s	
Frank (m)		Early 80s	
Elsie (f)		Late 80s	
Wanda (f)			Early 40s
Dale (m)			Late 40s

<b>Participant Pseudonym (sex)</b>	<b>Cardiac</b>	<b>Hip/Knee</b>	<b>Shoulder</b>
Greg (m)			Late 40s
Ray (m)			Late 40s
Peter (m)			Early 50s
Ruth (f)			Early 50s
Tina (f)			Mid 50s
Felicia (f)			Late 50s
Darryl (m)			Late 50s
Gerry (m)			Early 60s
Kathy (f)			Early 70s

The median age of the female participants was slightly higher than the median age for the male participants (62.5 years v. 59.5 years). Age of both male and female participants varied widely; 43-81 years for males, 43-89 years for females. As Table 4.2 suggests, the majority of the sample was in their 50s or 60s.

## 4.2 FINDINGS

The results are presented in three main sections according to the principal objectives of the study: the experience of time while waiting for consultation and surgery, the perception of maximum acceptable wait time for the patient's consultation or surgery and other similar procedures, and the patient's experience of the effects of waiting for consultation and surgery. Table 4.3 provides a synopsis of the findings according to each study objective. Each research objective is divided into the dominant themes that emerged when these three topics were discussed by participants. In some instances, the dominant themes were comprised of particular components

and these are discussed in subsections of the dominant theme. As Table 4.3 indicates, I found three dominant themes when I analysed participant experiences of time while waiting and their perspectives on wait time tolerance (MAWT) and five dominant themes when I examined participant reports of the effects of waiting.

Table 4.3 Overview of Results by Study Objective, Dominant Themes and Components

<b>Study Objectives</b>	<b>Dominant Themes</b>	<b>Components of Dominant Themes</b>
Time while Waiting	Time Drags	More suffering
		Less meaningfulness
		Less agency
	Time Flies	Less suffering/better coping
		Greater meaningfulness
		More agency
	Time Goes On	Less suffering/better coping
		Greater meaningfulness
		More agency
Maximum Acceptable Wait Time (MAWT)	Suffering	Pain
		Mobility restriction
		Deterioration of condition
	Resignation	Wait your turn
		Beyond your control
	Lethality	Contingent upon surgery type

<b>Study Objectives</b>	<b>Dominant Themes</b>	<b>Components of Dominant Themes</b>
Effects of Waiting	Restriction	Pain
		Role
		Mobility
	Uncertainty	Place on list
		Condition in future
		Meets expectation
	Resignation	Places waiting in healthcare context
		Distraction
	Coping with waiting	Downward comparison
		Social support
		Prepare for procedure
	Opportunity	Possibility to ‘use’ time

In general, these dominant themes were present for all three patient groups at each interview time. There were some exceptions. Some themes were more characteristic of certain groups. These exceptions are noted in subsections outlining each dominant theme and component. In accordance with the majority of IPA literature, I have not assigned numeric values to themes. Like other IPA authors who desire to reflect the idiographic nature of the data, I discuss the results in a qualitative manner using words rather than numbers to reflect frequency. For example, “many” is more than “several”, several is more than “some”, some is more than “few”.

#### 4.3 TIME WHILE WAITING

In the first interview, participants were asked about their experience of time while waiting for consultation with their surgeon. The second interview presented similar questions about

participants’ time experience since they had been waiting for surgery. In general, for participants in the three patient groups at both interview periods, the experience of time while waiting could be understood primarily according to lived duration. That is, participants responded to questions about time by articulating how long time had felt to them. Several participants described the duration of time while they waited as “dragging”. Some participants portrayed wait time as “flying by”. Many participants experienced wait time as the same as any other time, in other words, time “goes on”. These three experiences of time while waiting: “time drags”, “time flies”, or “time goes on”, were connected to three additional components. First, the degree of physical discomfort and emotional distress impacted how time was experienced while waiting. How effectively participants coped with this suffering was a related component of lived wait time duration. Second, the meaningfulness that could be connected to their wait time affected participants’ perceptions of time duration. Meaningfulness was associated with the ability of the participants to extract value from their wait time versus a perception that time was lost or wasted while waiting. Third, the amount of agency (ie, personal control) they felt over their time influenced how wait time’s duration was experienced. In the following sections, participant experiences of wait time duration are examined using these three concepts (see Table 4.4).

Table 4.4 Participant Experiences of Lived Wait Time Duration

<b>Lived Wait Time Duration</b>	<b>Associations with Lived Duration</b>		
	<b>Suffering/coping</b>	<b>Meaningfulness</b>	<b>Agency</b>
Time Drags	Increased/decreased	Decreased	Decreased
Time Flies	Decreased/increased	Increased	Increased
Time Goes On	Decreased/increased	Increased	Increased

#### 4.3.1 Time Drags

Many participants who awaited either hip or knee replacement surgery or shoulder surgery, (ie, those in the two orthopaedic surgery groups), described time as “long”, “slow” or “dragging” at both interview periods. For the participants awaiting orthopaedic surgery, a description of protracted wait time was often more common at their second interview than their first interview. While protracted wait time experience was somewhat typical among participants awaiting orthopaedic surgery, relatively few participants awaiting cardiac surgery described an experience of slow wait time.

As Table 4.4 suggests, there was a connection between protracted lived wait time duration and increased suffering, lack of meaningfulness, and less agency. Each of these relationships is discussed in the following sections.

##### 4.3.1.1 *Time Drags with Suffering*

Several participants referred to the physical discomfort and/or the emotional distress produced by their health condition. For some of these participants, physical and emotional suffering led to a prolonged experience of time while waiting. Nora, a participant awaiting hip replacement surgery, drew a clear link between the physical discomfort of pain and protracted wait time. In this quotation, she also noted how her experience of the passage of time corresponded with greater pain:

I was going to say that the time is passing quite slowly and one of the reasons for that is the pain – the pain as time has gone by the pain has increased, the hip has become more unstable and um I have had to go into my doctor several different times to try different types of pain medication to try and alleviate the pain...I guess it depends on the pain experience. If you are not having a lot of pain or it is intermittent and I think you could probably cope with it a little better but um, um, it just seems like a long – it is still a long journey. (Nora, late 50s, awaiting hip replacement surgery, second interview)

Not only did time pass slowly due to the presence of pain, but Nora's pain increased with time. The result was wait time experienced as a "long journey". Journeys tend to have a direction and a destination. Nora's journey had been particularly arduous due to her repeated trips seeking pain relief.

Pain appeared to act as an activity restrictor that prolonged wait time duration. A few participants made the association between pain, restriction and time dragging. For instance, Candice, who was awaiting knee replacement surgery, experienced leisure activity restrictions as a result of pain and felt like time had "dragged":

The time has felt as though it has dragged for a couple of years for me. It has limited travel, it has limited things that I would do for enjoyment and pleasure and it is due to the pain that goes with waiting. (Candice, early 60s, awaiting knee replacement surgery, second interview)

Candice described a protracted time experience that began prior to her presence on the 'official' wait list for surgery. Her limitations had encumbered her experience of time.

For those participants who experienced long wait time, physical discomfort and activity restriction were often coupled with mental distress. Some participants found the activity restriction itself frustrating, while others felt the uncertainty of wait time duration was unsettling. Two participants awaiting shoulder surgery expressed particular dissatisfaction. Dale was frustrated by his restrictions; Gerry was distressed by a sense of uncertainty and powerlessness. Each reported a protracted experience of time while waiting:

It's been a long time. It has been frustrating for a lot of reasons, like I say a lot of the things that I like to do, you just have to either do just a little bit of it or not at all. (Dale, late 40s, awaiting shoulder surgery, second interview)

It seems quite long and when I phone to try and find some information, where I was on the list or whatever, they just told me I would receive information when I received it. That was basically the answer. Um, it is starting to get me a little more upset now because I am experiencing more pain in the arm and the shoulder area so I would like to get it over with ... There is nothing for you to do but sit and you just wait and you get frustrated. (Gerry, early 60s, awaiting shoulder surgery, second interview)

The powerlessness that Gerry described relates to another basis for a protracted experience of time – lack of agency. The relationship between lack of agency and prolonged lived wait time duration will be discussed in section 4.3.1.3.

#### *4.3.1.2 Time Drags with Lack of Meaningfulness*

For some participants, waiting for consultation and scheduled surgery meant their normal roles and activities were disrupted. This disruption influenced some participants' identity and self-worth to the extent that their lives lacked their usual meaningfulness and protracted their experience of wait time. When time lacks meaning, it is likely to be experienced as 'wasted.'

In the following extract, Francine expressed her concerns over her role restrictions and the impact these limitations had on her family:

Oh, [*time is*] very long. I feel very useless...it's tough. Each day seems like a century because it's all the no's, the negatives rather than any positives. [ ] My husband does 90% of the work at home and that's not fair. (Francine, late 50s, awaiting shoulder surgery, first interview)

The constraints Francine experienced turned each day into a “century”. The longest ‘unit’ of time that any participant made reference to was a century – an amount of time that was not experienced chronologically. The limitations Francine experienced had an impact on her perception of time, altered her sense of self worth, and affected her relationships. Similarly, Nora, who was unable to work while she awaited consultation, struggled to find meaning in her new restricted role:

It was short [*the actual wait time to see the specialist*] but it’s when you can’t do anything. Like I said I make supper for my husband and I do the laundry, um, I have a housekeeper who does my cleaning, but I mean the time goes very slowly. It’s boring, it’s, I mean you tend to think about things too much [ ] I mean some people think ‘oh it would be just so wonderful to be off work and get to be at home’ and it would be if you could go and do the things that you wanted to do. But I mean it is not much fun sitting around just waiting for the hours to go by. (Nora, mid 50s, awaiting hip replacement surgery, first interview)

In Nora’s experience, despite a relatively short wait time for consultation with the specialist, time was passing very slowly. For Nora, time slowed as she was bored with her limited lifestyle. Her implication was she would rather have the ability to do things than be placed in the position to “think about things too much”. She rejected the notion that her experience of being off work might be perceived as “fun”. Instead, her life consisted of “just waiting for the hours to go by”.

It was difficult for these participants to find wait time meaningful when their activities decreased or their roles changed. Wait time lacked meaningfulness when physical restrictions impinged upon the ability of participants to fulfill normal role functions. When regular work and family activities were disrupted, time was experienced more slowly.

#### 4.3.1.3 *Time Drags with Less Agency*

When participants felt they lacked control over waiting, time dragged. The experience of protracted wait time was filled with uncertainty – common concerns were: when would surgery happen? What would the outcome of surgery be? What plans could be made in the meantime? As participants voiced their anxieties about waiting, it was clear they did not have a sense of agency or control over their wait time. In the following extract, Shelley, who was awaiting cardiac surgery, expressed a strong desire to know her surgery date. In describing how waiting was “long enough”, she connected her “antsy” feeling with the prospect of having her surgery at an unwelcome and inconvenient time:

Yeh, yeh, not terribly long, but long enough I was getting antsy, like it is getting close to the end of the month, [*the surgeon’s office*] hasn’t called me you know so. And I didn’t want to do it during [*particular month*], you know I have kids that live away and I know they are going to be there, you know – but I didn’t want it in [*particular month*] either. I wanted it done now, finished, over with, you know. (Shelley, mid 60s, awaiting cardiac surgery, first interview)

For Shelley, timing of her surgery was important due to family concerns and her personal well being. Similar to Shelley’s experience of time while waiting, when other participants focused on the uncertainty of their surgery date, time dragged. Participants were anxious to have surgery completed. Anxiety and frustration contributed to a sense of urgency for these participants who were awaiting shoulder surgery:

Once you are going to find out that you’re going to have surgery then it gets god damn aggravating and long drawn out waiting for it. Not that I am scared of it, I could give a shit, I would have it tomorrow but it is just you can’t do nothing. You can’t work properly, you can’t plan nothing. (Peter, early 50s, awaiting shoulder surgery, second interview)

Waiting is so long, is it going to be, is the surgery going to be ok now, like is it going to be the same kind, is there going to be something there to pin?  
(Francine, late 50s, awaiting shoulder surgery, second interview)

Both Peter and Francine experienced long drawn out wait time and each lacked a sense of agency over their wait time. Peter was incensed by his lack of control over work and his inability to make plans. Francine was very anxious about the prospect of further deterioration of her condition while waiting which in her view could lead to a poor surgical outcome.

For participants who experienced time dragging, lack of agency over wait time decelerated time duration. Lack of agency was related to the uncertainty of actual wait time duration and insecurity regarding the surgical outcome. When these participants felt a lack of agency, they also expressed anxiety and frustration.

#### 4.3.2 Time Flies

The subjective wait time experience of “time flying” was less typical of participants awaiting consultation and surgery than the experience of time dragging. Yet, the experience of “time flies” was evident in all three patient groups at both interview times and was more common for participants awaiting cardiac surgery. A swift passage of time usually corresponded with less suffering, greater meaningfulness and a higher level of agency. The relationships between participants’ accelerated experiences of wait time and degrees of suffering, meaningfulness and agency are outlined in the sections below.

##### 4.3.2.1 *Time Flies with Less Suffering*

The experience of accelerated wait time could be explained in part by the participant’s degree of suffering. For example, when participants described time as passing quickly, they

would often connect that experience to the absence of pain or anxiety. Awaiting consultation with the surgeon went quickly for Ray because he did not experience pain. He described the time as “it hasn’t been a bad ordeal” and dismissed any functional difficulties:

[*Time*] has gone by quickly I think and it hasn’t been a bad ordeal because I am not really – I don’t really have any pain of any sort to speak of, I just don’t function right so, so it hasn’t been awful. (Ray, late 40s, awaiting shoulder surgery, first interview)

In Ray’s case, wait time passed quickly because his level of suffering was minimal.

Alice attributed time passing quickly to her lack of stress about the outcome of her surgery and keeping busy. My second interview with Alice occurred the day before her surgery, approximately six weeks after her first interview. When asked about what time had been like since we last met, she said:

Short, short, seems like I saw [*Interviewer*] just last week, short...I think it is because I don’t feel stressed out most of the time and I always keep myself busy and I am not anxious about dying, I am not. (Alice, late 60s, awaiting cardiac surgery, second interview)

Accelerated wait time duration, parallel to protracted wait time duration, was related to the participant’s degree of suffering. Less pain and stress meant time passed more quickly. Alice also remarked on keeping herself busy which may have reflected her ability to find meaning in wait time. The relationship between meaningfulness and accelerated wait time is discussed in the next section.

#### 4.3.2.2 *Time Flies with Greater Meaningfulness*

The quick passage of time seemed to connect with the participant's state of well-being and capacity to find meaningfulness while waiting. A prime example was Alice who described her experience of time passing quickly as concomitant with contentment:

[*Time*] passes fast for me, really fast because I am pretty contented, not happy but I am contented, and I am always very tired and I must be dropping off in between doing things, no, time passes fast...I have very pleasant dreams...I think when I sit by the computer my thoughts wander off and I am not aware of time. It is going fast. (Alice, late 60s, awaiting cardiac surgery, first interview)

Although her physical condition caused activity restriction, Alice's experience of time was most affected by her state of contentment. Instead, she viewed her limitations as an opportunity for patience:

What has it felt like? I felt like in my physical movements and tiredness, I just feel so tired. I might go to sleep and not wake up...I felt hindered actually, hindered at what I wanted to do, restricted and going outside, I love to work in the garden and walk my dog longer than I do, I go out every day for a half an hour but I would like to be out there more than I do now. So time again though, according to what I hear.

Interviewer: So what has that done to your feelings about time, how has time felt?

[*My condition*] is teaching me patience which I don't have much of in some things. And if you can't change it then do your fitness the best you can, that is another thing you have to learn to put up with it until something gets done. (Alice, late 60s, awaiting cardiac surgery, first interview)

In the above passage, Alice expressed resignation to her limitations and to waiting for surgery. Her focus was on what she could do and learning from her limitations. She was able to find meaningfulness in her remaining abilities.

#### 4.3.2.3 *Time Flies with More Agency*

A higher level of agency was associated with the experience of an accelerated duration of wait time. When participants felt they had greater control over their time, they portrayed their experience of time as “flying by”. For instance, Lee, in the following passage, described time passing quickly despite the restrictions he faced as a result of his condition – that is, he was off work and unable to drive:

It's really fast, really quick. Everything is happening, the days are going by quickly, ummm, I am not having a lot of time to sit down and relax type thing. Like I am keeping quite busy and there is things to be done. The kids are out of school so it is time to spend as much as I can. I am not driving anywhere. Still keeping busy and active and, um, the days are flying by...my days go by really quick. They seem that they go by quicker now then they did ever before. Yup, I don't know why. And not being at work you would think days would drag especially when I can't go out and drive, but I am not going on a holiday anywhere and do stuff like that and, um, not doing any real heavy activities. Like the days do go by quickly. (Lee, early 40s, awaiting cardiac surgery, first interview)

By Lee's own choice, waiting involved hyper-activity. He kept busy and took the opportunity to spend time with his children. His decision to fill his time made his days go by very quickly, though he did not articulate that connection between busy time and quick time himself.

Another participant, Lionel, employed a form of temporal agency which rendered his experience of wait time shorter than the actual wait time. He described this temporal phenomenon in the next passage:

The older you get the time flies faster. There is a lot of stuff that you know you think you should have done in that time frame but the time just seems to go by and it's – I still picture, remember when it [*injury to hip*] happened so it doesn't seem like that long ago. (Lionel, late 50s, awaiting hip replacement, first interview)

When Lionel imagined the point in time where he injured his hip and compared the interval to the present, time seemed to have passed quickly for him. He made this comparison in an agentic way. He set his experience within the context of aging, where to him, time flies.

A comparable approach to having wait time pass more quickly was employed by another participant awaiting hip replacement surgery. In this extract, Joan discussed how she consciously manipulated her perception of wait time in order to make it seem more manageable:

Sometimes you think there is six months, or two seasons to change, and I will have my hip. Like you make it a short span by two seasons instead of 100 days of pain. (Joan, late 50s, awaiting hip replacement, second interview)

Rather than contemplating her wait time as six months (ie, 100 days), Joan considered two seasons of waiting. Joan exercised temporal agency to accelerate her perception of time. Participants experienced time passing more quickly when they practiced these specific strategies. Keeping busy and re-thinking time helped to accelerate wait time.

#### 4.3.3 Time Goes On

Waiting did not appear to have a substantial impact on time's duration for some participants. Indeed, it was time 'as usual' for these participants. While this experience of wait time was less typical than protracted or accelerated time duration, this theme did appear in all three patient groups at both interview times. Time seemed to 'go on' for these participants

because they experienced less suffering or were better able to cope with suffering. As participants found wait time to be meaningful, they perceived time to continue on as it normally would. Having a sense of agency over their time also enabled participants to experience time in a regular way. These connections between ‘usual’ time experience and less suffering, greater meaningfulness and more agency are described below.

#### *4.3.3.1 Time Goes On with Less Suffering*

For some participants, when their level of suffering was less acute, their experience of time while waiting passed undisturbed. These participants reported “not thinking about waiting” and waiting “not making any difference”. One participant awaiting cardiac surgery, Samuel, said his mind was not usually on his health as he went about his normal routine. In the following extract, another participant awaiting shoulder surgery placed his suffering in a larger social context:

Time just goes on [*laughs*]. I can accept the waits you know because as the baby boomers, you have seen it, more can happen to you, as the baby boomers get older and I just accept that if somebody needs it worse than I am, then they should be first. I can live with it if somebody needs it, really needs it done, I can live with it. (Darryl, late 50s, awaiting shoulder surgery, second interview)

Darryl considered demographic influences on waiting – aging baby boomers mean increased wait time. By contrasting his own level of need to another person who “really needs it done”, the comparison generates acceptance of his wait time. For Darryl, time goes on because he considered his own suffering in relation to others. Time went on because waiting was to be expected and he was not experiencing great distress.

Another participant talked about how life goes on normally because her experience of pain had diminished with treatment:

I think life is pretty much going on as normal. Before this cortisone shot it was excruciating, it was hard to get through the day. I couldn't sleep...but since that shot you find yourself wondering do I really need the surgery, but the answer is yes...so getting twinges every now and again to remind me why I am on the list. (Tina, mid 50s, awaiting shoulder surgery, second interview)

Prior to receiving a cortisone shot, Tina found it difficult to “get through the day”. In other words, time dragged for her. Once she had treatment, life continued as normal and she experienced only intermittent pain which reminded her she was waiting for surgery.

Degree of suffering was a factor in participants' experience of time “as usual”. Participants who experienced a minimal amount of suffering felt their time and lives were continuing normally. Suffering did not disrupt time's duration for these participants.

#### 4.3.3.2 *Time Goes On with Greater Meaningfulness*

When participants found their wait time to be meaningful, they did not experience a disruption in their experience of time. For these participants, time was not confined by the wait for consultation or surgery. In Jack's case, he continued on with his life:

You know time goes on and you do the things you have to do. I mean you are not there sitting on the edge of your chair waiting...You go on with life pretty much, you just continue to go on with life. I do anyway... [*Time*] doesn't seem any different. (Jack, mid 50s, awaiting hip replacement surgery, first interview)

Jack discussed several limitations he experienced due to the condition of his hip such as his inability to walk, hike and enjoy time in the “bush”. His attitude was acceptance of his condition as something to be expected as a normal aging process. Jack's time was meaningful despite his limitations. At his second interview, he remarked:

It just doesn't seem any different to me, I mean, time goes on. I don't know how to explain it to you. You keep asking about what's the difference in time...I think I get progressively more disabled with time. I think that happens to a certain extent. As time goes on, you get older, you have more aches and pains, you have a little bit more issues as time goes on but that's an expectation that's normally there so you just accept it, you know. (Jack, mid 50s, awaiting hip replacement surgery, second interview)

Despite these restrictions, he made remarks in both interviews regarding waiting: "don't be in a hurry, you just get old quick". When asked what advice he would offer someone else waiting, he said: "don't think about the time, but just enjoy what you're doing right now". Time went on for Jack because he was able to find meaning in his daily activities. Waiting did not impinge on his experience of time.

The ability to find meaning or continue with usual meaningful activity during wait time had an impact on lived duration. When participants saw their lives as meaningful, time went on as usual.

#### 4.3.3.3 *Time Goes On with More Agency*

For some participants, life continued and time went on as usual when they exercised control over their daily activities. In these cases, waiting was not an issue and did not affect the participant's experience of time. Samuel, who was awaiting cardiac surgery, described how waiting has been like any other time:

Oh, [*waiting*] really hasn't been much different than any other time. When I had something to do I went and done it. Did our gardening, dug the garden, weeded the garden, watered the garden, cut the grass. So really it didn't affect me very much. (Samuel, early 80s, awaiting cardiac surgery, first interview)

Samuel had control over doing whatever he needed to do, thus wait time did not feel different for him than any other time. His sense of agency was connected to a regular passage of time. In a similar way, Beatrice, who had asked to be put on the wait list to have hip replacement surgery on her other hip, expresses her sense of agency and how it was associated with her experience of time:

Well, I am sort of that strange situation where I told them when I wanted to have it done and they said, well that's 14 months from now so we will put you on [*the waiting list*] then and so I am doing fine. Like I don't even want it now. You know it depends on how you deal with these things whether they are a problem or not. And this just isn't a problem for me...Like any other time. Really hasn't been anything one way or the other. I pretty much do what I want. (Beatrice, early 70s, awaiting hip replacement, second interview)

Beatrice asserted a problem with waiting would occur if she dealt with the situation differently. In the case of waiting for surgery, she did not view waiting as a problem, and therefore, her experience of time is "like any other time". She exercised agency over whether waiting became a problem for her. In the first interview, she had berated herself for not getting on the wait list for her first hip surgery more quickly. In her words, "I left it too long". She viewed herself as responsible for any negative effects of waiting.

A participant in a comparable situation was Jack, who also experienced time passing as usual due to his ability to find meaningfulness in his wait time. At a certain point, Jack was on a wait list for hip replacement surgery, and with advice of his doctor, decided to take himself off the wait list:

I was previously on a wait list, and the doctor and I chose at that time that we should come off and wait longer and so I'm back on again. I'm not anticipating it, I'm not saying when is it going to come, things like that. You know, it enters

your mind once in a while. I don't see any difference in the passing of the time. You go on with life, you have to. (Jack, mid 50s, awaiting hip replacement surgery, first interview)

As the thought of surgery entered his mind, Jack's life and his perception of time was not affected – his time and life went on. Jack expressed agency, the ability to control his experience of the passage of time.

A sense of agency was related to the experience of time 'as usual'. The perception of having control over daily activities was associated with lived wait time duration. When participants were in control of their activities and felt agency over their time, wait time was experienced as 'usual' time.

#### 4.3.4 Summary

For participants in this study, wait time dragged, flew by, or went on as usual. These differences in lived wait time duration were noted in each patient group at both interview times. In general, a protracted experience of time was more characteristic of participants in the two orthopaedic groups whereas accelerated time was often reported among participants in the cardiac group. The lived wait time experience of 'time goes on' was not more typical of participants in one group versus another.

The experience of time while waiting varied in duration according to participant suffering, the meaningfulness participants attached to the experience, and the agency participants felt they had over the waiting period. Protracted lived wait time duration was associated with greater levels of participant suffering, less meaningfulness derived from waiting experience, and a lower sense of temporal agency. Accelerated lived wait time duration and lived wait time that

continued as usual was described by participants who appeared to experience less suffering, more meaning and greater agency during waiting.

#### 4.4 MAXIMUM ACCEPTABLE WAIT TIMES

The maximum acceptable wait time (MAWT) for consultation and surgery for patients awaiting cardiac, shoulder and hip or knee replacement surgery was explored by asking participants their perception on the longest amount of time patients should have to wait. In the literature, this concept is assessed by having patients write in days, weeks or months their MAWT perceptions. When participants had the opportunity to respond to questions regarding their perceptions of maximum acceptable wait times for the three conditions in the study, their typical answer was not a number of days, weeks or months. Instead, when prompted by the open ended question format, participants set their perceptions of acceptable wait times within a context of patient suffering, resignation to waiting, and lethality of the condition. These three main themes comprised participant perceptions of the maximum length of time a patient should wait for surgery.

In general, some participants from all three groups considered pain, mobility restriction and deterioration of the condition (ie, patient suffering) to be the chief determinants of wait time limits for the two types of orthopaedic surgery. The second theme, the perception that one had to be resigned to wait, was articulated by a minority of participants; however, at least one participant from each group expressed this idea. The final theme related to participant perceptions of the critical nature of cardiac surgery. The themes and their components are contained in Table 4.5 and are discussed in the sections below. Although the MAWT questions were asked at each interview time, regarding consultation or surgery, participant responses to

these two sets of questions were highly similar. That is, whether the perception of MAWT was for consultation or surgery, the same three dominant themes emerged.

Table 4.5 Summary of Themes Regarding Maximum Acceptable Wait Times (MAWT)

<b>Theme</b>	<b>Component</b>
Suffering	Pain
	Mobility restriction
	Deterioration of condition
Resignation	Wait your turn
	Beyond your control
Lethality	Contingent upon surgery type

#### 4.4.1 Suffering

Many participants maintained that the extent of patient suffering should be the biggest determinant of maximum acceptable wait time (MAWT) for surgery. Participants considered suffering to be the main criterion for determining acceptable wait time for their own surgery and for the other two types of surgery in the study. Patient suffering was described by participants as the experience of pain, the presence of mobility restriction, and the overall deterioration of patient health status. Although there is overlap among these aspects of suffering, participant descriptions are presented in individual sections.

##### 4.4.1.1 Pain

Participants' perceptions of the level of pain experienced by patients were a dominant factor in determining maximum acceptable wait time (MAWT). Participants viewed patients

with acute pain as requiring shorter wait times. Rolland, who was awaiting cardiac surgery, clearly articulated this relationship between pain and MAWT for shoulder surgery:

I would say the threshold of pain he is suffering or she is suffering would be kind of the thing that would determine how fast you could get in...and the faster the better. (Rolland, late 70s, awaiting cardiac surgery, on MAWT for shoulder surgery)

From Rolland's perspective, "threshold of pain" was the main determinant of MAWT.

In the following extract, Elsie echoed the perspective that pain should determine MAWT.

However, she also noted the complexity of MAWT in terms of the healthcare system:

But I think it [*MAWT*] just depends on how sore it is, you can say that yours is sore, but maybe the other fellow's is more sore than yours. [ ] Some people don't have the pain so severe...you know...and others have even worse than I have. And, uh, but how are you going in, it's not fair that you only got your name on two weeks ago and...you know...you were taken for surgery and somebody's been waiting for so long. But their pain wasn't as bad, but who is going to find out whose is the worse [*laugh*]. (Elsie, late 80s, awaiting hip replacement surgery, on MAWT for hip replacement surgery)

In this passage, Elsie placed herself in the context with other patients who suffer from pain and must wait for surgery. She acknowledged her own pain may or may not be as acute as others' on the wait list. For Elsie, basing MAWT on severity of pain raised the issues of fairness to others on the wait list who may have to wait longer. In fast tracking patients who are in acute pain, Elsie recognized a challenge for healthcare providers to assess who is in greatest need.

#### 4.4.1.2 *Mobility Restriction*

Similar to patient level of pain, degree of mobility restriction was considered to be a significant determinant for MAWT. That is, the greater the restriction caused by the patient's

condition, the shorter the MAWT in the view of many participants. Wanda, who was awaiting shoulder surgery, contrasted MAWT of the two types of orthopaedic surgery:

You need to be able to be mobile right? This doesn't affect my mobility, it is just my shoulder. So I guess with the hip you would want to wait even less time.  
(Wanda, early 40s, awaiting shoulder surgery, on MAWT for hip replacement surgery)

Wanda minimized her need for a shorter wait time when she compared her status to someone waiting for hip replacement surgery. Relative to someone waiting for hip replacement with greater mobility restriction, she had the perception that it was “just my shoulder” and therefore, she felt it was acceptable for her wait time to be longer.

In the following passage, Nora, who was awaiting hip replacement surgery, expressed a similar sentiment regarding those waiting for shoulder surgery. Like Wanda, Nora agreed functional impairment was a vital element of MAWT. Determining acceptable wait time was a specific process for each patient:

Assess what the pain is and the impact on a daily life, um, I guess everybody is different. Do they live alone? Do they have help? Like I have help, I have my husband to help me, I have got my housekeeper um so I have lot of help I mean maybe it is an individual thing you just can't put a blanket statement on it. Sometimes you have to look at people's lives if it is somebody who is older and has nobody and their shoulder is all gibbled. I mean can they get dressed on their own?...Can they cook their meals? (Nora, mid 50s, awaiting hip replacement surgery, on MAWT for shoulder surgery)

Nora carefully considered several influences on MAWT – living arrangements, social support, patient age, ability to dress, ability to cook. She made these considerations in the context of her own situation – she had her husband and housekeeper to help her. From Nora's perspective, the

length of wait time should depend on whether a patient lacked support and struggled to maintain daily activities.

#### 4.4.1.3 *Deterioration*

For some participants, their chief concern was the potential for the deterioration of their condition while waiting. Speaking about MAWT for her own type of surgery, Wanda expressed uncertainty regarding the deterioration of her shoulder:

I don't know how much more damage is being done while I wait...I guess it is hard to say it just depends on what is actually happening physically to my injuries and if they are getting worse. (Wanda, early 40s, awaiting shoulder surgery, on MAWT for shoulder surgery)

Myron, who was awaiting hip replacement surgery, was more certain regarding the deterioration of his condition. He knew his gait was affected and feared the function of his knee would be aggravated as well:

The longer you go, the worse it gets, the more areas of your body become ravaged because of the fact that you're not walking normally, you know, and you start to throw your weight onto the other side. My worst fear is my knee starts to go, you know, and all you're doing is creating more problems. (Myron, mid 60s, awaiting hip replacement surgery, on MAWT for hip replacement surgery)

Myron wanted surgery to occur before he faced further physical decline. In his view, the maximum time to wait would not involve the exacerbation of his existing condition or the development of "more problems".

#### 4.4.2 *Resignation*

Although most participants considered the degree of patient suffering to be the most significant factor in their assessment of MAWT, other participants viewed wait time as

influenced by conditions of the healthcare system. These participants saw maximum wait times as a function of the system where waiting was to be expected. These participants felt waiting was beyond the control of patients. For instance, Greg, when asked to comment on the MAWT for his type of surgery, stated:

I guess because a guy is so used to the way the system works that you can accept the fact that you have to wait up to six months or maybe longer. (Greg, late 40s, awaiting shoulder surgery, on MAWT for shoulder surgery)

Greg was resigned to how “the system works” and accepted his wait may be as long as or longer than six months. Jack conveyed a similar view when discussing MAWT for his type of surgery, hip replacement surgery, and shoulder surgery:

It takes as long as it takes, that is how I feel about it. I think that you have to accept that other people are probably using the service and that they need it just as much or more than you. (Jack, late 50s, awaiting hip replacement surgery, on MAWT for hip replacement surgery)

But if you just basically said it will come when it is going to come and you live the way the best you can until then, then it is not too bad [ ] you’ve got to understand other people need the services too. We’ve got a lot of services but a lot of people, there’s wait time. It happens. (Jack, on MAWT for shoulder surgery)

Resignation to wait time was a strong sentiment for Jack. He placed his own need for surgery in the context of those who may be in greater need. In his first interview, Jack had shared the experience of attending a pre-operative Telehealth session in his area with several others who were also waiting for surgery. This experience provided perspective on his wait time. By comparing himself with many others who required surgery, he acknowledged and accepted

circumstances of wait time. For him, wait time “happens”. The best way to cope with waiting was to realize surgery will come when it comes.

The notion that wait time is influenced by a larger context was echoed by Dale who was awaiting shoulder surgery. In the following passage, Dale contended shorter wait times are the ideal; however, he regarded waiting patients as powerless to alter waiting duration to a large degree:

The sooner a person has that problem repaired and is on the road to recovery the better. But, of course, there are always things beyond our control that, you know, scheduling, or I don't know what it is, or if it is cost related or what, you know, on the administrative side of it. (Dale, late 40s, awaiting shoulder surgery, on MAWT for shoulder surgery)

In Dale's view, potential administrative issues, such as scheduling or cost of surgery, determine wait time. These issues are beyond control of patients.

The sentiment that wait time was beyond the patient's control was exemplified by Samuel:

Well, really if it was acceptable or not, you ain't got much choice but to have to wait. (Samuel, early 80s, awaiting cardiac surgery, on MAWT for hip replacement surgery)

Similar to the other participants who expressed resignation to wait time, Samuel saw waiting as inevitable. Patients had no choice in waiting, so its acceptability was irrelevant.

#### 4.4.3 Lethality

A dominant theme emerged when participants were asked the MAWT questions related to one type of surgery – cardiac. Invariably, participants from each of the orthopaedic surgery

groups believed this type of surgery required the shortest MAWT to see a surgeon or to wait for surgery. The overall perception in these groups was waiting for heart surgery could be fatal. Half the participants who were awaiting cardiac surgery commented on the potential lethality of the procedure. The following are sample extracts from one participant in each group:

I think it should be as short as possible...I think with a heart condition or anything like cancer or anything like that I think it is really important that the people get into see their surgeon or the doctor that is going to help them as soon as possible. (Shelley, mid 60s, awaiting cardiac surgery)

I can live with a sore or no shoulder, or I can live with no hip or a bad leg but I can not live without a heart. I think when you ask me that question it is almost like it is the degree of importance of the need...you know. So now I am thinking you should not wait until you are dead before you see the doctor, you know what I am saying [*laugh*]. I think as soon as possible, it's a heart issue, it's a life and death thing, in your mind at least. (Jack, late 50s, awaiting hip replacement surgery)

That would be a whole lot different [*than MAWT for consultation for orthopaedic surgery*]...[*laughing*]...that would be more like you know tomorrow!... [*laughing*] ...that should be far more immediate. (Ruth, early 50s, awaiting shoulder surgery)

These participants, Shelley, Jack, and Ruth, represent what participants generally had to say regarding MAWT for waiting to see a cardiac surgeon or for cardiac surgery. “As short as possible” and “immediate” reflected participants’ urgency concerning wait time. For instance, Jack remarked “it’s a life and death thing”. Then he added the qualification “in your mind at least”, indicating patients’ perceptions should be respected in regards to maximum acceptable wait time.

Somewhat surprisingly, only half the number of participants who were awaiting heart surgery commented on the need for very short wait times due to the perception of the life threatening nature of a cardiac condition. The explanation for this lack of urgency on the part of some participants awaiting cardiac surgery is offered in the next chapter.

#### 4.4.4 Summary

Perceptions of maximum acceptable wait times (MAWT) for the three types of surgery in the study were not based on numeric perspectives of wait time. Instead, participants qualified MAWT to account for the degree of patient suffering. In particular, participants considered pain, mobility restriction, and deterioration while waiting to be central determinants of wait time. Some participants felt waiting was inevitable and was largely determined by more powerful and uncontrollable factors within the healthcare system. Hence, they felt MAWT involved resignation to waiting. Due to the perceived lethality of cardiac surgery, participants generally viewed consultation and surgery for heart problems to require the shortest MAWT.

#### 4.5 EFFECTS OF WAITING

The final section of the interview guide asked participants to describe how waiting was affecting them. Five dominant themes regarding waiting effects were identified as: restriction, uncertainty, resignation, coping with waiting, and waiting as opportunity. Each of these dominant themes, with the exception of waiting as opportunity, was detected in each patient group at both interview times. Restriction and uncertainty were the most frequently cited effects of waiting. Resignation to waiting was also very common. Reflections on how participants coped with wait time were discussed as well. While descriptions of waiting as opportunity were less typical than the other dominant themes, how some participants characterized wait time as ‘gifts

of time' is worthy of discussion. Table 4.6 outlines the five dominant themes and their components.

Table 4.6 Summary of themes regarding the effects of waiting

<b>Theme</b>	<b>Components</b>	<b>Consequences</b>
Restriction	Pain Role Mobility	Mental and emotional distress
Uncertainty	Place on list Condition in future	Mental and emotional distress
Resignation	Meets expectation Places waiting in healthcare context	Greater mental and emotional well-being
Coping with waiting	Distraction Downward comparison Social support *	Greater mental and emotional well-being
Opportunity	Prepare for procedure Possibility to 'use' time	Potential for greater mental and emotional well-being

\* absence or negative aspects of social support can lead to mental and emotional distress

These dominant themes and their components are described in the following sections. A final section follows changes in waiting effects over the two interview periods. In some cases, participants who articulated certain themes emphasized the same theme in both interviews, while other participants no longer expressed a particular theme and experienced different waiting effects. These differences in waiting experiences are outlined in this section.

#### 4.5.1 Waiting is Restricting

All participants, in qualifying for the study, were waiting for procedures to alleviate their symptoms. It is not surprising then that the most frequently reported theme regarding the effects of waiting was restriction. Restrictions due to pain were most common in the two orthopaedic groups. Participants from all three groups described activity and role limitations. The consequences of these restrictions were mental and emotional distress, primarily for participants awaiting orthopaedic surgery. Particular emotional disturbances such as frustration, anxiety and depression were often experienced in relationship to physical limitations. Due to the connections between physical limitations and mental and emotional disturbances, the individual components of the theme, 'restriction', are not discussed separately. Instead, participant experiences of physical wait time restrictions are presented in concert with their descriptions of mental and emotional disturbances. For a few participants, minimal physical limitation meant a much easier waiting period. Experiences of participants who described limitations leading to distress are outlined in the first section. The second section contains participant experiences where minimal limitations are described.

##### *4.5.1.1 Restrictions as Distress*

Participants who experienced pain, disability and role restrictions tended to view surgery as the remedy to their limitations. This perception of surgery as panacea made the wait time for the procedure a greater source of mental and emotional disturbance for some participants. Waiting to have their physical symptoms relieved created a sense of urgency for the surgery and a feeling of frustration regarding wait time. In the following passage, Candice linked her frustration with the pain and restriction association with waiting:

I think I am just frustrated because I can't get it [*surgery*] over with...I don't have as much patience with things as I am usually a fairly patient person...I do think that's because of the pain and the...inability to get around and have the freedom like I have always had. (Candice, early 60s, awaiting knee replacement surgery, second interview)

For Candice, her experience of pain and disability transformed her usual patient attitude and made waiting frustrating. She remarked on a loss of freedom to engage in her regular activities.

The losses associated with waiting affected Gerry as well as his family:

Well, you're waiting so far already and it is frustrating...um, it also diminishes you...because you can't do things that you have done all your life and you should be able to do, and you should be able to help people [*daughter*], like you want to and you can't...um and you have to keep waiting and waiting until you're fixed. [ ] I find that diminishing. (Gerry, early 60s, awaiting shoulder surgery, first interview)

Gerry was frustrated waiting for his restrictions to be "fixed". His distress was rooted in losing his usual role of being able to assist family members. Later in the interview, Gerry also noted an incident where he had to pay a tradesperson for work he could normally have done himself. Gerry described his inability to fulfill his usual role as "diminishing".

Nora, who was awaiting hip replacement surgery, was in a similar state. In her case, the effects of waiting had become both depressing and frustrating:

It [*waiting*] is mentally depressing, it's frustrating, it's a total waste of my life, a total waste of time...it is a huge waste of money. I am on disability ...right now I am being paid 75% of my wage, which is still a lot of money and the system is paying for me to wait for surgery, but it is, you know, a tremendous amount of money being spent to keep me at home. (Nora, mid 50s, awaiting hip replacement surgery, second interview)

Nora's limitations meant an inability to continue with work. She noted the absurdity of being paid to wait for a procedure that would restore her working status. Her depression and frustration were entwined with her perception of waiting as a waste of life, time, and money.

The experiences of these participants illustrate the relationship between restrictions while waiting and mental and emotional distress. Pain and mobility and role limitations were upsetting for participants. Descriptions of anger, frustration, and depression were frequent. Waiting was seen as an impediment to a much desired restoration of daily function.

An exception to the connection between restrictions and distress was the experience of many of the participants who were awaiting cardiac surgery. While these participants described varying degrees of role and mobility restrictions, they were not distressed for those reasons. Instead, many participants waiting for cardiac surgery were distressed by uncertainty. This association between uncertainty and distress will be considered in section 4.5.2.

#### *4.5.1.2 Fewer Restrictions Mean Less Distress*

Some participants with pain and mobility and role restrictions experienced mental and emotional distress; however, participants who recognized their lack of limitation had a relatively benign waiting experience. For instance, Ray who was awaiting shoulder surgery remarked:

It [*waiting*] hasn't [*affected me*], and again it is because of my situation – it is not that it's majorly holding me back from doing things so I don't see it as a negative. [ ] If it was something a little more critical that was stopping me from doing you know normal everyday things that I would do in my life, then I would probably have a little more anxiety and a heck of a lot less patience for it. (Ray, late 40s, awaiting shoulder surgery, second interview)

Ray was able to carry on with “normal everyday things”, thus he was more patient and less anxious. When participants’ physical symptoms impinged upon their everyday lives, waiting became an issue. Without these limitations, wait time was more easily tolerated.

#### 4.5.2 Waiting is Uncertain

Wait time was an uncertain time. Participants expressed uncertainty over many unforeseen contingencies which they felt were beyond their control. A primary concern of several participants was the uncertainty of their place on the waiting list. Others worried about the deterioration of their condition during the waiting period or the perceived seriousness of the surgery itself. For some participants, this uncertainty led to mental and emotional distress. Similar to the experience of restriction while waiting, uncertainty and the opposite, certainty, were interconnected with participant mental and emotional well-being. In the first section, participant experiences of uncertainty are described. The second section reports experiences of participants who were much less bothered by any uncertainty regarding their wait time. Some participants from all three groups expressed uncertainty regarding wait time. The reasons why distress related to uncertainty were somewhat different for participants awaiting cardiac surgery versus the two orthopaedic groups. These differences are highlighted in the following sections.

#### 4.5.2.1 *Uncertainty as Distress*

As an illustration of uncertainty regarding participants' place on the waiting list, in the following extract, Tina identified how "everybody" prefers to have an idea of when surgery will be:

Everybody likes to have a sort of tentative idea, rather than just having this tenuous date sometime in the future. It just gives you that little light at the end of the rainbow. You know you are working towards something. I think they could do a more customized wait list. (Tina, mid 50s, awaiting shoulder surgery, second interview)

A "more customized wait list" with greater certainty for patients is desirable for Tina – to provide that "light at the end of the rainbow". She uses this pleasant imagery to describe surgery – the end of a rainbow, where gold is found according to myth. If patients were given more information, they would know what they were working towards.

Other participants did not share Tina's potentially positive characterization of the uncertainty of wait time. Expressing a decidedly negative response to the uncertain experience of the waiting list, in this passage, Gerry described his anger with his perception of his ambiguous wait time status.

It gets me a little angry when you try and find out where you are on the list and nobody can tell you – it is hard to even find out if you are still on the list...they need a better communication system. (Gerry, early 60s, awaiting shoulder surgery, second interview)

Despite his efforts to assuage his uncertainty regarding his place on the list, Gerry remained frustrated. He found fault in the communication in his surgeon's office and continued to wonder where he was on the waiting list.

Other participants were more concerned with the procedure and the outcome of the surgery.

Dale described how the idea of his shoulder surgery and what was involved with the procedure was always present in the back of his mind:

You don't know what the surgery entails and you're to wait a year to have that done...it is always over your head wondering what it is going to be like and what the results are going to be like. So it is always kind of on the back of your mind.  
(Dale, late 40s, awaiting shoulder surgery, second interview)

In a similar way to Dale, Francine, who was also awaiting shoulder surgery, was worried about the success of the surgery and whether the procedure would be scheduled. In the following passage, Francine was concerned about potential disability:

The longer I wait, the more I think is it [*surgery*] going to be successful? Is it [*surgery*] going to happen? And am I going to [*be able to*] use my arm [*after surgery*]? (Francine, late 50s, awaiting shoulder surgery, second interview)

Francine also talked about her need for reassurance from the surgeon that her condition had not seriously deteriorated. Though she commented that an extra visit to her surgeon would interfere with his capacity to do more surgery, and this would potentially increase her overall wait time.

The oldest participant in the group awaiting shoulder surgery, Kathy, talked about how waiting made her feel “really old before my time”. Kathy was concerned that surgery would not restore her active lifestyle:

It just kinda makes you think – oh am I going to have to sit for the rest of my life and just do nothing, you know...it is just not a good feeling. (Kathy, early 70s, awaiting shoulder surgery, second interview)

Referring to her age, Kathy wanted to “live [her] life to the very fullest”. She was particularly distressed by the uncertainty of her surgery date as she felt like she had already “lost two years of [her] life”. At her age, she felt having to wait was a “tragedy”.

For some participants the uncertainty of waiting had profound implications for their career path. Peter, who had work limitations due to his need for shoulder surgery, viewed waiting as “goddamn aggravating” (see section 4.3.1.3). He was frustrated with the uncertainty of his work limitations and his inability to make plans for the future:

I would like to get it over with so I...then they could find out what I could do. Can I go back to [*physically demanding job*]? Maybe I won't have the strength. I mean this is going to be a long drawn out deal because I have to get them both done. [ ] Just that I wish I could get more information out of them like when things are happening [ ] I haven't got a definite answer how long this recovery is actually going to take, but maybe that's each individual, I don't know...it is just like you're kind of left in the dark. (Peter, early 50s, awaiting shoulder surgery, second interview)

Peter described being “left in the dark”, the uncertainty of not knowing when the surgery might be and the nature of the recovery period. He went on to exclaim:

I just want to know when the hell they are going to do it! [ ] It is just not knowing that is the biggest, greatest thing. [ ] You have no idea, where to start, what to do next...you just go day by day. (Peter, early 50s, awaiting shoulder surgery, second interview)

The uncertainty of waiting had forced Peter to live “day by day”, given the circumstances surrounding his job and his need for surgery. Peter found the uncertainty of waiting very frustrating and difficult.

Although they experienced uncertainty, some participants were hopeful that surgery would significantly improve their symptoms. Waiting was unpleasant due to the uncertainty of anticipating closure – finally knowing whether the procedure would be helpful. Brian, who was awaiting cardiac surgery, described this form of uncertainty in the following passage:

I hope that I get this done and wont have to go through this waiting experience again because I don't care for it. But it would be nice to get closure on it anyways, see if it's going to help. Because after open heart, you see, you feel like a new man. I sure hope so. (Brian, late 60s, awaiting cardiac surgery, first interview)

For Brian, waiting brought the uncertainty associated with the need for relief regarding the outcome of the surgery. Arnold, another participant awaiting cardiac surgery, expressed a similar level of uncertainty:

I do not know [*about the outcome of the surgery*]. I hope it [*surgery*] does, I mean, in a way that is like change that it is going to be in a positive way, type of thing. I certainly hope so...you know...but we will see. (Arnold, late 60s, awaiting cardiac surgery, second interview)

Although Arnold was eager for an improvement in his condition, his hopefulness was tempered with the uncertainty of the surgical outcome.

Waiting was uncertain for those participants with a strong desire to know their place on the wait list. Many participants wanted to know when they could anticipate surgery so they could make important decisions and plan for the future. What participants might expect from the procedure and the recovery process was also worrisome. Another concern related to participants' perceptions of possible deterioration of their condition while waiting. Participants awaiting orthopaedic surgery were usually bothered by the uncertainty of their place on the wait list,

whereas participants awaiting cardiac surgery were more troubled by the anticipation of surgery and recovery.

#### 4.5.2.2 *Certainty relates to Composure*

Just as uncertainty could bring frustration, anger and anxiety, the opposite, a sense of certainty or agency over wait time, brought greater composure. Unlike the participants who experienced uncertainty regarding their place on the list, the possible deterioration of their condition, and the outcome of the procedure, participants who felt a greater degree of certainty about their wait time experienced less distress while waiting. In the following extract, Beatrice described how knowledge of an approximate wait time and her experience of a relatively short waiting period resulted in a “very non-traumatic” wait time.

My waiting experience has been very non-traumatic...it just hasn't been a problem because I knew approximately how long I was going to be waiting and I was lucky I didn't have to wait that long. (Beatrice, early 70s, awaiting hip replacement surgery, second interview)

Samuel described a similar sense of certainty associated with waiting for cardiac surgery. He felt his past experiences would ensure a positive outcome:

I am not excited about it, I am not depressed about it and I just know it is going to come soon. Because really it doesn't bother me one bit that I know I am going to go for surgery because I have had enough surgeries to understand that it will come out good. (Samuel, early 80s, awaiting cardiac surgery, first interview)

Samuel's sense of equanimity can be explained by his confidence in the successful outcome of the procedure. He was an experienced patient and had multiple encounters with surgery. Another

participant awaiting cardiac surgery, Shelley, expressed the great relief that came when she was booked for surgery:

I will be really honest with you, whenever I got the phone call yesterday, it was just like a weight off my shoulders...ok, like whew, now I've got a date, now I know I can make arrangements, I can do things...you know, like get everything organized. (Shelley, mid 60s, awaiting cardiac surgery, first interview)

In Shelley's case, she had been greatly distressed by her inability to coordinate the details regarding her surgery. Once the uncertainty of the date of her surgery was resolved, Shelley felt like a weight had been lifted off her shoulders. She became very animated in her efforts to ready herself for surgery.

The states of uncertainty and certainty are important determinants of the quality of waiting experiences for participants. Uncertainty led to anxiety and frustration and generally made the waiting period unpleasant. On the other hand, when participants were satisfied with an approximate wait time and were less plagued with uncertainty, waiting was more easily tolerated.

#### 4.5.3 Resigned to Wait

The perspective of some participants was to adopt an approach of passive acceptance of wait time. In their view, consultation and surgery would happen at some point in time. Waiting was seen as part of life; waiting was to be expected, especially considering the conditions of the current healthcare system. Generally, participants who were resigned to wait were not distressed by their waiting experience. Alice, who was awaiting cardiac surgery, was an exemplar of this attitude:

It's been relaxing. I have made up my mind to wait so I waited. Waiting was nice. I made it nice. Shocked it is here already. (Alice, late 60s, awaiting cardiac surgery, second interview)

Alice demonstrated agency in waiting – she made up her mind to make waiting “nice”. Another participant awaiting cardiac surgery, Hillary, was unaffected by waiting due to her particular attitude of not being “mad about things”:

I don't think [*waiting*] has affected me at all because I am not one that, you know, is kind of mad about things...I could understand that the doctors are busy and that...you just got to learn and do the best you can so that is what I done. (Hillary, late 70s, awaiting cardiac surgery, first interview)

In the above passage, Hillary also noted that the “doctors are busy”, a perspective that there are uncontrollable conditions within the healthcare system. The alternative for Hillary was to “do the best you can” and wait.

The idea that the healthcare system is an uncontrollable entity was iterated by Jack, who was awaiting hip replacement surgery. Using the analogy of a driving a train, Jack described how he was resigned to waiting:

Like I have no control, I'm not driving the train, you know. There's a whole bunch of other things and other needs and other people and other commitments that are driving the train so having resigned yourself to the fact that you have no control over any of this, just kind of accept the fact that it's a wait and be on with it. (Jack, late 50s, awaiting hip replacement surgery, second interview)

For Jack, resignation to lack of control and acceptance of wait time determined how to get “on with it” – his recipe for how to carry on with life while waiting for surgery.

In addition to his use of the ‘not driving the train’ analogy, Jack was resigned to wait in a manner that to him did not actually involve ‘waiting’. In the following passage, he described his criteria for when waiting actually becomes ‘waiting’:

So, you accept the doctor’s suggestions and what he says. And, he sets the timeframe, so in my mind it’s going to be [*season/month*] and that’s the two portions of information that I have received so far. And so that’s what it will be. I guess when it gets to be [*past season/month*], then I consider myself waiting. Right now I’m not really waiting, you see. Maybe after I don’t have it by [*particular month*], well then I’m thinking geez now I’m waiting...like cause I was kind of told that it was going to be early spring or if you phone the number it’s going to be [*particular month*]. Now it gets to be [*past particular month*] and now you’re thinking okay from that point on you’re waiting. (Jack, late 50s, awaiting hip replacement surgery, second interview)

Jack accepted the season and month that his surgeon told him as his surgery date. His surgeon set “the timeframe”. When those dates passed, then waiting would begin for Jack. He was resigned to his surgeon’s timeframe. Jack extrapolated his view of waiting to other patients’ experiences:

[*Doctors*] set a date, and patients...I think...they accept that date. I don’t know if you have a patient stand up in front of a doctor and say, ‘hold it, hold it, I want it tomorrow, what do you mean it’s going to be six months’. They say, ‘okay whatever you think, that’ll be good’. Once you accept it you go with the flow. I think if you had to wait quite an extended period of time after that [*date*], you would become frustrated, especially if you are in quite a bit of pain. And then again, you have to understand that other people need their services too. They’ve got to service a lot of people, there is a wait time. It’s going to happen. (Jack, late 50s, awaiting hip replacement surgery, second interview)

In this passage, Jack recognized several circumstances which he felt influenced waiting experience. That is, doctors control the system which means it is unreasonable for patients to demand quick treatment. Accepting wait time allows one to “go with the flow”. Jack had compassion for those waiting in “quite a bit of pain”, though he qualified this by citing the

relative shortage of health services coupled with high demand. In his view, wait time was inevitable.

The relationship between high demand for service and a relatively short supply was echoed by other participants. Resignation to waiting was expressed by recognizing finite healthcare resources and a desire to place oneself in a 'fair' place in the queue for surgery. Darryl, who was awaiting shoulder surgery, talked about waiting his turn:

You know it [*waiting*] is just part of life people have to do. I will wait my turn and like I say there is probably thousands of people that in more dire need to have something done medically than me and if there was and I knew of somebody that was, I would give them my spot in the line up. (Darryl, late 50s, awaiting shoulder surgery, first interview)

Darryl assessed his relative place on the waiting list and expressed willingness to relinquish his position. In his mind, waiting was something "people have to do".

Similarly, Lionel, who was awaiting hip replacement surgery, reiterated in both interviews how waiting was "part of life". In his first interview, Lionel emphasized how expectations of short wait times are unrealistic:

It's all part of life, I mean. If your expectations are high to get in the next day, well your expectations were too high. Like I said, anything in life it doesn't happen like right now. (Lionel, late 50s, awaiting hip replacement surgery, first interview)

In his second interview, Lionel recognized waiting could be problematic for patients with greater pain. He connected his resignation to waiting to a relatively low degree of joint pain.

It is a part of life to wait so. I know some people are anxious but I guess I am probably at the lower end of like joint pain, so I guess waiting is not an issue for me. (Lionel, late 50s, awaiting hip replacement surgery, second interview)

Another participant awaiting hip replacement surgery viewed waiting as “just part of life”.

Beatrice contended that a long wait was “common knowledge” as wait times are widely publicized:

I knew it was going to be a long wait and so it was just, you know, common knowledge all you have to do is listen to the radio, read the paper, talk to your doctor, you know it’s gonna be a while. So to me it was just part of life, I just carried on doing what I could. [ ] The waiting was not a problem, ever. It was at my discretion and I knew it was at my discretion. [ ] I chose when to deal with it. (Beatrice, early 70s, awaiting hip replacement surgery, first interview)

Beatrice was in a somewhat unique position in that she put herself on the waiting list 14 months in advance of her surgery for her second hip replacement. She planned the time of year in order to accommodate her travel plans and to consider optimal weather patterns (ie, after spring thaw). In this way, waiting was at her “discretion” and she “chose when to deal” with her condition with her hip.

In some cases, participants accepted wait time to the extent that they did not feel as though they waited at all.

I just carry on, you know I mean if...you’re asking the question if there has been anxiety and stuff – not one iota. I don’t feel like I’ve been waiting to be honest with you. In the scope of all the negative publicity you hear about [*wait times*]...I feel like I’ve been fast tracked. (Ray, late 40s, awaiting shoulder surgery, first interview)

Ray had predicted a much longer wait because he was influenced by media reports regarding long wait times. Because his wait to see the surgeon was shorter than he anticipated and the surgeon told him an approximate surgery date that was closer than he thought, Ray felt he had been “fast tracked” and just carried on.

Resignation to waiting was tantamount to acceptance. Participants who were resigned to waiting accepted and expected waiting as part of the healthcare system. For these participants waiting was not a source of distress, but rather an anticipated experience of ‘normal’ life.

#### 4.5.4 Coping with Waiting

Questions regarding the effects of waiting evoked discussion of participant coping strategies for wait time. Three common strategies were noted: distraction from thoughts of being on the wait list, downward comparison to those patients in less fortunate circumstances, and social support. Examples of how participants used these strategies are discussed in the sections below.

##### 4.5.4.1 *Distraction*

Participants noted that waiting was more difficult when the waiting experience appeared to be a prominent part of daily life. Therefore, to minimize the effects of waiting participants discussed the strategies they used to distract themselves from the fact they were waiting. In the following passage, Lorraine listed the activities that helped her to avoid thinking about waiting:

I don't think about it [*waiting*]. Main thing, if I thought about it, it would be kind of hard to put up with. But you just don't think about it. Just think about other things and I'm good at doing that. Well, I like TV, I like puzzles, I like hand work. (Lorraine, mid 70s, awaiting hip replacement surgery, first interview)

Lorraine distracted herself from waiting with activities she enjoyed. Another participant Wanda, who was awaiting shoulder surgery, described the connection between thinking about waiting and the magnification of negative effects from waiting:

One thing that helps me is not to dwell on it. To go on with my day to day living and not sit there and just think about it all the time, because that makes it worse. (Wanda, early 40s, awaiting shoulder surgery, second interview)

Carrying on with daily activities had helped Wanda cope with the effects of waiting for shoulder surgery. Similarly, Rolland, in this extract from his interview the day before his cardiac surgery, kept “so busy” he did not let the idea of surgery “interfere” with his thoughts:

I have been so busy, it [*concern about surgery*] makes no difference. In fact as soon as I leave here I am going bowling...I don't let this [*surgery*] interfere with my thoughts. (Rolland, late 70s, awaiting cardiac surgery, second interview)

Rolland pointed out that even on the day prior to surgery, he was engaged in his usual busy lifestyle. Another participant awaiting cardiac surgery, Shelley, felt coping with waiting for surgery involved staying as busy as possible:

I think you do as much as you can, you know, just don't stop dead and do nothing. (Shelley, mid 60s, awaiting cardiac surgery, second interview)

For Shelley, waiting for surgery meant carrying on and doing as much as possible. In her case stopping “dead and do[ing] nothing” was not the way to cope with waiting for surgery.

#### 4.5.4.2 *Downward Comparison*

Comparing oneself to a relatively less fortunate other or others (ie, using downward comparison) was a very common component of coping with wait time among participants from all three groups. Elsie, the oldest participant in the study, employed downward comparison to consider herself “lucky”:

You sit there and you think and think how lucky you are and how unlucky they are. Naturally your heart goes out for somebody worse than you are. (Elsie, late 80s, awaiting hip replacement surgery, first interview)

In her second interview, Elsie described the process whereby downward comparison made her better able to cope with waiting.

Right away you compare yourself to somebody else who is worse than you are. And when you see that they are not complaining, half as hard as say as I am, then it makes you feel relieved. You feel, hey come on and smarten up, this is something that you’ve got to go through and you have to put in the waiting time that is required. (Elsie, late 80s, awaiting hip replacement surgery, second interview)

When a comparison was made to someone in worse physical condition, who was not complaining about their ailments, it inspired Elsie to endure the “required” wait time.

When Ray, Lee and Lionel used the technique of comparing their state to the situations of those less fortunate, they expressed the same notion as Elsie:

There are probably a lot more pressing issues that other people are living with than for myself having a rotator [*surgery*] done. (Ray, late 40s, awaiting shoulder surgery, second interview)

Some people have to wait in a lot worse conditions so I am pretty fortunate. (Lee, early 40s, awaiting cardiac surgery, first interview)

There is always somebody out there that is in worse condition than you are. (Lionel, late 50s, awaiting hip replacement surgery, second interview)

Each of these participants employed downward comparison to assert that their waiting experience was not as negative as the situations others may have to endure. Darryl took downward comparison even further to contrast his fortunes with “the world’s population”:

Hey, I’m probably better off than 99% of the world’s population. That is the way I look at it...my family is relatively healthy, got a roof over my head, three meals a day, what more can a person ask for? (Darryl, late 50s, awaiting shoulder surgery, second interview)

Comparing themselves to less fortunate others allowed these participants to have a more positive waiting experience. To think about others who were waiting in greater distress or those who had fewer supports while waiting enabled participants to feel better about their wait time. Downward comparison appeared to be an effective coping strategy.

A few additional participants used downward comparison to compare their current waiting situation to a past wait or circumstance that was more distressing. These other waits included surgery for cancer or waiting to find out a result from a cancer test. Gerry reported an experience where he had to advocate for himself to be placed on the waiting list for consultation with a surgeon:

It was horrible. [ ] I am waiting for cancer surgery and my file is sitting there on her desk in the office not referred to the surgeon [ ] after I started really complaining, and I phoned the surgeon's office [ ] I would still be waiting. [ ] when you have cancer like you worry about that, it's...10 times more than worrying about my shoulder. (Gerry, early 60s, awaiting shoulder surgery, first interview)

For Gerry, waiting for consultation with a surgeon about cancer surgery was “10 times” worse than his concerns for his shoulder. His use of downward comparison provided context for his current situation.

Rolland, who was awaiting cardiac surgery, found wait time for surgery to be another event in his life to not worry about:

I have never worried about anything...I just do it and hey that's all there is to it. [ ] I wouldn't be giving [*surgery*] any more thought. In fact it bothered me more when my wife passed away than this stuff. (Rolland, late 70s, awaiting cardiac surgery, second interview)

By categorizing life events according to what is worthy of concern and what is not, Rolland emphasized the contextual aspects of wait time. Waiting for surgery paled in comparison to his experience of losing his wife.

When participants compared their situations to a group of less fortunate others or when they compared their present circumstance to a past negative event, they benefited from the use of downward comparison. The effects of waiting appeared to be ameliorated in these cases.

#### 4.5.4.3 Social Support

Several participants discussed the advantages of supportive friends and family. The availability of a network to talk about the wait time or the surgery itself was important to Shelley who was awaiting cardiac surgery. She stated this explicitly in her first interview:

I think people have to have a good network of people to understand what is going on and you've got to talk about it. (Shelley, mid 60s, awaiting cardiac surgery, first interview)

Shelley noted in her second interview that she was relieved to know the date of surgery, in part to be able to share the news with her network. Arnold, another participant awaiting cardiac surgery, shared the importance of social support to keep "your mind busy":

You do not want to stay home and start to think too much, you want to have your mind busy or talking about different things...and that is what seniors do. They can talk about little things that even the younger generation do not even think about talking about. (Arnold, late 60s, awaiting cardiac surgery, second interview)

Lack of social support was evident for one participant awaiting shoulder surgery. At both interviews, she described the need to talk about her wait time for surgery, however, she alluded to finding little support from others in her small town:

They always want to be nice and polite because they know you got pain or whatever so: 'how are you today?'...[laughs]...you know, and then pretty soon they go to a different coffee place because they know you're going there...[laughs]...no I don't know, but you feel like that. (Francine, late 50s, awaiting shoulder surgery, second interview)

In her first interview, Francine mused about having a friend who would be unable to hear so that she could speak in an unrestricted manner regarding her waiting experience. Although Francine valued social support as a form of coping, she also found it lacking in her life.

The presence of a social network did not always have a beneficial effect. Mary, who was awaiting hip replacement surgery, commented on how inquiries by her support network sometimes exacerbated the negative effects of waiting:

Well, when you are talking to people they always say, ‘have you been scheduled yet?’ And then you look kind of annoyed and say, ‘no, I haven’t yet, I am still waiting’ [ ] That kind of stuff kind of bothers me when people keep saying, ‘well you should have heard by now, you know’. (Mary, mid 60s, awaiting hip replacement surgery, second interview)

Mary felt a form of negative social pressure from those who inquired about her surgery date. Rather than experience support from her network, Mary was irritated by the insistence that she “should have heard by now”.

The coping efforts of participants were influenced by social support and by the lack of appropriate social support. The quality of wait time for participants was affected by the effectiveness of their support network.

#### 4.5.5 Waiting as Opportunity

This particular theme, waiting as opportunity, appeared in only two of the three patient groups – participants awaiting cardiac surgery and participants awaiting hip or knee replacement surgery. Some participants in each of these two groups construed their wait time as an opportunity to appreciate particular aspects of their lives. Wait time could provide opportunity to

use time in remarkable ways. Joan, who was awaiting hip replacement surgery, associated waiting with the chance to appreciate the “beautiful” things in her life:

One of the positive things about it [*waiting*] is it makes you appreciate family, your friends, things that go well, things that are beautiful. (Joan, late 50s, awaiting hip replacement surgery, second interview)

Joan felt waiting did have positive aspects. Waiting provided the time to be grateful for the important people and pleasant experiences in life. For Lee, who was the youngest participant in the study waiting for cardiac surgery, waiting provided an incentive for contemplating lifestyle changes:

I want to see my grandchildren, you got to live differently...you have got to control stress and all of the stuff that causes problems...if you can't do that...you won't be around...but those are the things that you can control. (Lee, early 40s, awaiting cardiac surgery, first interview)

Waiting for surgery had given Lee an opportunity to assess his ways of coping and adjust how he lived. He viewed his heart condition as potentially lethal. Wait time provided time for reflection on life priorities (ie, living long enough to have grandchildren).

Other participants saw waiting as an opportunity to prepare for surgery, whether preparation meant physical healing or organizing the details necessary to get ready for the upcoming procedure. For Paul, waiting was an opportunity to heal so his heart would be ready for surgery:

I realize I have to wait for this side of the heart to heal and I want to make sure of that...so that waiting part there, that is not a big deal. (Paul, early 60s, awaiting cardiac surgery, first interview)

Paul wanted his heart to be physically prepared for surgery. It was “not a big deal” for him to wait, because his body was priming itself for the procedure. Dianne, another participant awaiting cardiac surgery, purposefully avoided activities such as planting a garden and making complex meals in order to minimize the stress for her pre and postoperative periods. In this way, Dianne used her wait time to plan ahead so she would have minimal obligations during waiting and recovery times.

Although waiting remained difficult, Candice used wait time as an opportunity to follow her surgeon’s instructions. She had been encouraged to lose weight while waiting to improve her recovery after surgery. For Candice, waiting was also a chance to recognize the important things in her life:

It [*waiting*] has made me really tune into the important things within your lifestyle...and what are your priorities. (Candice, early 60s, awaiting knee replacement surgery, second interview)

Not only did wait time provide Candice with the opportunity to “tune into the important things” in her life, but it also gave her a chance to get into the best possible physical condition prior to surgery.

Some participants who were awaiting cardiac surgery and hip or knee replacement surgery viewed wait time as an opportunity, in a sense, as a ‘gift of time’. Participants were able to contemplate lifestyle changes, appreciate positive aspects of their lives, evaluate their priorities, and prepare themselves physically and mentally for surgery. This theme did not appear for

participants awaiting shoulder surgery. Possible reasons for the absence of this theme among this group of participants are discussed in the next chapter.

#### 4.5.6 Changes in Effects of Waiting over Time

Interviewing participants on two separate occasions in their waiting period allowed for an analysis of potential temporal changes in the effects of waiting. For many participants, the effects of waiting were consistent over the two interview periods. If, for example, participants were resigned to their wait time for consultation at their first interview, they expressed the same resignation to waiting for surgery at their second interview. However, for some participants, mainly those from the two groups awaiting orthopaedic surgery, there were changes in how they experienced the effects of waiting over time.

At their initial interview, when the decision to treat had been made, some participants expressed relief at consultation or were resigned to waiting. For example, Mary, Nora, and Frank, all awaiting hip replacement surgery, were resigned to wait at the first interview:

I have the patience and the time to wait now that I didn't have before, you know. So it has been kind of easier this time than last time. (Mary, mid 60s, awaiting hip replacement surgery, first interview)

Good because I know it is coming. What I think if people know there is resolution, even if it down the road, it's a good thing. It's more the unknown that bothers me than the known. I know it's going to be fixed eventually and I've got something to look forward to. (Nora, mid 50s, awaiting hip replacement surgery, first interview)

It doesn't bother me. It's part of getting old and I have to live with it so that's it. [ ] I'll just carry on normally. I know that I have to wait and it don't affect me. (Frank, early 80s, awaiting hip replacement surgery, first interview)

Mary reported having the patience and time to wait. Nora expressed great relief in the certainty of knowing surgery would occur. Frank was resigned to wait and claimed to be unaffected. By the time of the second interview, about midway through their wait time for surgery, each of these participants reported a somewhat different experience regarding the effects of waiting.

It seems like a lot of plans and I am sitting here kind of on hold as to how much do I do or how far do I plan ahead. Maybe a little more to the point of being impatient. (Mary, mid 60s, awaiting hip replacement surgery, second interview)

I can't commit to something like that [*running for political office*] with my health the way it is (Nora, mid 50s, awaiting hip replacement surgery, second interview)

I can't get around, it just is bad for me to get around the building so you are sitting in the house, nothing much to do. [ ] I mean I am pretty bad, I can't get around, hard to get into a vehicle or anything, that makes it bad. (Frank, early 80s, awaiting hip replacement surgery, second interview)

Unlike how she described waiting in her first interview, Mary reported impatience with the uncertainty of the waiting experience in her second interview. Similarly, Nora, who was initially buoyed by the certainty of knowing her surgery would occur remarked on how the uncertainty of waiting has interfered with her ability to pursue particular activities. Originally, Frank was not bothered by waiting but by the time of his second interview he discussed his restrictions at length.

Changes in the experiences of the effects of waiting were also reported in the group awaiting shoulder surgery. For example, Greg recounted no effects of waiting in his first interview: "I haven't gotten frustrated with the amount of wait so – I had no negative impact".

However, in the second interview, he was concerned about the possibility he had been lost from the waiting list:

I keep wondering if they have forgotten about me because I haven't heard a thing yet. So I don't know if I am still on a list or where I am or if things are going according to what they figured for the end of [*the month*] – I don't know. I am beginning to worry now, so that's all. (Greg, late 40s, awaiting shoulder surgery, second interview)

By the midpoint in his wait time for surgery, Greg, like Mary and Nora, was affected by uncertainty.

For some participants, the quality of their waiting experience changed as they waited for surgery. In some cases, the effects of waiting for consultation were relatively innocuous. That is, participants were either relieved or resigned to waiting. On the other hand, by midpoint in their waiting period, these participants experienced increased restriction or uncertainty. For these participants, waiting became more negative with time.

#### 4.6 SUMMARY OF RESULTS

The results were analyzed in three main sections according to the format of the interview guides. Two of the sections were intended to tap participants' lived experience of time and waiting. In Table 4.7, the first column describes the dominant themes associated with lived time and the third column recounts waiting effects. The middle column of the table presents the themes related to maximum acceptable wait time (MAWT).

Table 4.7 Participant Experiences by Research Objectives and Dominant Themes

<b>Time while Waiting</b>	<b>Maximum Acceptable Wait Time</b>	<b>Effects of Waiting</b>
Time drags	Suffering	Restriction
Time flies	Resignation	Uncertainty
		Resignation
Time goes on	Lethality	Coping with waiting
		Opportunity

Lived wait time could be understood in terms of duration. Participants perceived time passing slowly or quickly, or going by ‘as usual’. The key determinants of lived wait time duration were the experience of suffering, the presence of meaningfulness, or the implementation of agency. Protracted wait time was associated with greater suffering, less meaningfulness and less agency. Accelerated and ‘usual’ wait time was experienced when less suffering or better ability to cope with suffering occurred. Greater meaningfulness and more agency were linked to wait times passing more quickly or ‘as usual’.

What participants viewed as ‘acceptable’ wait times varied according to how much suffering they felt a patient endured. Many participants felt wait times were to be accepted regardless of the conditions that surrounded waiting. Wait times were an unchangeable part of the healthcare system. Consultation or surgery for a cardiac condition was perceived as requiring immediate attention.

Participants described a range of experiences regarding the effects of waiting. For some participants, waiting was a very restrictive and uncertain time which resulted in a great degree of distress. For others, waiting either held few limitations or they coped well with those restrictions.

Those participants who were more certain about the outcome of their surgery or did not worry about their place on the list were more composed in regards to waiting. Some participants were entirely resigned to wait for what they felt were finite healthcare resources – resources which might be better used to help someone else in greater need. The notion of comparing oneself to others in greater need was a common way of coping with wait time. Distraction and using social support were other effective means of dealing with wait time. Finally, for a subset of participants, wait time presented opportunities to explore positive aspects of life and to prepare for surgery.

## **5 Discussion**

The purpose of this interpretative phenomenological inquiry was to explore the lived experience of patients awaiting scheduled surgery. Specifically, this study had three principal objectives: to understand participant experiences of time while waiting, to gather participant perspectives of maximum acceptable wait times, and to describe the effects of waiting for scheduled surgery. Therefore, the discussion of the research findings is organized according to these three areas. How the research findings compliment the existing literature is also described within each section. Particular attention is given to the most revealing or unanticipated aspects of the findings. The present study was the first to explore the experiences of patients awaiting orthopaedic surgery and patients awaiting cardiac surgery. By considering the experiences of patients awaiting these different surgery types with different wait times, it was possible to examine the differences and similarities in wait time experiences more directly. The final section in this chapter explores general issues that emerged from the study.

### **5.1 TIME WHILE WAITING**

This study was the first to examine patients' experiences of time while waiting for consultation and scheduled surgery. Time experiences could be understood in terms of lived duration, or how long participants perceived time to pass while they waited. I interpreted participants' experiences of time dragging, time flying, and time as usual as reflecting their degree of suffering, the level of meaningfulness of their experience, and the extent of agency they could implement in their waiting period. When time dragged, participants were suffering, lacked meaningfulness in their lives and were short of agency. When time was accelerated or continued 'as usual', participants suffered less, found greater meaningfulness, and were agentic

regarding their time. While each experience of lived duration was evident in all patient groups at both interview periods, the experience of time flying was more common among participants awaiting cardiac surgery, and time dragging was frequent in the two groups awaiting orthopaedic surgery.

As this was the first study to explore patients' experiences of time while waiting for consultation and surgery, how these findings might fit with other samples of patients awaiting surgery cannot be ascertained. However, this study may be compared to the limited research that has examined patients' experiences of time in connection with various disease states (ie,9,13,14,75). This literature suggests that confrontation with serious chronic disease elicits an awareness of time. I contend that time awareness is further impacted by lived duration (eg,74), meaningfulness of temporal experience (eg,10,76) and temporal agency (eg,78,79). These comparisons between the current study and this literature are presented in the following sections.

#### 5.1.1 Time, Waiting and Suffering

Time experiences of patients with a number of diseases have been explored using qualitative methods (9,13,14,75). The most comprehensive and comparable study was conducted by Charmaz (9) who interviewed a total of 55 participants with a variety of illnesses from cancer and diabetes to rheumatoid arthritis and emphysema. In Charmaz's analysis, the acknowledgment of illness affected time experience. She asserted the perception of time's duration accelerated when people engaged in a fight against their illness. Time slowed as patients became passive and embraced a 'sick role'. Parallel findings were reported by patients with chronic pain where time seemed to 'stop' as their life rhythms were halted and disrupted by their experiences of pain (75).

To a certain degree, the time experiences of the participants in my study reflected the duality that Charmaz proposed – that is, time seemed to accelerate or decelerate according to how participants perceived or coped with their illness. When a participant could not ameliorate either the physical or emotional suffering associated with waiting for consultation and surgery, time became excruciatingly slow. Each day became a century for one participant awaiting orthopaedic surgery. However, when participants coped effectively with their symptoms or experienced relatively little suffering, time was ‘flying’. Weeks seemed like days for one participant awaiting cardiac surgery.

Decelerated time was more common among participants awaiting orthopaedic surgery while accelerated time experiences were frequent among the group of participants awaiting cardiac surgery. This difference may be explained in part by chronological wait times; participants from the orthopaedic groups waited months rather than the weeks the participants from the cardiac group waited. Nevertheless, lived duration while waiting could not be fully understood by surgery type. Although the chronological wait time for orthopaedic surgery was substantially longer than wait times for cardiac surgery, not every participant in these respective groups experienced duration in accordance with chronology. That is, some participants awaiting orthopaedic surgery experienced accelerated wait time and some participants awaiting cardiac surgery experienced protracted wait time. This illustrates the relative arbitrariness of chronological time and the importance of factors like physical and emotional distress on lived time experience.

Charmaz described another time experience for people with chronic illness – time ‘as usual’. In this scenario, people did not define themselves as ill, but rather waited for an assured outcome, such as an expected test result. These experiences were typical of short term waits. In my study,

some participants in each of the patient groups experienced time 'as usual' where waiting did not appear to affect their sense of time's duration. Similar to Charmaz's findings, these were participants who were not especially affected by the suffering associated with their condition, and therefore did not appear to view themselves as particularly sick. When participants compared their level of suffering to 'others' who were perceived as having greater need, wait time was accepted and life went on. Intermediate treatments such as cortisone shots helped time go on as usual. In some cases, participants had lived with their condition for many years and their temporal experience leading up to consultation or surgery was indistinguishable from any other time. These participants waited for an 'assured outcome' (ie, consultation or surgery); in the meantime, time carried on as usual.

#### 5.1.2 Time, Waiting and Meaningfulness

Some participants in this study found waiting robbed them of the meaning usually associated with their time. Activity and role restriction rendered time long and boring. When time lacked meaningfulness, its duration lagged. Hale (76) described Sisyphean time as a temporal dimension with the potential to be filled with either anguish and misery or enrichment and meaningfulness. Using the experience of Sisyphus, the mythical Greek king who was condemned by the gods to perpetually roll a rock up a hill, Hale contended time that appears to be filled with the eternal drone of each heavy moment can be meaningful. Rather than a sentence of suffering, personal determination can render Sisyphean time meaningful. Some participants in my study reflected such determination. While some participants experienced the heaviness of time while waiting, others found acceptance of their condition as a 'normal' part of aging and carried on with their lives. Restrictions were accepted and wait time either passed quickly or was experienced as any other time.

The importance of meaning in relationship to temporal experience has been found in other studies (12,14). Zhou (14) described her participants' experiences with HIV/AIDS as an interruption of linear time, which led to the need for participants to reconstruct the meanings of their time. Participants rearranged their priorities in terms of their daily lives, their relationships with others, and their perceptions of themselves. Correspondingly, in a study of participants with inoperable lung cancer, temporal uncertainty encouraged a re-prioritization of remaining time and a focus on the present (12). In my study, a similar interruption in linear time occurred when waiting was viewed as a 'waste of time', an experience of participants for whom time dragged. Other participants reconstructed their time to make waiting meaningful. Wait time was even experienced as an opportunity to appreciate the present. In some cases, waiting was not an interruption in time, but an expected part of life and an anticipated aspect of the healthcare system.

Wait time as a meaningful experience reflects one of three perspectives on waiting (10). Waiting can be viewed as a blockage of action (time wasted), as an experience filled with substitute meanings (time goes on with regular activities), and as a competed and meaningful experience (10). Participants in my study embodied each of these perspectives. While time was experienced as wasted by some participants, others carried on and found meaning in regular activities. For a few participants, waiting provided an opportunity to discover greater temporal meaning, such as learning patience or taking time to contemplate existential concerns (eg, participants awaiting cardiac surgery referring to compiling their last will and testament). Temporal meaningfulness had an impact on wait time duration.

### 5.1.3 Time, Waiting and Agency

The relationship between agency and time in samples of patients has been described as a fundamental determinant of lived duration (9) and aspects of health related quality of life (12,13). These studies have discovered patients can be temporal agents and/or victims of uncertainty. Regarding uncertainty, Charmaz (9) asserted that when uncertainty escalated to fear and dread as participants waited for information about their illness or changes in symptoms, time halted. She described these participants as “locked into a protracted limbo” (p32). Moreover, people with chronic illness often experienced wait time as lost time because waiting represented a loss of control over time (ie, loss of agency over time) (9). Similarly, patients with inoperable lung cancer experienced uncertainty in protracted periods of waiting (12). However, concomitant to uncertainty was participants’ desire to remain agentic and act as their own advocates. Temporal agency was also reported in a study of cancer survivors (13). Although the experience of cancer had led to an interruption in temporality, participants described an increased awareness of time and their desire to appropriate time. These participants spent time parsimoniously and judiciously in their most desirable pursuits.

Agency was also an important capacity among participants in my study. Those participants who lacked temporal agency endured long, dragging wait times. Those who recognized and exercised control over their time either felt time passing quickly or that time passed at its usual pace. Participants who were focused on the ‘business’ of daily activity and took an active role in the decisions associated with their care were less likely to experience protracted wait time. Staying busy meant time passed quickly; claiming responsibility for initiating the process of consultation and surgery meant time passed as usual. Participants who were more temporally agentic were less troubled by wait time.

#### 5.1.4 Suffering, Meaningfulness, Agency and Wait Time

A distinctive finding of this study was the duration of wait time experienced by participants fluctuated regardless of the actual chronology of the wait. Whether participants felt waiting was long, short or ‘usual’ time, their experiences of lived duration were better understood by employing the concepts of suffering, meaningfulness and agency. How these three concepts interrelate warrants further discussion. Does suffering hinder meaningfulness and agency, or does agency and meaningfulness enable suffering to be transcended? Will meaningfulness enhance agency, or is meaningfulness possible only through agency? These potential interrelationships are discussed in the following sections using three participants who exemplified each experience of lived duration. These participants were particularly expressive about their experience of time while waiting and their discussions of time revealed potential connections between the concepts of suffering, meaningfulness, agency and duration.

##### 5.1.4.1 *Time drags: Nora*

Nora epitomized a person who had been robbed, albeit temporarily, of important meanings in her life. She was disturbed by the many restrictions related to waiting to have her hip replacement surgery. On disability from her professional job, Nora felt being paid to wait for surgery was absurd. Yet, she described the ambivalence associated with her family’s wish for her to pursue private healthcare and her need to support the system she believed in. In the meantime, she portrayed her daily living as long and boring. At the second interview, her degree of suffering was high, and she was tearful as she outlined the restrictions linked to her pain.

Nora’s suffering had a significant impact on her ability to maintain and manifest meaning in her life. This, in turn, affected her perceived duration of wait time. At the same time, her statement “waiting for the hours to go by” implied a lack of temporal agency. If suffering, lack of

meaningfulness and lack of agency were dominoes in Nora's life, waiting elicited their chain reaction to protracted duration.

#### *5.1.4.2 Time flies: Alice*

Of the participants awaiting cardiac surgery, Alice had the second longest interval between interviews. Yet, for her, time had passed very quickly. Alice reported several physical restrictions – she was often very tired and unable to engage in activities for more than a half an hour. Physical aspects of suffering for Alice were quite significant; however she reported her mental and emotional state as one of contentment, absent of anxiety.

Alice insisted she made her wait time “nice”. In other words, she made it meaningful. She remarked on how the physical restrictions were essentially teaching her to be more patient. Temporal agency enabled Alice to have a relatively pleasant experience while waiting for surgery. While physical suffering could have protracted her experience of time, her agentic approach meant time passed quickly and meaningfully.

#### *5.1.4.3 Time goes on: Jack*

Jack, who was in his mid fifties, had experienced serious difficulties with his hip since an accident in his late thirties. In the past, he had undergone several procedures and endured life-threatening complications. After a series of consultations, both he and his specialist decided he would return to the wait list for hip replacement surgery. Due to his history with surgery, Jack described being anxious about the outcome of the procedure. Therefore, it could be said that Jack experienced both physical and emotional suffering during his wait time. Yet, time went on ‘as usual’ for Jack.

The basis for Jack's temporal experience was strongly linked to his attitude of acceptance. He accepted his physical limitations and expected increased disability with age to be a normal process. For him, wait time was filled with its usual meaningfulness because he "[went] on with life". He recognized that he was the instrument of his temporality.

#### *5.1.4.4 Agency as Principal Determinant of Lived Duration*

The limited literature on chronic disease and temporality has established a link between suffering and lived duration (9,75). The present study mirrored this fundamental connection. For many participants, suffering increased wait time duration; for others, less suffering or effective coping with suffering decreased or had no impact on wait time duration. However, when the individual temporal experiences of Nora, Alice and Jack are considered, more complex relationships emerge.

Nora, Alice, and Jack, though from different backgrounds and circumstances, shared two commonalities. First, they awaited consultation and surgery. Second, they were temporal agents to varying degrees. This variation in temporal agency had a considerable impact on suffering, meaningfulness, and lived duration. For instance, Nora felt little agency over her time and suffered greatly in protracted waiting. Alice and Jack also suffered, but 'made' their time go by in meaningful ways. Possibly, the moderation of Alice's and Jack's suffering was engendered by their ability to exercise temporal agency. Temporal agency appeared to ameliorate suffering and augment meaning. Thereby, capacity for temporal agency influenced lived duration.

The importance of agency in temporal experience has been documented by Flaherty (78). In a narrative analysis of daily temporal experiences, Flaherty (78) concluded the practice of customizing and controlling how individuals experience time (ie, temporal agency) was ubiquitous

regardless of contextual restraints. Flaherty argued the experience of time was always agentic with varying degrees of self-awareness on the part of the agent. Individual choices, mental or behavioural, determine time's perceived passage.

The experiences of the participants in this study provide a preliminary description of temporality while waiting for consultation and surgery. Not surprisingly, their descriptions of time were tied to duration. The condition of waiting generally evokes the awareness of how long one will wait and has waited. Based on the experiences of three exemplars of the various experiences of duration, I contend the primary determinant of lived duration is embedded in temporal agency. The implication of the significance of temporal agency in the current study will be discussed in the final chapter.

## 5.2 MAXIMUM ACCEPTABLE WAIT TIME

How long patients will tolerate waiting has received considerable attention in the wait time literature (eg,40,41,43). However, prior to this study, perceptions of maximum acceptable wait times (MAWT) had not been collected using qualitative methods where patients were given the opportunity to respond to open-ended questions. Instead, MAWT perceptions had been assessed using questionnaires and closed-ended interview questions. When given the opportunity to respond, the participants in this study discussed aspects of suffering as the determinants of maximum wait time. Pain, mobility restriction, and deterioration while waiting were concerns for participants. Other participants felt waiting lists were controlled by larger systemic forces and resignation to waiting was the best approach. Delays in consultation for cardiac surgery and the procedure itself were perceived as potentially lethal and therefore required immediate attention.

How these findings correspond with other studies of patient perspectives of MAWT is discussed in the following sections.

### 5.2.1 MAWT and Suffering

Patient suffering as a determinant of MAWT was a resounding theme in the current study. My findings correspond with other research of MAWT among patients awaiting hip or knee replacement surgery in Canada (40,41,43,99). These studies have found patients tend to base their MAWT ratings on pain, mobility restriction, and overall urgency or severity. In the present study, participants considered similar factors in their determination of wait time tolerance for hip or knee replacement surgery. The greater suffering (ie, pain, mobility restriction) the patient was perceived to endure, the lower the maximum acceptable wait time.

Participants also discussed several nuances regarding suffering as a determinant of MAWT. For instance, Elsie, who was awaiting hip replacement surgery and the oldest participant in the study, identified the difficulties involved in the assessment of relative amounts of suffering (ie, the subjective experience of pain). In addition, she recognized the potential for an unfair queue – those with greater pain taking precedent over those who have waited a long time. Her inference was someone with less severe symptoms could wait almost indefinitely while those assessed with greater needs occupied the front of the queue.

The determinants of maximum wait time identified by participants in this study have been displayed to a certain extent in the scoring tools for priority criteria for hip and knee replacement surgery (22,23,32). Priority criteria developed by the Western Canada Waiting List Project for hip and knee replacement surgery include assessments of pain, functional limitations, abnormal physical findings, potential progression of disease, and threat to patient role and independence. An

additional priority criterion was raised by a participant in the present study. Nora, who was awaiting hip replacement surgery, raised the issue of available supports to patients. She implied if a person lacks support to maintain daily activities, then he or she should be given priority for surgery. For Nora, having the support of a husband and housekeeper meant she could tolerate a longer wait time than someone without such assistance.

The findings from the present study reflect previous quantitative research into patient perspectives of maximum acceptable wait times for hip and knee replacement surgery. Suffering in the manifestation of pain, mobility restriction and disease progression were primary concerns of participants who were awaiting all types of surgery in this study. Notably, participants were less focused on a specific wait time duration for surgery than providing considerations of the context (ie, degree of suffering) in which patients wait.

### 5.2.2 MAWT and Resignation

The qualitative nature of this research enabled participants to describe any determinant of MAWT they deemed relevant. Given this opportunity, some participants in the study resolved wait time duration was to simply be tolerated. These participants held fatalistic views about waiting. Wait time was portrayed as inevitable and to be endured regardless of patient status. The healthcare system was in the control of wait times; patient views on wait time maximums were immaterial. Another aspect of resignation to waiting appeared in participants' beliefs that waiting was an orderly and fair process. That is, surgery was provided to those in greatest need. Your time would come. Until then, accept that you wait.

Similar ideas were expressed by participants who provided reasons for maximum acceptable wait time and ideal wait time (99). Pain, quality of life impacts, and time to prepare for the

procedure were the most commonly cited reasons by this sample of respondents who were waiting for or had received surgery. Content analysis from the written portion of the questionnaire indicated a small percentage of participants also considered health system-related issues and the presence of others on the waiting list as reasons for wait time. What is not clear from the report of their findings is whether participants who cited these reasons were resigned to wait for surgery. In the present research, some participants cited similar reasons for wait time, and ostensibly these reasons led them to accept waiting.

Resignation or acceptance of wait time is a theme that rarely appears in the wait time for surgery literature. In general, MAWT has been presented as a measurement of the maximum patients will tolerate waiting, with the underlying assumption being waiting is a naturally intolerable state. The participants in this study who described resignation to wait time expressed waiting as an expected and therefore normal occurrence. Resignation is further discussed in the section on the effects of waiting, as some participants described how they accepted wait time.

### 5.2.3 MAWT and Perceived Lethality of Cardiac Surgery

Participants awaiting orthopaedic surgery consistently viewed consultation for cardiac surgery and the procedure as necessitating a very short wait time. Possible delays for cardiac surgery and consultation were seen to risk imminent mortality. This result is not particularly surprising given the portrayal of cardiac events in our culture as potentially lethal. Interestingly, some participants who were waiting for cardiac surgery did not share this perception. That is, they did not emphasize the need for immediate consultation and surgery. Possibly, these participants had been influenced by their own experience with wait time. For instance, three participants had

been told by their surgeons that they needed to wait a certain amount of time for surgery in order for their bodies to recover from a cardiac event.

The literature on the actual risk of mortality while waiting for coronary artery bypass surgery (CABG) has revealed mixed results (100,101). One prospective study (100) found wait time variables were not associated with increased mortality among 561 patients awaiting CABG. Instead, preoperative physical conditions predicted in-hospital death (from any cause), prolonged postoperative ventilation, and prolonged length of stay. On the other hand, a retrospective study (101) of 9233 patient records revealed delays for CABG surgery resulted in a higher proportion of preoperative deaths (from any cause) on the nonurgent waiting list compared to the semiurgent group. At the same time, there was equal probability of patient preoperative death from cardiovascular causes in each of the prioritization areas (urgent, semiurgent, nonurgent). Results from this research suggest some of my participants may have an exaggerated sense of the actual risk involved in waiting for cardiac surgery.

#### 5.2.4 Summary

This study was the first to take a qualitative approach to gathering participant perceptions of maximum acceptable wait times (MAWT) for orthopaedic and cardiac surgery. Similar to previous research, participants in this study emphasized the magnitude of patient suffering in determining wait times. However, in some cases participants identified the complexities in establishing priority criteria and noted the significance of individual circumstances such as support availability. Resignation to waiting typically does not appear in MAWT literature, but some participants in this study accepted wait time as part of their perception of the reality of the healthcare system. Acceptance was also related to recognition of one's place in the queue. Although shortages in the

system and fairness of waiting have been identified as reasons for MAWT in other studies (99), this study found participants felt wait time should be accepted for these reasons. Participant perceptions of the lethality of cardiac surgery reported in this study reflect a cultural sensitivity to the potential consequences of waiting for this type of surgery.

### 5.3 EFFECTS OF WAITING

The effects of wait time have been studied in several settings with a number of different patient groups. In the current study, waiting appeared to affect different participants to varying degrees, and these effects were not necessarily contingent on the duration of their wait time. There were effects that seemed more typical of particular patient groups. The effects of waiting could be understood within five dominant themes (restriction, uncertainty, resignation, coping with waiting, and opportunity) each of which had a number of components and either positive or negative effects. The consequences of waiting were distressing when participants felt restricted and uncertain. Waiting meant less distress for those with fewer restrictions or who managed well with their limitations. When participants felt more certain about their surgical outcome or were less concerned about their spot on the queue, waiting was less bothersome. Resignation to waiting resulted in less distress and greater well-being. Participants who were resigned to wait saw healthcare resources as finite and to be provided to those in greatest need. Participants described a number of ways to cope with wait time, including distraction (ie, staying busy with pleasant activities), using social support and making comparisons to others in greater need. Waiting as opportunity was expressed by some participants awaiting hip or knee replacement and cardiac surgery. For these participants, wait time imparted chances to consider positive aspects of life and to make preparations for surgery.

Each of these themes is discussed in the following sections. In some cases, these themes have appeared in other wait time research. In particular, the experiences of restriction and uncertainty have been frequently reported. The other three themes, however, appear less frequently in the literature. To provide context for these themes patient experiences with health problems other than waiting are provided.

### 5.3.1 Waiting is Restricting

The experience of restriction while waiting is well-documented among patients awaiting hip and knee replacement surgery (45,56,61) and patients awaiting cardiac surgery (57,60,63). Pain has been described as a significant issue for both patients awaiting hip or knee replacement surgery (45,56,61) and cardiac surgery (57,60). Mobility restrictions were a particular concern among patients awaiting hip or knee replacement surgery (45,56,61), though some studies indicate patients awaiting cardiac surgery also report limitations due to their anxiety regarding the potential to exacerbate symptoms (57,60). Role restrictions were also common among patients awaiting hip or knee replacement surgery (58). For some younger and blue collar patients awaiting cardiac surgery, role restriction has taken on the form of economic hardship (63).

I found the participants in the present study had similar complaints about the restricting nature of wait time. The participants awaiting hip or knee replacement surgery were bothered by pain, mobility and role restrictions while participants awaiting cardiac surgery primarily experienced mobility and role restrictions. The participants awaiting cardiac surgery often attributed restrictions to instructions from their doctors to minimize activity. These restrictions

often had distressing consequences for most participants. However, when these restrictions were minimal or managed effectively, these participants found wait time had negligible effects.

While wait time restrictions are commonly cited in the literature, accounts that waiting may have only nominal impacts are not frequently reported. Instead, the severity of wait time effects has been correlated with intolerance for waiting (48) and health related quality of life impacts (45). Some participants in the present study described wait time effects as relatively innocuous. For these participants, pain and role and mobility restrictions were either minimal or easy to manage. These findings present a somewhat different picture of wait time experience than is typically reported. This study suggests for some participants wait time was not entirely negative, despite restrictions.

### 5.3.2 Waiting is Uncertain

The uncertainty of waiting is another commonly documented experience in the wait time literature. The nature of uncertainty for patients awaiting hip or knee replacement surgery ranges from difficulty planning holidays (45) to fear of unsuccessful surgery (55) and the experience of struggling against a ‘faceless’ system (61). Uncertainty has also figured prominently among patients awaiting CABG surgery (60). Ambiguous length of time on the wait list has been a main concern of these patients (58,60). Anxiety has often accompanied the uncertainty patients experience while waiting for CABG surgery (57,58,60). In some cases, however, the uncertainty of a preoperative waiting period has been perceived as an opportunity for a ‘second chance’ where patients hope for a positive outcome (58).

While other research has emphasized the deleterious effects of uncertainty (60,61), in the current study, some participants were less disturbed by the uncertainty of wait time. For some an

approximate wait time was sufficient to assuage uncertainty and anxiety, and others felt confident in the outcome of the procedure. Many participants in each group spoke of their perception of surgery as the elixir for their condition. Perhaps the ability to view uncertainty of surgical wait time as an opportunity to focus on a positive outcome was an adaptive stance for these participants. Additional methods used by participants to cope with wait time are discussed in section 5.3.4.

### 5.3.3 Resigned to Wait

The notion that some participants were resigned to wait or accepted the wait for surgery is an unusual finding for patients awaiting scheduled surgery. One study (95) examined patient satisfaction with wait time for hip or knee replacement surgery and determined wait time satisfaction was related to fulfilment of expectations about wait time and patient perception of fairness. While satisfaction or fairness and acceptance or resignation are not the same constructs, participants in my study who expressed resignation to wait sometimes discussed their expectations. These participants were influenced by the public perception of wait time (eg, media reports, descriptions of friends/family experience, personal knowledge of healthcare system) and expected to wait. In some cases, their waits to see a specialist or for scheduled surgery were shorter than expected and wait time satisfaction was reported. They also expressed a desire for fairness in the system. That is, they compared their condition to others who might be in greater need. Reasons for wait time such as health system related issues and others on the wait list have been reported with samples of patients awaiting hip or knee replacement surgery (99).

Some participants in the current study expressed a particular form of resignation to waiting. They contended, in a simply fatalistic manner, that waiting was an inevitable part of life. Waiting

was beyond an individual's control, and therefore, acceptance of wait time was the only way to avoid frustration and maintain meaning in life. In his analysis of waiting in western culture, Gasparini (10) identified a similar response to waiting. In his view, waiting could allow the development of patience, a virtue not often extolled in western life. For some of my participants, wait time did instil patience and the accentuation of this quality was seen as an important feature to improve the quality of time while waiting.

#### 5.3.4 Coping with Wait Time

Several participants in this study described their wait time coping efforts, including distraction, use of downward comparison, and social support. These efforts alleviated suffering, enabled time to pass more quickly, and allowed participants to maintain their routines. Other studies have revealed similar findings regarding social support where patients awaiting hip or knee replacement were able to maintain full lives within a supportive environment (61). Family and social relationships also influenced the coping ability of patients awaiting cardiac surgery (57,60). In this study, complex connections between social support and coping emerged. While many participants found their social and personal relationships to be supportive, some participants expressed negative effects from their social networks regarding their wait time. These participants felt social pressure to 'know' their surgery date.

How patients cope with wait time has not been a usual area of interest in the wait time literature. This absence of interest in coping methods could be attributed to the emphasis in the literature on symptom severity and wait time duration tolerance. Other recent research has attended to patient expectations (65) and patient willingness to change surgeons for a shorter wait time (42). The present study indicated that for some participants the experience of waiting elicited

descriptions of efforts to cope. These ways of coping were similar to reactions people have when faced with a health threat (102). When people encountered either acute or chronic health issues, distraction was one of the means used to cope with illness (103). Social comparison, including comparison with a less fortunate reference group, is a common method of coping with health problems (104,105). Some participants in the current study described these methods of coping with waiting. That is, when participants compared their health status to others who were less fortunate in terms of severity of illness or waiting conditions, they tended to minimize the effects waiting had on their own status.

The recognition of coping efforts by participants awaiting scheduled surgery suggests patients are active in their attempts to ameliorate the effects of waiting. The coping methods employed by participants in this study offer a complex picture of coping with wait time experience. For example, some methods such as social support were effective for some participants and not for others. The investigation of coping among patients awaiting scheduled surgery could lead to strategies to improve the waiting experience.

#### 5.3.5 Waiting as Opportunity

With the exception of one study of patients awaiting cardiac surgery (54), the theme of waiting as opportunity does not appear in the wait time literature. In one study of patients awaiting hip or knee replacement surgery, participants identified the need to prepare mentally or physically as a reason for wait time (99). Some participants in the present study also experienced wait time as an opportunity to prepare for the procedure. In addition, they ‘used’ wait time in ways that were not typically available to them. In this sense waiting offered a ‘gift of time’ to some participants.

Interestingly, the participants awaiting shoulder surgery did not describe waiting as an opportunity to either prepare for the procedure or to augment their time. A possible explanation for this absence may be the age and employment status of this group of participants. Nine of the 11 participants were in the work force and seven of those participants expressed concerns regarding the restrictions of their shoulder condition as related to their current or future work situations. The remaining two retired participants were involved in physical activities and viewed their conditions, and therefore waiting, as limiting. It is possible that these participants who were more troubled by their employment and functional status may have been less likely to experience wait time as an opportunity.

The notion that waiting may serve as an opportunity for some patients contradicts the prevailing stance that waiting is an inherently negative experience. Some participants in this study experienced wait time as a chance to explore possibilities that were not available at 'regular' times. In this way, participants had a positive experience of wait time.

#### 5.3.6 Summary

The effects of waiting for this sample of participants reflect findings from other studies of patients awaiting scheduled surgery. Restriction and uncertainty have been reported in other samples of patients awaiting orthopaedic surgery or cardiac surgery. Some notable differences emerged in the present sample of participants regarding waiting effects. Some participants noted that certainty – knowing when surgery might occur – influenced their level of distress. Other participants were decidedly resigned to wait and viewed waiting as a reality of the healthcare system and a normal part of life. For certain participants waiting elicited coping reactions, a response not previously noted in the literature. Like others patients contending with chronic

illness, participants used distraction, downward comparison and social support to better manage wait time. Waiting as opportunity, an uncommon theme in wait time literature, appeared for some participants awaiting cardiac surgery or hip or knee replacement surgery. Participants awaiting shoulder surgery, perhaps due to their age and employment status, did not experience waiting as an opportunity. This theme of wait time as opportunity contradicts the dominant negative perception of wait time experience.

## 5.4 GENERAL DISCUSSION

This final section of discussion of the findings considers the differences and similarities among participant groups, some of the more idiosyncratic findings, and how the results can be situated within a social and cultural context. Each of these topics is examined in more detail in the following subsections.

### 5.4.1 Group Comparisons

The intent of this research was to recruit groups of patients with different wait times for surgery so that lived wait time experiences could be compared. Although there were commonalities in terms of participant experiences of time while waiting, perceptions for maximum acceptable wait times, and waiting effects, these similarities among participants did not necessarily correspond to surgery type. There were subtle differences between groups – many participants awaiting cardiac surgery experienced time passing more quickly than many participants awaiting orthopaedic surgery; some participants awaiting cardiac surgery, unlike participants awaiting orthopaedic surgery, did not remark on the need for short wait times for consultation and cardiac surgery due to its lethality; and the effects of waiting, in particular restriction, uncertainty and

opportunity manifested somewhat differently in the patient groups. This suggests only tentative statements about waiting and differences in illness condition can be made based on these findings.

The relative lack of marked differences between the participant groups implies other factors may be more important in wait time experience. Characteristics such as age, residence, and employment status may be significant determinants of the quality of waiting experiences. In accordance with the exploratory purpose of this research, there were no specific parameters regarding age range, residence, disease condition, or employment status, or any other variable that could potentially impact intra or intergroup differences. In order to facilitate patient recruitment and draw on a variety of experiences, inclusion criteria for the study were kept very broad. Perhaps, as a result, this study was better able to capture the diversity of experiences of patients awaiting scheduled surgery.

#### 5.4.2 Notable Themes and Remarkable Individuals

When reviewing the literature on wait time effects, I had anticipated my study would yield similar findings. However, in keeping with IPA, the analysis of the participant transcripts rendered themes based on the data, rather than a pre-existing framework. Consequently, unique themes and the idiosyncratic qualities of the participants became more apparent. This section presents these themes and qualities as a distinct contribution of this study to the wait time literature.

First, this study offers an alternative depiction of wait time effects where the findings suggest waiting is not an unequivocally negative experience. Indeed, some participants were resigned to wait despite their own suffering. Rather than passive ‘patients’, participants were agentic and appropriated their time in ways that held meaning for them. Participants actively

coped with waiting's effects by seeking distraction and social support and by referencing less fortunate others. Although many participants in this study experienced restrictions and uncertainty – common findings in the literature – this did not mean perpetual suffering for some participants. This denotes the experience of waiting for scheduled surgery is complex and not necessarily a linear relationship between greater symptom severity and less tolerance for wait time.

Second, the waiting experiences of certain participants appeared exceptional. Nora, Peter, Jack, and Beatrice who were awaiting orthopaedic surgery seemed exemplary. On one hand, the experiences of Nora and Peter were very much influenced by their employment conditions. Nora, whose wait time had rendered her time meaningless due to the extent of her pain and disability, observed the absurdity of being paid a large portion of her salary to wait. Yet, she was steadfast in her support of a publicly funded healthcare system where patients were prioritized and waited for treatment. Peter, who lacked similar employment benefits, was not sympathetic to the system and vehemently ranted and cursed in regard to the limitations he associated with waiting for surgery. He pondered the possibility of paying out-of-province for the procedure.

Conversely, time went on as usual for Jack and Beatrice. In Jack's experience all control was relinquished to doctors and the healthcare system that "drove the train", and he was not bothered by the notion he was not in control. Whereas Beatrice saw herself in complete control of her time and her wait time. Similarly, Alice, who was awaiting cardiac surgery, "made" her time "nice". She took waiting as an opportunity to learn patience – an opportunity not expressed by other participants.

Although the descriptions by these particular participants connected to other themes in the study (ie, restriction, resignation, time drags without meaning, time as usual with agency, waiting as opportunity), each participant described what appeared to be extreme instances of waiting experiences. This raises the question of the commonality of these results. Are there more Alices and Jacks than Noras and Peters? Furthermore, questions arise regarding how these particular participants develop and maintain their perspectives on waiting. In other words, what determines when an apparent Sisyphean experience like waiting for help with a health problem becomes meaningful? Can the determinants of their experiences be explained by employment status, personal disposition, or other variables? These questions also relate to the methodological issue of transferability that will be discussed in the next and final chapter.

#### 5.4.3 Social and Cultural Context of Wait Time

These results are situated within a particular social and cultural context. Data collection occurred at a main tertiary centre in the province of Saskatchewan that provides services to patients from in and outside Saskatoon. Moreover, data were collected during a period when wait time was (and remains) a highly political and publicized issue. For instance, after its launch in April 2010, the Saskatchewan Surgical Initiative announced the goal of “wait no longer than 3 months by 2014” for scheduled surgery. The Initiative continues to provide specific information on wait times in general and by individual specialist. The availability of this information may explain some participant perspectives of three month maximum acceptable wait times. Nevertheless, the prevalent discussion of wait times in the public sphere raises the matter of the context in which patients wait.

Generally, in western culture having to wait is not met with great alacrity (10,67), especially when the wait time is for health services. It follows that the experiences of wait time are imbued in where and how people live. During the course of this study, wait time for surgery figured prominently in the media and the Saskatchewan government made a promise to reduce surgical wait times to three months. Some participants in this study reported their experience of wait time duration was contrary to their expectation; surprisingly it was shorter than they anticipated. Participants did not develop such expectations in isolation, but were influenced by media reports and the experiences of other patients. Similar to other studies (65), participants were pleased by shorter than expected wait times. At the same time, some participants appeared to be unaffected by the social milieu of wait time angst and were resigned to wait. Perhaps there is also a cultural imperative to remain positive despite adverse conditions. Why certain participants appeared more vulnerable to potentially negative social and cultural aspects of wait time is unclear and may be a direction for further research. Future research directions are discussed in the final chapter.

## **6 Conclusion**

The final chapter concludes this study by offering recommendations about improving wait time experience, discussing strengths and limitations of the study, and exploring directions for future research. The last section describes my reflections on how the research impacted my initial ideas regarding wait time.

### **6.1 RECOMMENDATIONS**

These recommendations are based in part on the suggestions participants offered in response to the question: If you had to offer someone advice about how to deal with waiting to see a specialist/for surgery, what would you tell them? The suggestions participants offered to other patients diverged into two main categories: guidance on managing wait time experience and advice on navigating the healthcare system. The suggestions are discussed in the following subsections.

#### **6.1.1 Managing Wait Time Experience**

Participants had many suggestions for how the wait time experience could be improved. Their ideas ranged from keeping busy to keeping a positive perspective. Being busy with whatever daily activities were possible was seen as an important distraction. Having a positive perspective on waiting meant not dwelling on the experience and comparing oneself to less fortunate others. Self-care while waiting was also critical and included such activities as exercise and spirituality. The use of social support, especially consultation with others who had similar waiting experiences, was noted. Consultation with other patients related to information gathering, another important component of the waiting experience. Wait time could be time to prepare for surgery.

### 6.1.2 Navigating the Healthcare System

Participants advised other patients on the importance of navigating the healthcare system. When waiting for consultation with a specialist, participants emphasized the significant role of the family doctor in the referral process. Contacting one's family doctor as soon as symptoms appeared was viewed as paramount. One participant went to the extent of writing a letter to the specialist outlining symptom severity in order to accelerate wait time. Another suggestion was to garner a place on the cancellation list. However, being a 'squeaky wheel' was viewed with ambivalence. On one hand, frequent contact with the patient's family doctor or specialist regarding wait time was seen as effective and empowering. At the same time, repeated contact with the healthcare system was thought to risk the alienation of practitioners. One participant felt recurrent calls had rendered no new information. Another participant was frustrated with waiting to the point that he advised to "go somewhere to get it done" and not waste time with interim therapies such as cortisone shots. Other participants suggested seeking provisional treatments for pain management.

The suggestions made by participants in this study indicate more can be done to assist patients in the waiting period for consultation and surgery. In particular, the restrictions and the uncertainty experienced by patients could be ameliorated. In regards to alleviating restrictions, healthcare practitioners can encourage patients awaiting hip and knee replacement surgery to exercise in the preoperative period. A systematic review and meta-analysis of the non-surgical and non-pharmacological literature on preoperative interventions for patients awaiting hip and knee replacement demonstrated that preoperative exercise decreased pain and that exercise accompanied by preoperative education increased activity postoperatively (106). Implementation of structured exercise programs and additional education for patients awaiting orthopaedic

surgery could improve the quality of wait time experience and postoperative outcomes, keeping in mind that exercise regimes and educational supports must be made accessible and adaptable for all patient groups (ie, rural/urban, age range, education and income level). As one rural participant in this study remarked on the advantages of attending a preoperative Telehealth session on orthopaedic surgery, these sessions may improve the waiting experience of patients.

Some participants in this study were content to wait to hear from their surgeon, while others voiced distinct desires to know their place in the queue. In other words, participants had different reactions to dealing with the uncertainty inherent in illness and in the healthcare system. When patients are diagnosed, direct assessments could be made of their information needs and appropriate resources could be matched to those needs. Since uncertainty in chronic illness has been clearly linked with negative psychosocial outcomes (107), providing patients with information regarding wait list scheduling protocols may decrease ambiguity in the preoperative period. Whether through public education regarding the reasons for wait time (108) or via systematic efforts to maintain contact with patients while they wait (61), increasing the transparency of the healthcare system may improve patient experience of wait time.

## 6.2 STRENGTHS AND LIMITATIONS

Inherent in this study, like all research methods, are strengths and limitations. I chose an interpretative phenomenological method in order to achieve the goal of exploring wait time experience from the perspective of the patient. While this method allowed me to explore the depth of these experiences, the qualitative nature of the study and its use of non-probability sampling means generalizability of the findings in a statistical sense are limited. Instead, qualitative researchers insist that all research is contextual (109). Therefore, how patients

experienced waiting in this study (and my interpretation of their wait time experience) is transferable to another group of patients only when the context for both groups is congruent (110). Using these results to understand the experience of all patients awaiting all types of surgery or wait time experience for healthcare in general may not be appropriate. For instance, it is possible these results could apply in other publically funded health care systems where similar issues may exist regarding protracted wait times (eg, the U.K., New Zealand). However, only when contextual factors (eg, demographic and societal influences) are taken into account may the themes that emerged from my participants' experiences reflect other patients' experiences who are awaiting cardiac and orthopaedic surgery. There may be too many divergent conditions where patients await surgery in other countries for these results to be applied.

Moreover, my interpretation of participant wait time experience is imbued by my personal context. This may be both a strength and a limitation of the study. Though I am a long time researcher, my experience is mainly in the quantitative realm. Doing qualitative research was a relatively new and challenging experience. On another note, I benefited from my years of clinical interviewing experience and was comfortable establishing rapport with my participants. As a long time resident of both urban and rural Saskatchewan, I could easily relate to the circumstances of many participants. For example, I have witnessed first hand the nature of social support in rural areas and could understand the impact of its nuances on participants. Also, I am fortunate to know many people from various socio-economic and educational backgrounds so my own biases became less dominant. For instance, I understood the frustration and hostility expressed by a participant awaiting shoulder surgery when his job was threatened. Retraining was not and never would be an option for him. My capacity to appreciate participants' individual circumstances assisted my interpretation and was a fundamental benefit to the study. At the same

time, I recognize I could not truly 'know' what it was like to wait, having never waited myself for consultation or for these procedures and being limited by my inherent and intractable presuppositions.

The study was intended to make a relatively direct comparison between participants awaiting orthopaedic surgery and participants awaiting cardiac surgery. Unfortunately, data collection rendered this comparison less direct than intended. For the two orthopaedic groups, participants awaiting hip or knee replacement and participants awaiting shoulder surgery, there were similar intervals between the two interviews. That is, the first interview took place shortly after the decision to treat was made, and the second interview occurred approximately three months later. Participants awaiting cardiac surgery generally had a much shorter wait time. They were interviewed approximately a week or more after their angiography. For their second interview, all participants awaiting cardiac surgery were interviewed the day before their surgery. In other words, for participants awaiting cardiac surgery, their waiting period was coming to a close. The participants awaiting orthopaedic surgery, on the other hand, were still facing a relatively indeterminate waiting period. Only two of the 22 participants awaiting orthopaedic surgery, both of whom were in the shoulder group, knew their surgery date at the second interview. This systematic difference in data collection may have influenced some results. Although the inclusion of the three groups in the same study allowed comparisons to be made, some differences between groups may be an artefact of when the data were collected (eg, participants awaiting cardiac surgery experiencing an accelerated passage of time).

The focus of this exploratory study was on three areas of wait time experience. It is possible that other aspects of waiting are also important to participants, and these areas were not

addressed by the study. However, the areas that were explored were examined thoroughly by virtue of two interviews and a carefully crafted and pre-tested interview guide. Participants were also given the opportunity at the end of interviews to add any additional observations and experiences. Future directions for study of other aspects of wait time experience are discussed in the next section.

### 6.3 FUTURE RESEARCH

In the overall wait time literature, investigation of patients' perspectives has often been limited to the duration of wait time tolerance and its correlates. As an exploratory study, this research raised many questions regarding wait time experience that merit further examination. The primary comparison in this study was surgery type. Nevertheless, other differences among participants could be more relevant to lived experience of wait time. That is, participant age, residence, gender, employment and/or marital status may be important determinants of how patients experience waiting. As the main lens in the study was surgery type, these other conditions received less direct attention in the overall analysis. Because participants were not recruited according to age group, for instance, understanding wait time experience of particular age groups was not attempted.

In this study, waiting experience was considered from the perspective of the patient prior to surgery. Further research could follow patients postoperatively to examine their experiences of time during the recovery period. A postoperative study could also ask patients about the impact of waiting on their postoperative experience. Many studies have investigated preoperative wait time, while few have considered the patient perspective on waiting once surgery is complete.

Some of the findings that emerged from this study could be supported using quantitative research methods. For example, I contended that agency appears to be the principal determinant of lived time duration while waiting for consultation and surgery. While there is evidence to suggest the significance of agency in the experience of time (78), this relationship has not been directly examined in a population of patients awaiting consultation or surgery. A possible causal link between agency and time experience would indicate the need to assist patients to enhance their awareness of opportunities to be more agentic regarding time.

A wider investigation of coping strategies used by this population of patients is warranted. In this study, participants used similar coping strategies to other patients with chronic disease (103). Again, research using quantitative methods in a larger sample could identify the range of coping strategies used while waiting for consultation and surgery. The aim of such research would be to discover strategies that were most consistent with positive outcomes.

Participant experience with social support as a coping mechanism was mixed in this study. While social support and chronic illness has been studied extensively (eg,111), the role a support network plays when waiting for help with chronic illness is relatively unknown. If support is supportive only under certain conditions, knowledge of those conditions would assist both patients and practitioners.

Finally, identifying the predictors of resignation to wait time is a worthy area of investigation. Why some patients are able to resign themselves to wait time and experience relatively little suffering while others are overwhelmed by distress is unexplained. In the current study, this relationship seemed to be only partially accounted for by symptom severity. Since

wait time will inevitably occur in the healthcare system, understanding and promoting resignation to waiting may be a laudable goal.

#### 6.4 FINAL REFLECTIONS

An important and sometimes overlooked aspect of academic research is the dissemination of results beyond publication in the academic literature. Because wait time continues to be a topic of concern among practitioners and policy makers, dissemination of the present findings need to occur. There are a number of avenues for disseminating this work. During the course of my research, I had the opportunity to speak with the Assistant Deputy Minister of Health who invited me to share my findings with him. The surgeons who assisted with recruitment are also a logical starting point for dissemination. Sending a brief report to family practitioners in the province may improve understanding of the breadth of wait time experiences. A literature review has already been published in the journal of Psychology Research and Behavior Management, and full publications of the research and its findings will be submitted to Qualitative Health Research and other appropriate journals in the field of health science. Wider public education about wait time experience is warranted. Perhaps this can be accomplished through a greater association with health policy makers.

From my personal perspective, a main impetus for this study was my friendship with Bill, a patient who I suspected had a decidedly unique wait time experience. As a patient who seemed to be minimally affected by waiting, I thought his unusual circumstances (ie, his ability to control the timing of his surgery) would set his experience apart from other patients. After interviewing patients who had awaited consultation and were awaiting surgery and analysing their experiences, I recognized I could interpret Bill's wait time experience as emulating

participants who viewed wait time as an opportunity to prepare and who were agentic regarding their time. In other words, I could 'fit' Bill's experience into the findings and transfer his context into my research.

This study fits with the overall importance of wait time as a public concern and a healthcare system issue. The experiences of these participants point to an imperative to understand waiting as a complex and individual process. Time while waiting was experienced more and less quickly than chronological time, yet time remained 'usual' for some participants. The seemingly Sisyphean task of wait time became meaningful. As some participants were less troubled by wait time, the notion that waiting is a thoroughly and universally negative experience has been challenged. At the same time, many participants had a pressing necessity to allay the restrictions and uncertainty associated with waiting. Ultimately, this research conveys a need to focus resources on identifying and alleviating the deleterious effects of waiting for some patients rather than reducing absolute wait times for all patients.

The uncertainty expressed by many participants in this study indicates that simply improving communication with patients may be sufficient to assuage negative waiting effects (106, 111). For example, participants awaiting cardiac surgery could have benefited from information about the procedure whereas updated information about the approximate time of surgery could have assisted participants awaiting orthopaedic surgery. Delineating patient information needs as they wait for scheduled surgery has the potential to improve their waiting experiences. In this study, participants also shared their strategies on how to effectively manage the waiting period. These strategies focused on individual efforts to pass wait time fruitfully, and

on strategic ways to ‘work’ the system to one’s advantage. To this end, assisting patients to navigate wait time could become the responsibility of specific healthcare providers.

In Chapter 2, I proposed a conceptual framework on lived time duration that posited a potentially complex relationship between time, suffering, meaningfulness, and agency. Among the participants in this study, agency emerged as the most useful concept to understand time experience. However, situational factors, which were not fully explored in this study, could have determined the extent of the agency of participants. In this sense, the framework remains incomplete and worthy of further investigation.

Finally, these findings may offer greater appreciation for other waiting experiences for patients. For instance, differences in patient agency found in this study could be generalized in order to understand time experiences in settings such as emergency departments. By further opening the door to patients’ experiences of time these findings invite healthcare practitioners to consider this aspect of patient experience when offering and evaluating patient care.

## 7 References

1. Smith JA, Flowers P, Larkin M. *Interpretative Phenomenological Analysis; Theory, Method and Research*. Thousand Oaks CA, Sage; 2009.
2. McDonald P, Shortt S, Sanmartin C, Barer ML, Lewis S, Sheps S. Waiting lists and waiting times for health care in Canada: more management!! More money?? Summary Report. <http://www.chspr.ubc.ca/files/publications/1998/hpru98-09D-A.pdf>. Published July, 1998. Accessed February 16, 2009.
3. Pitt DF. Waiting lists: management, legalities and ethics. *Can J Surg*. 2003;46(3):170.
4. McGurran J, Noseworthy T; Steering Committee of the Western Canada Waiting List Project. Improving the management of waiting lists for elective healthcare services: public perspectives on proposed solutions. *Hosp Q*. 2002;5(3):28-32.
5. Canadian Medical Association; Wait Time Alliance. It's about time! Achieving benchmarks and best practices in wait time management. [http://www.cma.ca/multimedia/CMA/Content/Images/Inside\\_cma/Media\\_Release/pdf/2005/wta-final.pdf](http://www.cma.ca/multimedia/CMA/Content/Images/Inside_cma/Media_Release/pdf/2005/wta-final.pdf). Published August 2005. Accessed February 16, 2009.
6. Canadian Medical Association; Wait Time Alliance. Time for progress: New benchmarks for achieving meaningful reductions in wait times. [http://www.waittimealliance.ca/images/Fall\\_2007/time\\_for\\_progress.pdf](http://www.waittimealliance.ca/images/Fall_2007/time_for_progress.pdf). Published November 2007. Accessed February 16, 2009.
7. Western Canada Waiting List Project. Moving forward: final report. [http://www.wcwl.org/media/pdf/news/moving\\_forward/report.pdf](http://www.wcwl.org/media/pdf/news/moving_forward/report.pdf). Published February 28, 2005. Accessed February 18, 2009.
8. Sanmartin C; Steering Committee of the Western Canada Waiting List Project. Toward standard definitions for waiting times. *Healthc Manage Forum*. 2003;16:49-53.
9. Charmaz K. *Good days, bad days: the self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press; 1991.
10. Gasparini G. On waiting. *Time & Soc*. 1995;4(1):29-42.
11. Gross E. Waiting at Mayo. *Urban Life*. 1986;15(2):139-164.
12. Lovgren M, Hamberg K, Tishelman C. Clock time and embodied time experienced by patients with inoperable lung cancer. *Cancer Nurs*. 2010;33(1):55-63.
13. Rasmussen DM, Elverdam B. Cancer survivors' experience of time – Time disruption and time appropriation. *J Adv Nurs*. 2007;57(6):614-622.

14. Zhou Yanqiu R. The phenomenology of time: Lived experiences of people with HIV/AIDS in China. *Health*. 2010;14(3):310-325.
15. Morse JM, Richards L. *Readme First for a User's Guide to Qualitative Methods*. Thousand Oaks, CA: Sage; 2002.
16. Denzin NK, Lincoln YS. Introduction: The discipline and practice of qualitative research. In: Denzin NK, Lincoln YS, eds. *The Sage Handbook of Qualitative Research*. Thousand Oaks, CA: Sage; 2011:1-20.
17. Altheide DL, Johnson JM. Reflections on interpretive adequacy in qualitative research. In: Denzin NK, Lincoln YS, eds. *The Sage Handbook of Qualitative Research*. Thousand Oaks, CA: Sage; 2011:581-584
18. Masri BA, Cochrane N, Dunbar M, et al. Priority criteria for hip and knee replacement: addressing health service wait times. Report 1 Literature Review: Waiting, Consequences & Benchmarks for Joint Replacement. [http://www.plexia.ca/masri/Waiting %20Report%20I%20July%2021\\_Final\\_.pdf](http://www.plexia.ca/masri/Waiting%20Report%20I%20July%2021_Final_.pdf). Published July 2005. Accessed February 20, 2009.
19. Glynn P, Taylor M, Hudson A. Surgical wait list management: a strategy for Saskatchewan. <http://www.health.gov.sk.ca/surgical-wait-list-management>. Published January, 2002. Accessed February 20, 2009.
20. Canadian Institute for Health Information. Waiting for health care in Canada: what we know and what we don't know. [http://secure.cihi.ca/cihiweb/dispPage.jsp?cw\\_page=AR\\_1385\\_E](http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=AR_1385_E). Published 2006. Accessed February 20, 2009.
21. Canadian Medical Association. The economic cost of wait times in Canada. <http://www.oaa.ca/files/economic%20costs%20of%20wait%20time.pdf>. Published January 15, 2008. Accessed February 20, 2009.
22. Arnett G, Hadorn DC; Steering Committee of the Western Canada Waiting List Project. Developing priority criteria for hip and knee replacement: results from the Western Canada Waiting List Project. *Can J Surg*. 2003;46(4):290-296.
23. Conner-Spady B, Estey A, Arnett G, et al. Prioritization of patients on waiting lists for hip and knee replacement: validation of a priority criteria tool. *Int J Technol Assess Health Care*. 2004;20(4):509-515.
24. Conner-Spady BL, Arnett G, McGurran JJ, Noseworthy TW; Steering Committee of the Western Canada Waiting List Project. Prioritization of patients on scheduled waiting lists: validation of a scoring system for hip and knee arthroplasty. *Can J Surg*. 2004;47(1):39-46.

25. Derrett S, Devlin N, Hansen P, Herbison P. Prioritizing patients for elective surgery: a prospective study of clinical priority assessment criteria in New Zealand. *Int J Technol Assess Health Care*. 2003;19(1):91-105.
26. Hadorn DC, Holmes AC. The New Zealand priority criteria project. Part 1: Overview. *BMJ*. 1997;314(7074):131-134.
27. Hadorn DC, Holmes AC. The New Zealand priority criteria project. Part 2: Coronary artery bypass graft surgery. *BMJ*. 1997;314(7074):135-138.
28. Hadorn DC; Steering Committee of the Western Canada Waiting List Project. Developing priority criteria for magnetic resonance imaging: results from the Western Canada Waiting List Project. *Can Assoc Radiol J*. 2002;53(4):210-218.
29. MacCormick AD, Collecutt WG, Parry BR. Prioritizing patients for elective surgery: a systematic review. *ANZ J Surg*. 2003;73(8):633-642.
30. Martin DK . Priority setting in surgery: improve the process and share the learning. *World J Surg*. 2003;27(8):962.
31. Naylor CD, Szalai JP, Katic M. Benchmarking the vital risk of waiting for coronary artery bypass surgery in Ontario. *CMAJ*. 2000;162(6):775-779.
32. Noseworthy TW, McGurran JJ, Hadorn DC; Steering Committee of the Western Canada Waiting List Project. Waiting for scheduled services in Canada: development of priority-setting scoring systems. *J Eval Clin Pract*. 2003;9(1):23-31.
33. Ray AA, Buth KJ, Sullivan JA, Johnstone DE, Hirsch GM. Waiting for cardiac surgery: results of a risk-stratified queuing process. *Circ*. 2001;104(12 Suppl 1):S92-S98.
34. Romanchuk KG, Sanmugasunderam S, Hadorn DC; Steering Committee of the Western Canada Waiting List Project. Developing cataract surgery priority criteria: results from the Western Canada Waiting List Project. *Can J of Ophthalmol*. 2002;37(3):145-154.
35. Taylor MC, Hadorn DC; Steering Committee of the Western Canada Waiting List Project. Developing priority criteria for general surgery: results from the Western Canada Waiting List Project. *Can J Surg*. 2002;45(5):351-357.
36. Wright D, Arthur H. An analysis of the impact of a management system on patients waiting for cardiac surgery. *Can J Cardiovasc Nurs*. 1996;7(1):5-9.
37. Hadorn DC; Steering Committee of the Western Canada Waiting List Project. Setting priorities for waiting lists: defining our terms. *CMAJ*. 2000;163(7):857-860.
38. Conner-Spady BL, Sanmugasunderam S, Courtright P, et al. Patient and physician perspectives of maximum acceptable waiting times for cataract surgery. *Can J of Ophthalmol*. 2005;40(4):439-447.

39. Conner-Spady BL, Sanmugasunderam S, Courtright P, McGurran JJ, Noseworthy TW; Steering Committee of the Western Canada Waiting List Project. Determinants of patient satisfaction with cataract surgery and length of time on the waiting list. *Br J Ophthalmol*. 2004;88(10):1305-1309.
40. Conner-Spady BL, Johnston GH, Sanmartin C, McGurran JJ, Noseworthy TW; Saskatchewan Surgical Care Network; Western Canada Waiting List Project Research and Evaluation Working Group Committee. A bird can't fly on one wing: patient views on waiting for hip and knee replacement surgery. *Health Expectations*. 2007;10(2):108-116.
41. Conner-Spady B, Estey A, Arnett G, et al. Determinants of patient and surgeon perspectives on maximum acceptable waiting times for hip and knee arthroplasty. *J Health Serv Res Policy*. 2005;10(2):84-90.
42. Conner-Spady B, Sanmartin C, Johnston G, McGurran J, Kehler M, Noseworthy T. Willingness of patients to change surgeons for a shorter waiting time for joint arthroplasty. *CMAJ*. 2008;179(4):327-332.
43. Llewellyn-Thomas HA, Arshinoff R, Bell M, Williams JI, Naylor CD; Ontario Hip and Knee Replacement Project Team. In the queue for total joint replacement: patients' perspectives on waiting times. *J Eval Clin Pract*. 1998;4(1):63.
44. Dunn E, Black C, Alonso J, Norregaard JC, Anderson GF. Patients' acceptance of waiting for cataract surgery: what makes a wait too long? *Soc Sci Med*. 1997;44(11):1603-1610.
45. Derrett S, Paul C, Morris JM. Waiting for elective surgery: effects on health-related quality of life. *Int J Qual Health Care*. 1999;11(1):47-57.
46. Ho E, Coyte PC, Bombardier C, Hawker G, Wright JG. Ontario patients' acceptance of waiting times for knee replacements. *J Rheumatol*. 1994;21(11):2101-2105.
47. Lofvendahl S, Eckerlund I, Hansagi H, Malmqvist B, Resch S, Hanning M. Waiting for orthopaedic surgery: factors associated with waiting times and patients' opinion. *Int J Qual Health Care*. 2005;17(2):133-140.
48. Snider MG, MacDonald SJ, Pototschnik R. Waiting times and patient perspectives for total hip and knee arthroplasty in rural and urban Ontario. *Can J Surg*. 2005;48(5):355-360.
49. Oudhoff JP, Timmermans DR, Rietberg M, Knol DL, van der Wal G. The acceptability of waiting times for elective general surgery and the appropriateness of prioritising patients. *BMC Health Serv Res*. 2007;7:32.

50. Ackerman IN, Graves SE, Wicks IP, Bennell KL, Osborne RH. Severely compromised quality of life in women and those of lower socioeconomic status waiting for joint replacement surgery. *Arthritis Rheum.* 2005;53(5):653-658.
51. Davis AM, Agnidis Z, Badley E, et al. Waiting for hip revision surgery: the impact on patient disability. *Can J Surg.* 2008;51(2):92-96.
52. Kili S, Wright I, Jones RS. Change in Harris hip score in patients on the waiting list for total hip replacement. *Ann R Coll Surg Engl.* 2003;85(4):269-271.
53. Rigge M. Quality of life of long wait orthopaedic patients before and after admission: a consumer audit. *Qual Health Care.* 1994;3(3):159-163.
54. Mahon JL, Bourne RB, Rorabeck CH, Feeny DH, Stitt L, Webster-Bogaert S. Health-related quality of life and mobility of patients awaiting elective total hip arthroplasty: a prospective study. *CMAJ.* 2002;167(10):1115-1121.
55. Sampalis J, Boukas S, Liberman M, Reid T, Dupuis G. Impact of waiting time on the quality of life of patients awaiting coronary artery bypass grafting. *CMAJ.* 2001;165(4):429.
56. Gustafsson BA, Ponzer S, Heikkila K, Ekman SL. The lived body and the perioperative period in replacement surgery: older people's experiences. *J Adv Nurs.* 2007;60(1):20.
57. McCormick KM, McClement S, Naimark BJ. A qualitative analysis of the experience of uncertainty while awaiting coronary artery bypass surgery. *Can J Cardiovasc Nurs.* 2005;15(1):10-22.
58. McCormick KM, Naimark BJ, Tate RB. Uncertainty, symptom distress, anxiety, and functional status in patients awaiting coronary artery bypass surgery. *Heart Lung.* 2006;35(1):34-45.
59. Fitzsimons D, Parahoo K, Stringer M. Waiting for coronary artery bypass surgery: a qualitative analysis. *J Adv Nurs.* 2000;32(5):1243-1252.
60. Fitzsimons D, Parahoo K, Richardson SG, Stringer M. Patient anxiety while on a waiting list for coronary artery bypass surgery: a qualitative and quantitative analysis. *Heart Lung.* 2003;32(1):23-31.
61. Sjoling RN, Agren RN, Olofsson N, Hellzen RN, Asplund RN. Waiting for surgery; living a life on hold--a continuous struggle against a faceless system. *Int J Nurs Stud.* 2005;42(5):539-547.
62. Janzen JA, Hadjistavropoulos HD. Examination of negative affective responses to waiting for surgery. *Can J Nurs Res.* 2008;40(4):72.

63. Petrie JF, Cox JL, Teskey RJ, Campbell LB, Johnstone DE. Preliminary assessment of patients' opinions of queuing for coronary bypass graft surgery at one Canadian centre. *Qual Health Care*. 1996;5(3):166-171.
64. Weingessel B, Richter-Mueksch S, Vecsei-Marlovits PV. Which factors influence patients' maximum acceptable waiting time for cataract surgery? – a questionnaire survey. *Acta Ophthalmol*. 2011;89:231–236.
65. Conner-Spady BL, Sanmartin C, Johnston GH, McGurran JJ, Kehlere M, Noseworthy TW. The importance of patient expectations as a determinant of satisfaction with waiting times for hip and knee replacement surgery. *Health Policy*. 2001;101(3):245–252.
66. Vergara I, Bilbao A, Gonzalez N, Escobar A, Quintana JM. Factors and consequences of waiting times for total hip arthroplasty. *Clin Orthop Relat Res*. 2011;469(5):1413–1420.
67. Hoffman, E. *Time*. London, UK; 2009.
68. Carr T, Teucher U, Mann J, Casson AG. Waiting for surgery from the patient perspective. *Psychol Res Behav Manage*. 2009;2:107-119.
69. Kupke C. Lived time and to live time. *Philosophy, Psychiatry & Psychol*. 2005;12(3):199-203.
70. Giddens, A. *The constitution of society: Outline of the theory of structuration*. Berkley: University of California Press; 1984.
71. Fuchs, T. Implicit and explicit temporality. *Philosophy, Psychiatry & Psychol*. 2005;12(3):195-198.
72. Chadwick, H. *Saint Augustine Confessions*. Oxford: Oxford University Press; 2008.
73. Grodin, S. *Psychology of time*. UK: Emerald Group Publishing Limited; 2008.
74. Flaherty MG. *A watched pot: How we experience time*. New York: New York University Press; 1999.
75. Taylor SP. Chronic pain affected the way individuals viewed their bodies, their relationships with others, and their sense of time. *Evidence-Based Nurs*. 2001;4 (3): 94.
76. Hale CS. Time dimensions and the subjective experience of time. *J Humanistic Psychol*. 1993;33(1):88-105.
77. Emirbayer M, Mische A. What is agency? *Am J Sociol*. 1998;103(4):962-1023.
78. Flaherty MG. *The textures of time: Agency and temporal experience*. Philadelphia: Temple University Press; 2011.

79. Hitlin S, Elder GH. Time, self, and the curiously abstract concept of agency. *Sociol Theory*. 2007;25(2):170-191.
80. Starks H, Brown Trinidad S. Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research*. 2007;17(10):1372-1380.
81. Dowling M. From Husserl to van Manen. A review of different phenomenological approaches. *Intern J Nurs Stud*. 2007;44:131-142.
82. Ray MA. The richness of phenomenology: Philosophic, theoretic, and methodologic concerns. In: Morse JM, ed. *Critical Issues in Qualitative Research Methods*. Thousand Oaks CA, Sage; 1994:117-133.
83. Cohen MZ, Omery A. Schools of phenomenology: Implications for research. In: Morse JM, ed. *Critical Issues in Qualitative Research Methods*. Thousand Oaks CA, Sage; 1994:136-156.
84. Omery A, Mack C. Phenomenology and science. In: Omery A, Kasper CE, Page GG, eds. *In Search of Nursing Science*. Thousand Oaks CA, Sage; 1995:139-158.
85. Gearing RE. Bracketing in research: A typology. *Qualitative Health Res*. 2004;14(10):1429-1452.
86. Lawn C. *Gadamer: A Guide for the Perplexed*. London: Continuum Books; 2006.
87. Giorgi A. The phenomenological movement and research in the human sciences. *Nurs Sci Q*. 2005;18(1):75-82.
88. Colaizzi PE. Psychological research as the phenomenologist views it. In: Valle, R.S. King, M. (Eds.) *Existential-phenomenological alternatives for Psychology*. New York: Oxford University Press; 1978:48-71.
89. Munhall, PL. *A phenomenological method. Nursing research: A Qualitative Perspective*. Sudbury MA: Jones & Bartlett; 2007.
90. Morse JM, Field PA. *Qualitative Research Methods Health Professionals*. Thousand Oaks CA: Sage; 1995.
91. Smith JA. *Qualitative Psychology: A Practical Guide to Research Methods* (2nd ed). London: Sage; 2008.
92. Brocki JM, Wearden AJ. A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychol and Health*. 2006;2(1):87-108.
93. Shinebourne P. The theoretical underpinnings of Interpretative Phenomenological Analysis (IPA). *Existential Analysis*. 2011;22(1):16-31.

94. Senior V, Smith JA, Michie S, Marteau TM. Making sense of risk: An Interpretative Phenomenological Analysis of vulnerability to heart disease. *J Health Psychol.* 2002;7(2):157-168.
95. Kohler C, Riessman C. *Narrative Methods for the Human Sciences.* Thousand Oaks, CA: Sage; 2008.
96. Gannon K, Glover L, O'Neill M, Emberton M. Men and chronic illness: A qualitative study of LUTS. *J Health Psychol.* 2004;9(3):411-420.
97. Yardley L. Dilemmas in qualitative health research. *Psychol & Health.* 2000;15:215-228.
98. Bollman RD, Alasia A. A profile of self-employment in rural and small town Canada: Is there an impending retirement of self-employed business operators? *Statistics Canada, Rural and Small Town Canada Analysis Bulletin.* 2012;9(1):1-38. <http://www.statcan.gc.ca/pub/21-006-x/21-006-x2007007-eng.htm>. Accessed March 16, 2013.
99. Conner-Spady B, Sanmartin C, Johnston G, McGurran J, Kehler M, Noseworthy TW 'There are too many of us to fix.' Patients' views of acceptable waiting times for hip and knee replacement. *J Health Serv Res Policy.* 2009;14(4):212-218.
100. Légeré J-F, MacLean A, Buth KJ, Sullivan JA. Assessing the risk of waiting for coronary artery bypass graft surgery among patients with stenosis of the left main coronary artery. *CMAJ.* 2005;173(4):371-375.
101. Sobolev BG, Levy AR, Kuramoto L, Hayden R, FitzGerald JM. Do longer delays for coronary artery bypass surgery contribute to preoperative mortality in less urgent patients? *Medical Care.* 2006;44(7):680-686.
102. Endler NS, Parker JDA, Summerfeldt LJ. Coping with health problems: Conceptual and methodological issues. *Can J Behav Sci.* 1993;25:384-399.
103. Endler NS, Kocovski NL, Macrodimitris SD. Coping, efficacy, and perceived control in acute vs chronic illnesses. *Personality and Individual Differences.* 2001;30:617-625.
104. Van der Zee K, Buunk B, Sanderman R, Botke G, van den Bergh F. Social comparison and coping with cancer treatment. *Personality and Individual Differences.* 2000;28:17-34.
105. Baldwin AS, Kellerman QD, Christensen AJ. Coping with chronic illness. In Suls JM Eds. Davidson KW, Kaplan, RM. *Handbook of health psychology and behavioral medicine.* New York NY: Guilford Press; 2001:494-507.

106. Wallis JA, Taylor NF. Pre-operative interventions (non-surgical and non-pharmacological) for patients with hip or knee osteoarthritis awaiting joint replacement surgery: a systematic review and meta-analysis. *Osteoarthritis and Cartilage*. 2011;19:1381-1395.
107. Neville KL. Uncertainty in illness: an integrative review. *Orthopaedic Nursing*. 2003;22(3):207-214.
108. Postl BD. Final Report of The Federal Advisor on Wait Times. Health Canada Web site. [http://www.hc-sc.gc.ca/hcs-sss/alt\\_formats/hpb-dgps/pdf/pubs/2006-wait-attente/index-eng.pdf](http://www.hc-sc.gc.ca/hcs-sss/alt_formats/hpb-dgps/pdf/pubs/2006-wait-attente/index-eng.pdf). Accessed August 14, 2012.
109. Quinn Patton M. *Qualitative Research and Evaluation Methods* 3rd Ed. Thousand Oaks CA: Sage; 2002.
110. Lincoln YS, Guba EG. *Naturalistic Inquiry*. Beverly Hills CA: Sage; 1985.
111. Rosland AM, Heisler M, Piette JD. The impact of family behaviors and communication patterns on chronic illness outcomes: a systematic review. *J Behav Med*. 2012;35:221–239.

**Appendix A**  
**Waiting for Surgery**  
**Interview Guide**  
**Time 1**

ID \_ \_ . \_ . \_ \_ \_ \_ \_

- Consecutive Participant #
- IV 1 = A; IV 2 = B
- Surgery Site (CABG, Hip, Shoulder)
- M/F (Male/Female)
- First name initial
- Age (in years)
- *Example: CABG James Smith aged 72 = 01.A.CMJ72*

Date:	
Interview Begin:	
Interview End:	
Interview Duration:	
Location:	

Consent Form Reviewed and Signed

Before we begin, I wanted to go over a couple of things. First, thank you very much for volunteering to be part of the study. I want to remind you that what you say is between you and me. It will not be shared with any of your health care providers, including your surgeon. You have the right to withdraw from the interview at any time and you can skip any questions that you'd rather not answer. This will not affect your treatment in any way. When the results are reported, if you are quoted, any information that identifies you will not be included; I will assign you a code when I am analyzing the information.

I have some questions to guide our discussion, but I'm thinking we might just have a general conversation about your experiences with waiting to see a specialist. As I ask you to tell me about your experiences, keep in mind there are no right or wrong answers.

Do you have any questions for me before we begin?

## Section A – Demographics

### Gender:

- Male
- Female

Age: \_\_\_\_\_

### Where do you live?

- Urban (100,000+)
- Small Urban (5,000-100,000)
- Rural (<5,000)

### What is your present marital status?

- Married, or living as married
- Widowed
- Divorced
- Separated
- Single (never married)

### To which cultural/ethnic group do you belong?

- Aboriginal
  - First Nations
  - Métis
  - Inuit
- Chinese
- South Asian
- Black
- Filipino
- Latin American
- Southeast Asian
- Arab
- West Asian
- Korean
- Japanese
- Visible minority, not included elsewhere
- Multiple visible minority
- Not a visible minority

### What is the highest level of schooling you have completed?

- Some elementary
- Graduated elementary
- Some high school or less
- Graduated high school
- Some trade/vocational training
- Graduated trade/vocational training
- Some community college/technical institute
- Certificate or diploma below Bachelor's level
- Some university
- Bachelor's level or above

### Which best describes your present employment status?

- Employed full time all year
  - Employed part time (less than 40 hours per week) all year
  - Seasonal worker
  - Self-employed full time (include farmers here)
  - Retired
  - Homemaker
  - Student
  - Unemployed
  - Other
- Please describe:
-

**Section B – General Questions about Health Condition**

a) When did you first start having problems with your _____?	
Patient Response	Chart Validation
b) Have you had any treatments to help you with your _____? If so, which ones?	
Patient Response	Chart Validation
c) When have those treatments happened?	
Patient Response	Chart Validation
d) So, how long has it been since you've had to deal with your _____ problems?	
Patient Response	Chart Validation
e) What has it been like to deal with these problems with your _____?	
Patient Response	

### Section C – Waiting and Time

<p>One main focus of our study is to learn about how people with health problems experience wait time. Sometimes when we wait, time seems to pass very slowly to the point of being motionless. Other times it can seem to pass very quickly. I'd like to ask you about the time it has taken to see the surgeon.</p>
<p>1) Which type of doctor referred you to see the surgeon? When did that happen? (Probe for the length of time between steps)</p>
<p>2) What has the time been like between being first referred to the surgeon and getting to see the surgeon? Has the time seemed long? short? alright? Why?</p>
<p>3) When you had your appointment for the surgeon, about how long did you have to wait that day? What was it like on the day of the appointment (or today) to wait to see the surgeon?</p>
<p>We wait for all kinds of things in our lives, health related and non-health related. I'd like you to bring to mind a couple of examples of when you've had to wait for something that was important to you. And I'm going to ask you to think about those experiences in relationship to waiting to see the surgeon.</p>
<p>4) How does this experience, of waiting to see the surgeon, compare to past experience you've had with waiting to see doctors? In what way is this experience the same? How is this experience different?</p>
<p>5) How does waiting for the appointment to see the specialist compare to other times when you've waited in your life, times that are not related to your health? Can you tell me more about that? (Probe: what, when, how long)</p>
<p>6) When you consider the time that has passed since the trouble started with your _____, what has the time felt like for you?</p>
<p>7) If you were having this experience when you were younger, what do you think the wait time would have been like? (Probe: how much younger) Would your experience of time have been different in any way? How so?</p>

**Section D – Maximum Acceptable Wait Time**

a) Because you've had to wait to see the surgeon for ___ (time), I'd like to know how long you think is the maximum amount that is an acceptable amount of time to wait to see a surgeon for your condition.	
b) How does that compare to wait times for other conditions? Say for example, a person was waiting to see a surgeon for their (name ONE of other two groups) condition, what would the maximum acceptable amount of time be to wait to see a surgeon?	
c) What about for a person waiting to see a surgeon for their (name final group) condition, what would the maximum acceptable amount of time be to wait to see a surgeon?	

Notes:

## Section E - Effects of Waiting

<p>Waiting for help with a health problem can affect us in many ways; for example, it can affect our bodies, our ability to think (ie, concentrate), how we feel (in terms of our emotions), how we relate with others or may depend on others (or want to be independent), and it may change our expectations about our lives.</p>
<p>1) How have you been spending your time since you've been waiting for your appointment to see the surgeon? (Probe for possible gender differences)</p>
<p>2) What would you be doing if you didn't have to wait for the appointment to see the surgeon?</p>
<p>3) What was it like to wait between the referral to see the surgeon and the appointment to see the surgeon? How has waiting affected you? (Probe: what effects on work; effects on day to day activities, mobility, pain; effects on family and social life, including hobbies &amp; holidays)</p>
<p>4) If you had to offer someone advice about how to deal with waiting to see a specialist, what would you tell them?</p>
<p>5) Has your condition/illness changed in any way how you think about your life in the future?</p>
<p>6) If so, have such thoughts about your life in the future changed how you feel about waiting?</p>
<p>7) Now you will be waiting to have your surgery. What do you think that will be like for you?</p>
<p>8) Do spiritual values or faith play an important role in your life? How religious or spiritual do you consider yourself to be?</p>
<p>What else would you like to add about your waiting experience?</p>

## Patient Contact Information

(Page to be destroyed at the end of the study)

Name	
Address	
Home #	
Work #	
Cell #	
Email address	
Family member/Friend name	
Alternate #	
Date – Time 2 Interview	

Notes:

**Appendix B**  
**Waiting for Surgery**  
**Interview Guide**  
**Time 2**

ID \_ \_ . \_ . \_ \_ \_ \_ \_

---

Date:	
Interview Begin:	
Interview End:	
Interview Duration:	
Location:	

Before we begin, I wanted to go over a couple of things. Thank you very much for continuing to be part of the study. I want to remind you that what you say is between you and me. It will not be shared with any of your health care providers, including your surgeon. You have the right to withdraw from the interview at any time and you can skip any questions that you'd rather not answer. This will not affect your treatment in any way. When the results are reported, if you are quoted, any information that identifies you will not be included; I will assign you a code when I am analyzing the information.

Similar to our first interview, I have some questions to guide our discussion, but I'm thinking we might just have a general conversation about your experiences with waiting for surgery. As I ask you to tell me about your experiences, keep in mind there are no right or wrong answers.

Do you have any questions for me before we begin?

## Section A - Demographics

Since our last interview, has there been any change in your:

Place of residence


Marital status


Employment status


**Section B – General Questions about Health Condition**

a) Since we had our first interview, have you been having any treatment to help with your _____?	
Patient Response	Chart Validation
b) If so, when have those treatments happened?	
Patient Response	Chart Validation

**Section C – Waiting and Time**

<p>One main focus of our study is to learn about how people with health problems experience wait time. Sometimes when we wait, time seems to pass very slowly to the point of being motionless. Other times it can seem to pass very quickly. I'd like to ask you about the time that you have been waiting for surgery.</p>
<p>9) What has the time been like between being placed on the waiting list for surgery and now? Has it seemed long? short? alright? why?</p>
<p>We wait for all kinds of things in our lives, health related and non-health related. I'd like you to bring to mind a couple of examples of when you've had to wait for something that was important to you. And I'm going to ask you to think about those experiences in relationship to waiting for surgery.</p>
<p>10) How does this experience, of waiting for surgery, compare to past experiences you've had with waiting for other treatments? In what ways are they the same? How are they different?</p>
<p>11) How does waiting for surgery compare to other times when you've waited in your life, times that are not related to your health? Can you tell me more about that? (Probe: what, when, how long)</p>
<p>12) When you consider the time that has passed since the trouble started with your _____, what has the time felt like for you?</p>
<p>13) If you were having this experience when you were younger, what do you think the wait time would have been like? (Probe: how much younger) Would your experience of time have been different in any way? How so?</p>

**Section D – Maximum Acceptable Wait Time**

a) Because you've had to wait for surgery for ____ (time), I'd like to know how long you think is the maximum amount that is an acceptable amount of time to wait for surgery for your condition.	
b) How does that compare to wait times for other conditions? Say for example, a person was waiting for surgery for their (name ONE of other two groups) condition, what would the maximum acceptable amount of time be to wait?	
c) What about for a person waiting for surgery for their (name final group) condition, what would the maximum acceptable amount of time be to wait?	

## Section E - Effects of Waiting

Waiting for help with a health problem can affect us in many ways; for example, it can affect our bodies, our ability to think (ie, concentrate), how we feel (in terms of our emotions), how we relate with others or may depend on others (or want to be independent), and it may change our expectations about our lives.
7) How have you been spending your time since you've been waiting for surgery? (Probe for possible gender differences)
8) What would you be doing if you didn't have to wait for surgery?
9) What has it like to wait between being put on the wait list and now? How has waiting affected you? (Probe: what effects on work; effects on day to day activities, mobility, pain; effects on family and social life, including hobbies & holidays)
10) If you had to offer someone advice about how to deal with waiting for surgery, what would you tell them?
11) What impact has waiting had on your thoughts and feelings about your future?
12) Has your condition/illness changed in any way how you think about your life in the future?
7) If so, have such thoughts about your life in the future changed how you feel about waiting?
What else would you like to add about your waiting experience?

## Appendix C

### WAITING FOR SURGERY

#### DIARY

#### Using Your Waiting for Surgery Diary

Please take about five minutes at the beginning or the end of the day to reflect on your wait for surgery. Try to think about and describe what waiting for surgery meant to you today. If you like, you could answer a few of these questions.

- What did you think about your upcoming surgery today?
- What did you feel about your upcoming surgery today?
- What did waiting for surgery mean for you today?
- What helped or hindered you today regarding your wait for surgery?

Please note:

- Don't worry about spelling or grammar.
- Use point form if you like.

## **Appendix D**

### **CONSENT FORM**

You are invited to participate in a research project entitled “Exploring how surgical patients wait: Implications for quality of life” Please read this form carefully, and feel free to ask questions you might have.

**Researcher(s):**

Tracey Carr, PhD student, College of Medicine, University of Saskatchewan, (306) 230-3696

Dr. A. Casson, Department of Surgery, University of Saskatchewan, (306) 966-8641

Dr. U. Teucher, Department of Psychology, University of Saskatchewan, (306) 966-6657

**Purpose and Procedure:** We are interested in what patients experience while they are waiting for surgery. We are offering you the option to keep a diary for a period of two weeks to record any thoughts or feelings you have each day about waiting. We would also like to interview you twice before you go for surgery. It is expected the interviews will each take about 1 hour. We will ask to audio-tape the interviews. The interviews would take place in the hospital. The results from the study will be reported in a summarized form and you will not be identified in any way. If we use something that you say directly we will ensure you remain anonymous.

**Potential Benefits:** You may not have any direct benefits from participating in this study; however, some people find it helpful to talk to someone about their health. What the researchers learn from this study may assist us to better manage wait times for surgery.

**Potential Risks:** While there are no known risks associated with participation in this study, talking about the topic of waiting for surgery may be upsetting to some patients. If this happens to you, we can refer you to someone else to speak with about your experiences or you may decide to withdraw from the study.

**Storage of Data:** The information you share will not be kept with your name or any other identifying information. All information from the study will remain in a locked cabinet at the Qualitative Research Centre at the University of Saskatchewan and will be accessible only to the researchers. After five years the data will be destroyed beyond recovery.

**Confidentiality:** When you enter the study all the information you provide will be identified by a confidential code that will be known only by the student researcher. If the tapes are transcribed by anyone other than the student researcher, confidentiality agreements will be signed by the person who transcribes. No one will be able to identify you by your responses, and your surgeon will not know whether or not you were a participant in this study.

**Right to Withdraw:** Your participation is voluntary, and you can answer only those questions that you are comfortable with. The information that is shared will be held in strict confidence and discussed only with the research team. You may withdraw from the research project for any reason, at any time, without penalty of any sort and participation in this study will not affect your wait time for surgery—your wait time will not be any longer or shorter if you participate. If you withdraw from the research project at any time, any data that you have contributed will be destroyed at your request.

**Questions:** If you have any questions concerning the research project, please feel free to ask at any point; you are also free to contact the researchers at the numbers provided if you have other questions. This research project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on (March 6, 2009). Any questions regarding your rights as a participant may be addressed to that committee through the Ethics Office (966-2084). Out of town participants may call collect.

**Follow-Up:** When the study is complete, approximately 2 years from now, you will receive a summary sheet of the results in the mail. You will have the opportunity to ask any further questions.

**Consent to Participate:**

(a) Written Consent

I have read and understood the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project, understanding that I may withdraw my consent at any time. I also understand that my decision to participate or not will in no way affect my access to health care services. A copy of this Consent Form has been given to me for my records.

For the purposes of this study, I consent to the release of information from my health record to the researchers. I understand that my health record will be looked at by the researchers in order to confirm my diagnosis and document when I have received treatment for my condition.

Yes

No

\_\_\_\_\_ (Name of Participant)

\_\_\_\_\_ (Date)



## Appendix E

Behavioural Research Ethics Board (REB)

### Certificate of Approval Study Amendment

PRINCIPAL INVESTIGATOR  
Alan Casson

DEPARTMENT  
Surgery

Beh #  
09-27

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT  
University of Saskatchewan

SUB-INVESTIGATOR(S)  
Ulrich Teucher

STUDENT RESEARCHER(S)  
Tracey Carr

SPONSORING AGENCIES  
IN APPLICATION

TITLE  
Exploring How Surgical Patients Wait: Implications for Quality of Life

APPROVAL OF  
Revised protocol & ethics application  
Revised consent form

APPROVED ON  
07-Aug-2009

CURRENT EXPIRY DATE  
05-Mar-2010

Full Board Meeting

Date of Full Board Meeting:

Delegated Review

#### CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

#### ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: [http://www.usask.ca/research/ethics\\_review/](http://www.usask.ca/research/ethics_review/)

Please send all correspondence to

Research Ethics Office  
University of Saskatchewan  
Box 5000 RPO University, 1602-110 Gymnasium Place  
Saskatoon SK S7N 4J8