Beyond the Pain: An Occupational Perspective on Knee Osteoarthritis

by

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A thesis submitted in conformity with the requirements for the degree of Master of Science

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Abstract

Total knee replacement (TKR) is an increasingly common surgery among individuals with osteoarthritis (OA). The outcomes of this surgery are positive; yet, many individuals do not fully resume their pre-TKR occupations. Literature is limited to describing the activity changes that occur but does not investigate the significance of those changes. A secondary analysis of eight purposively extracted transcripts from a primary study examining engagement in instrumental activities of daily living and personal and social roles among people with OA scheduled for surgery was conducted. A thematic analysis approach was used to examine the pre-TKR experiences of these individuals from an occupational perspective. Three themes were identified: (1) living with OA: it is more than just the knee, (2) gradually losing my occupational identity, and (3) losing too much—a “tipping point.” The findings suggest that the significance of occupational changes are unique across individuals and affect their decision for surgery.
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Osteoarthritis (OA) is a form of arthritis that causes degeneration of the cartilage and thickening of the subchondral bone in one or more joints (Burger et al., 1996; Gonzalez Saenz de Tejada et al., 2010; Public Health Agency of Canada [PHAC], 2010; Walker, 2010). Of all the joints, the knee joint is the most frequently affected by OA (Badley & Wang, 1998; Ozturk, Atamaz, Hepguler & Argin, 2006) and the outcomes after surgery are poorer than for other joints (Bachmeier et al., 2001; Ethgen, Bruyere, Richy, Dardennes, & Reginster, 2004; Kapstad, Rusteon, Hanestad, Moum, Langeland & Stavem, 2007). Accordingly, the knee will be the focus of the present study.

Total knee replacement (TKR) surgery is becoming increasingly common for individuals with knee OA who experience persistent symptoms and disability despite pharmacological, physical, and rehabilitative interventions (Edwards, Haythornthwaite, Smith, Klick, & Katz, 2009; Gooberman-Hill et al., 2010; Gossec et al., 2011; Holtzman, Saleh, & Kane, 2002; PHAC, 2010). In Canada, in the years 2010 and 2011, there was a 15% increase in the number of TKR surgeries (50,733) performed as compared to the number of TKR surgeries (44,106) performed in 2006 and 2007 (Canadian Institute for Health Information, 2013). A TKR is considered one of the most effective treatments for individuals with severe knee OA (Bachmeier et al., 2001).

Despite the documented effectiveness of a TKR in relieving pain, and improving function and quality of life (Gonzalez Saenz de Tejada et al., 2010; Hawker et al., 2009; Healy, Sharma, Schwartz, & Iorio, 2008), many people do not return to their previous physical functioning (Fitzgerald et al., 2004) or resume their previous level of activity following a TKR (Bradbury, Borton, Spoo, & Cross, 1998; Chatterji, Ashworth, Lewis, & Dobson, 2005). In a study by Nunez and colleagues (2009) 20% of the participants report not being satisfied with their improvement in physical function post-TKR. These results are a matter of concern given the increasing number of more active individuals with knee OA (Lutzner, Kirschner, Gunther, & Harman, 2012).

Numerous studies have evaluated the outcomes of individuals with knee OA (Bachmeier et al., 2001; Nunez et al., 2007; Perruccio, Davis, Hogg-Johnson, & Badley, 2011). Generally, these studies have focused on symptoms, for example, pain, (Gandhi, Davey, & Mohamed, 2009; Riddle, Wade, Jiranek, & Kong, 2010; Salmon, Hall, Peerbhoy, Shenkin & Parker, 2001),
basic mobility, and daily activities (Holtzman, Saleh, & Kane, 2002; Kennedy, Hanna, Stratford, Wessel & Gollish, 2006; Lavernia, D’Apuzzo, Rossi, & Lee, 2009). However, it has been reported that individuals with knee OA are concerned about a much broader range of outcomes (Rastogi, Davis, & Chesworth, 2007; Trousdale, McGrory, Berry, Becker, & Harmsen, 1999). For example, individuals reported being concerned about more personally important activities such as the ability to do their paid work and return to recreational activities (Trousdale et al., 1999).

These findings suggest that there is a need to understand the experiences of individuals with knee OA not only from a medical perspective, but also from an occupational perspective. They suggest that to affect a more positive outcome it is important to understand the experience of living with OA beyond issues of pain and mobility loss; to understand the occupational issues of living with OA. From an occupational perspective, the meaning a particular activity holds, and not the activity in and of itself, determines the extent to which its loss is of importance and the extent to which its continued loss post-surgery affects satisfaction with outcomes. Further, the meaning, and importance, an activity holds is highly individual (Polatajko et al., 2007). Accordingly, to affect a more positive outcome it is important to understand the occupational changes an individual living with OA experiences and the meaning and importance of those changes to the individual.

In a search of the literature, only two studies were found that examined the experiences of individuals with knee OA taking into account the meaning or importance of activities to the individual. Weiss and colleagues (2002), worked with pre-TKR patients to understand the activities they considered to be important post-TKR. The importance of an activity was determined by the personal value that the individual ascribed to a particular activity using a 5-point scale of a knee-function instrument survey developed for that purpose. They found that the TKR successfully restored a significant degree of function and mobility; they noted that, “Notwithstanding the success of knee replacement in relieving pain, many patients still experience significant difficulty in doing activities that they regard as important” (p. 178).

In a similar vein, Wylde, Livesey, and colleagues (2012) explored how important and difficult participation in leisure activities was to individuals with hip and knee OA before and after a joint replacement. They found that a vast majority of their OA participants rated their activities as “quite important” or “very important” (Wylde et al., 2012, p. 248). For example, participants rated 86% of their leisure activities, such as sports and exercise (e.g., walking,
golfing, and swimming), hobbies, (e.g., gardening and reading), and social activities (e.g., visiting family and going to church), as important. Unfortunately, these investigators did not explore the particular importance of, or value, participants ascribed to particular activities.

Generally, activities are addressed within the pre-TKR literature in broad groupings such as “functional status” (Bischoff-Ferrari et al., 2004), “physical function” (Kennedy, Stratford, Riddle, Hanna, & Gollish, 2006), “athletic activity” (Healy et al., 2008), “return to work” (Styron, Barsoum, Smyth, & Singer, 2011), and at-work limitations (Sankar et al., 2013) with little regard to the particular meaning or importance of the activities to the specific individual. Accordingly, these studies shed little light on the issue raised by Weiss and colleagues (2002), that is, to understand the importance of the activities lost due to OA to the individual. Adopting an occupational perspective in examining the experience of living with OA could provide this.

An occupational perspective is “a way of looking at or thinking about patterns of doing” (Njelesani, Tang, Jonsson, & Polatajko, 2012, p. 8) that examines such aspects of doing as meaning and importance. From an occupational perspective, the importance or meaning one ascribes to an activity one can or cannot do, has major significance for one’s identity and well-being. As Polatajko and colleagues (2007) have noted, “Engagement in occupations that are situated in a person’s life and hold meaning for that individual are particularly potent, bringing validation to the person and helping them gain a sense of self” (p. 22). There is increasing evidence that an individual’s cognitive, physical, social, psychological, and spiritual well-being are supported by engaging in a wide range of meaningful activities, i.e., occupations, in the language of occupational science (Hocking, 2009). Thus, it was considered that, applying an occupational lens to the examination of the experiences of people living with OA while awaiting surgery may provide some insights into the occupational impact of living with OA.

Accordingly it was decided to bring an occupational perspective to the examination of data from a larger study (primary study) exploring the activities of individuals scheduled for a total joint replacement; a secondary analysis of the data collected by the primary study was undertaken (Davis, Webster, Jaglal, Jenkinson, Perruccio, Schemitsch, & Waddell, n.d). The primary study, broader in scope than the study being presented in this thesis, was designed to understand engagement in instrumental activities of daily living (IADL) as well as personal and social roles among people with OA both before and after total joint replacement surgery. Of interest here was the experience of people living with OA who were scheduled for a TKR.
Chapter 2
Background

2.1. Osteoarthritis (OA)

OA is considered the most common type of arthritis (PHAC, 2010). OA typically affects the hands, feet, knees, spine, or hips, but it is most prevalent in the hands and weight-bearing joints (e.g., hips and knees) (PHAC, 2010) with the knee joint being more frequently affected (Badley & Wang, 1998; Ozturk et al., 2006).

Arthritis affects adults, including older adults, regardless of physical condition, gender, marital status, socioeconomic status, or ethnic background, and is among the leading causes of disability in Canada (Public Health Agency of Canada [PHAC], 2010). Arthritis affects more than 4.2 million Canadians and is a major public health challenge (PHAC, 2010). It is estimated that by 2031, 6.7 million Canadians 15 years or older will have arthritis (PHAC, 2010). Individuals 55 years or older will account for the greatest increase in the number of people affected by arthritis because of the increase in the aging population (PHAC, 2010). Arthritis has had a significantly negative impact on the Canadian work force, with 44% of people experiencing job constraints and 33% of workers requiring modifications to their jobs due to restricted mobility, pain, and other OA symptoms (PHAC, 2010).

2.1.1. Management of OA.

OA management is generally described as the management of the symptoms. The primary goals of OA management are to relieve pain and maintain range of motion, while simultaneously preventing joint damage and functional disability (Ozturk, Atamaz, Hepguler, Argin, & Arkun, 2006). There are a number of approaches to OA management, including education (e.g., OA management strategies), intra-articular (IA) corticosteroid injections (Creamer, 1999; Raynaud et al., 2003), exercise (Bennell & Hinman, 2005), bracing (Brouwer, Van Raaij, Verhaar, Coene, & Bierma-Zienstra, 2006), alternative therapy (Williamson, Wyatt, Yein, & Melton, 2007), physiotherapy (Mitchell et al., 2006; Lenssen, & de Bie, 2006), pharmacological therapies (e.g., non-steroidal anti-inflammatory drugs) (Stanos, 2013), and surgery (Dieppe et al., 1999). Surgery, such as a total joint replacement (TJR) is generally seen as a last resort, recommended only after all other options have failed to bring the desired relief (Ballantyne, Gignac, & Hawker, 2006; Ethgen et al., 2004; Hamel, Toth, Legedza, & Rosen, 2008).
2.1.1.1. Total Joint Replacement (TJR)

A TJR involves the removal of the affected cartilage and bone, which is then replaced with an artificial joint (Orbell, Johnston, Rowley, Espley, & Davey, 1998). A total knee replacement (TKR) is one type of TJR. Indications for whether an individual with OA is a surgical candidate for a TKR are based on a physical examination of the joint, radiological findings, and the patient’s reports of his or her OA symptoms (Llewellyn-Thomas, Arshinoff, Bell, Williams, & Naylor, 1998). Nevertheless, the final decision rests with the individuals living with OA, who eventually have to decide whether to have a joint replacement (Clark et al., 2004; Hamel et al., 2008; Gooberman-Hill et al., 2010; McHugh & Luker, 2009) or avoid the surgery (Ballantyne et al., 2007). The period leading up to the surgery, once the decision for a TKR is made, is referred to as the “pre-TKR” period.

2.2. Pre-Total Knee Replacement (Pre-TKR) Period

Hall and colleagues (2008) discussed the considerable attention that has been paid to the pre-TKR experience with the expectation that understanding this period is helpful for pain management, pre-operative preparation, post-TKR recovery, rehabilitation, and discharge planning. As Marcinowski, Wong & Dignam (2005) noted, various aspects of the pre-TKR period have been examined using both quantitative and qualitative research methods. A majority of the literature examining the pre-TKR period focuses on predicting outcomes of a TKR (Noble et al., 2005; Wylde, Dieppe et al., 2007), patient characteristics influencing post-TKR outcomes (Gandhi, Dhotar, Razak, Tso, Davey, & Mahomed, 2009; Unver, Karatoson, Bakirhan, & Gunal, 2009; Bourne, Chesworth, Davis, Mahomed, & Charron, 2010), and predictors of post-TKR outcomes (Brander et al., 2003; Kennedy, Hanna, Stratford, Wessel, & Gollish, 2006; Brander, Brander & Stulberg, 2010; Perruccio, Davis, Hogg-Johnson, & Badley, 2011; Styron et al., 2011). Generally, these studies used a quantitative approach to examine the pre-TKR status as a basis for comparison with post-TKR outcomes or as a predictor of outcomes. This pre-TKR literature has provided considerable information regarding activity and OA.
2.3. Activity Limitations

Over 10% of Canadian adults’ participation in everyday activities is severely limited by their OA symptoms (PHAC, 2010). Generally speaking, OA has been reported to limit the ability to participate in activities of self-care (Jacobson et al., 2008), work (Bieleman et al., 2011; Demierre, Castelao, & Piot-Ziegler, 2011; Weiss et al., 2002), and leisure (Toye, Barlow, Wright, & Lamb, 2006; Weiss et al., 2002). More specifically, Hall and colleagues (2008) have reported that OA pain affected the quality of sleep of their participants. Other physical symptoms related to OA, such as locking, swelling, and stiffness, have been reported to limit the individuals’ ability to perform daily activities such as cooking, walking, and dancing (Hall et al., 2008; Jacobson et al., 2008). Further it has been reported that participation in activities, such as walking, can aggravate the knee joint and cause knee pain (Jacobson et al., 2008). Even a resting activity, such as sitting for long periods of time, can cause discomfort and pain (Hall et al., 2008).

With regard to work-related activity limitations and OA, Bieleman and colleagues (2011) conducted a systematic review that examined the effect of hip and knee OA on work participation. The authors selected 53 papers that examined individuals with hip or knee OA and outcome measures of work participation and extracted data from fourteen of these studies. It was found that many individuals with paid work managed to stay at work despite the limitations imposed by their OA (Bieleman et al., 2011). The authors noted a “bidirectional relationship” between work and OA (Bieleman et al., 2011). Specifically, participation in physically demanding work-related activities was identified as a risk factor for developing OA. On the other hand, participants described their joint OA as negatively affecting their work participation (Bieleman et al., 2011).

2.3.1. Challenges associated with activity limitations and knee OA.

It has been shown that individuals with knee OA experience challenges with their daily activities, which, in turn, affect their social relationships (Sjoling, Agren, Olofsson, Hellzen & Asplund, 2005; Demierre et al., 2011), emotional well-being (Hall et al., 2008; Jacobson et al., 2008), self-image/identity (Sjoling et al., 2005; Jacobson et al., 2008; Demierre et al., 2011) and independence (Cott & Gignac, 1999; Toye et al., 2006; Hall et al., 2008).
2.3.1.1. Activity limitations, social relationships and knee OA.
Activity limitations were found to negatively affect social relationships. Hall and colleagues (2008) found their participants lost social contact with their family and friends because of increasing activity losses. In a study by Sjoling and colleagues (2005), participants described a sense of isolation and feeling like outsiders because they were no longer able to participate in certain activities that once made them feel a part of society (e.g., going to work). Demierre and colleagues (2011) reported that individuals with knee OA described challenges with maintaining intimacy with their spouses because of their symptoms. They also noted that activity limitations were found to negatively affect these participants more severely than others as they chose to lead a secluded existence and restrict themselves to their homes (Demierre et al., 2011).

2.3.1.2. Activity limitations, emotional well-being and knee OA.
The activity limitations, as a result of the OA symptoms, have been reported to contribute to difficulties with coping for some individuals with knee OA (Hall et al., 2008). For example, some participants described their coping difficulties as a loss of control in their lives because of their reliance on social supports (Hall et al., 2008; Jacobson et al., 2008). Participants’ emotional well-being was negatively affected, with participants reporting feelings such as depression, frustration, inadequacy, and embarrassment (Hall et al., 2008).

2.3.1.3. Activity limitations on self-image, identity and knee OA.
Some studies reported that participants experienced changes in their self-image because of their activity limitations. For example, Sjoling and colleagues (2005) found that participants who felt limited in their involvement in previously enjoyed activities perceived their self-images in a negative light. They also reported that some participants described having a disrupted self-image because they used to be more active prior to their joint OA progression (Sjoling et al., 2005).

Jacobson and colleagues (2008) examined the patients’ perspectives of their pre-and post-TKR experiences. The authors found that the participants’ views of themselves had changed due to their activity limitations (Jacobson et al., 2008). Some participants perceived themselves to be “active people who had been forced into inactivity” (Jacobson et al., 2008, p. 56). Participants were also concerned about how they believed others viewed them based on their activity limitations. These participants described their OA symptoms to “constrict” and even “control” their lives (Jacobson et al., 2008, p.56).
Demeirre and colleagues’ (2011) study found that participants’ experiences with activity limitations affected their identities. Specifically, some participants’ identities were challenged as they felt a combined sense of burden and guilt from having to rely on their social supports (Demierre et al., 2011). For example, some participants were unable to accept their new identity of being dependent on others and felt their identities were challenged when family members did not understand the fluctuating activity limitations caused by their knee OA (Demierre et al., 2011). Demeirre and colleagues (2011) noted that the effect on identity was gradual in keeping with the gradual loss of activity due to the progression of their OA symptoms.

2.3.1.4. Activity limitations, independence and knee OA.
Individuals with knee OA who experienced difficulty with completing their daily activities described a loss of independence. Many reported gradually having to rely on their loved ones for assistance. Participants have been reported to use the term dependent to refer to the inability to carry out tasks that would normally be done without the help of another (Cott & Gignac, 1999; Hall et al., 2008; Toye et al., 2006). Cott and Gignac (1999) examined the meanings of independence and dependence in older adults with disabilities resulting from OA or osteoporosis. Three categories of disabilities were identified: community mobility, household activities, and personal care activities.

Under the community mobility category, participants perceived their independence to be compromised because of their OA symptoms, and many were gradually unable to “do what they wanted when they wanted” (Cott & Gignac, 1999, p. 16). Examples of community mobility activities included going shopping or running errands. Under the household activities category, many participants were unable to carry out their activities without assistance because of their joint OA symptoms. Household category included activities, such as meal preparation and housekeeping. Under the personal care category, participants experienced challenges with activities such as bathing and getting dressed because of their joint OA. Participants were found to consider their ability to perform personal care activities to be of higher value in relation to their self-perceptions of independence than their ability to perform household activities (Cott & Gignac, 1999).
2.4. An occupational perspective.

The findings within the pre-TKR literature with respect to the challenges associated with activity changes in individuals with knee OA, and in particular, with respect to the importance and meanings of the activities where change is experienced, are consistent with an occupational perspective and suggest that an occupational perspective could serve to deepen our understanding of the impact of knee OA on the lives of individuals. An occupational perspective examines multiple aspects of doing, including personal meaning and importance (Njelesani et al., 2012). The use of an occupational perspective was shown to facilitate the design of interventions to promote participation (Hocking, 2009) and may provide a new perspective on the reported outcomes of TKR.

An occupational perspective is widely used to guide occupational science research (Njelesani et al., 2012). The field of occupational science, which is the study of human occupation (Hocking, 2009), concerns itself with all aspects of human doing. Occupational scientists use the term “occupation” rather than “activity” or “task” to capture the complexity of human doing (Christiansen, Clark, Kielhofner, & Rogers, 1995). From an occupational science perspective, occupations are comprised of activities but the terms are not interchangeable and should not be used synonymously (Christiansen & Townsend, 2004; Pierce, 2001).

2.4.1. The language of occupation.

In occupational science, occupations are understood to be a group of activities and tasks done to accomplish a purpose; they are more than a simple activity (Canadian Association of Occupational Therapists [CAOT] 1997). The concept of occupation is defined as:

Groups of activities and tasks of everyday life, named, organized and given value and meaning by individuals and a culture; occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure) and contributing to the social and economic fabric of their communities (productivity) (CAOT, 1991, p. 30).

2.4.2. Taxonomic Code of Occupational Performance.

Despite this and numerous other definitions, considerable confusion remains regarding the terms related to human doing, most specifically terms such as activity (Christiansen & Townsend, 2004). To address this issue, in 2004, Polatajko and colleagues (2004) proposed a taxonomic
code, which consisted of seven levels of what they referred to as occupational performance. In 2006, Zimmerman, Purdie, Davis, and Polatajko tested the code and proposed revisions. The resultant Taxonomic Code of Occupational Performance (TCOP) (Polatajko et al., 2007) (Table 1) identifies five levels of occupational performance and specifies the distinction between activity and occupation.

<table>
<thead>
<tr>
<th>Level of complexity</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupation</td>
<td>An activity or set of activities that is performed with some consistency and regularity that brings structure, and is given value and meaning by individuals and culture</td>
</tr>
<tr>
<td>Activity</td>
<td>A set of tasks with a specific endpoint or outcome that is greater than that of any constituent task</td>
</tr>
<tr>
<td>Task</td>
<td>A set of actions having an endpoint or a specific outcome</td>
</tr>
<tr>
<td>Action</td>
<td>A set of voluntary movements or mental processes that form a recognizable and purposeful pattern (such as kneeling, standing, walking, etc.)</td>
</tr>
<tr>
<td>Voluntary movement or mental processes</td>
<td>A simple voluntary muscle or mental activation (such as flexion, extension, memory, attention, etc.)</td>
</tr>
</tbody>
</table>


An activity differs from an occupation in three ways: first, occupations are composed of activities (Polatajko et al., 2007); second, meaning is an essential aspect of occupation. Indeed, Hammell (2004) asserts that all occupations are considered to have some meaning for the individual engaged in them. The meaning that is associated with an occupation involves a subjective aspect that is considered idiosyncratic to the individual and cannot be understood by observation alone (Polatajko et al., 2007). Third, occupations differ from activities in that occupations are completed with some consistency and regularity (Christiansen & Townsend, 2004).

Occupations can be classified in many ways. The Canadian occupational therapy guidelines (CAOT, 1997; Townsend & Polatajko, 2007) classify occupations in three ways:
self-care, productivity, and leisure. *Self-care* occupations involve looking after the self and include personal care (e.g., eating, dressing, bathing) and other occupations that are considered to be necessary for survival or health (e.g., sleep, self-medication) (CAOT, 1997). *Productivity* occupations are those that “make a social or economic contribution or that provides for economic sustenance which include play in infancy and childhood, school work, employment, homemaking, parenting, and community volunteering” (CAOT, 1997, p. 27). *Leisure* occupations are occupations for enjoyment, including socializing, outdoor activities, and sports (CAOT, 1997). Leisure occupations are characterized by the individual having freedom of choice in participation with no goal in mind other than enjoyment (Kelly, 1972).

2.4.3. **Assumptions of an occupational perspective**

Occupational scientists consider occupation as essential to living. They hold that occupation serves the “basic human needs essential for survival, provides the mechanism for people to exercise and develop innate capacities of a biological, social, and cultural nature; to adapt to environmental changes; and to flourish as individuals” (Wilcock, 1993, p. 17). Occupation is viewed as the mechanism for many purposes (Wilcock, 1993). For example, occupation provides the mechanism for social interaction and for societal development and growth as individuals may engage in occupations independently and in groups (Wilcock, 1993). Occupations provide ways to enable individuals to achieve their goals and provide a way for them to demonstrate who they are and what they hope to become (Clark, 2003; Hocking, 2009; Wilcock, 1993).

According to Polatajko and colleagues (2007), there are six basic assumptions related to “occupation” that are inherent within an occupational perspective: (1) Humans are occupational beings. (2) Occupation brings meaning to life. (3) Occupation affects health and well-being. (4) Occupations are idiosyncratic. (5) Occupations have potential therapeutic value. (6) Occupation organizes time and brings structure to living.

The first assumption, that the *human is an occupational being*, (Yerxa, Clark, Parham, Carlson, Frank, Jackson, et al., 1991; Townsend & Polatajko, 2007; Wilcock, 1993) implies that humans need to be occupationally engaged. Implicit in this assumption is that occupation is a basic human need, as integral to health and well-being as food and drink.

The second assumption, that *occupation has potential therapeutic value*, follows from the first assumption and indicates that occupation can be health giving. Health professionals,
such as occupational therapists (OTs), are specifically trained to use occupations to improve the health status of the clients. The therapeutic value of occupations lies in the relationship between characteristics of the occupation and the specific needs of the individual, e.g., bead threading can improve fine motor and eye-hand coordination skills (CAOT, 2008).

The third assumption is *Occupation brings meaning to life*. According to Townsend and Polatajko (2007), people in the Western culture commonly identify themselves by their occupations making them “the crucible in which our identities are formed” (p. 21). There are two sources influencing the way individuals ascribe meanings to occupation: cultural and individual (Polatajko et al., 2007). From a cultural perspective, individuals or groups ascribe meaning to occupations and find a place within their own cultures by engaging in occupations that enable them to participate in society (Yerxa, 1991). The meaning an individual ascribes to an occupation is personal and cannot be understood by observation alone (CAOT, 1997). As Christiansen and Townsend (2004) wrote: “People understand the meaning of their lives by considering their occupations as part of their life stories” (p. 8).

The fourth assumption is that *occupation affects health and well-being*. CAOT (2008) implies that participation in activities can influence health and well-being, positively or negatively (Law, Steinwender, & Leclair, 1998). This link between health and living everyday life is internationally recognized (World Health Organization [WHO], 1978; 2003).

The fifth assumption, *occupation organizes time and brings structure to living*, refers to the way individuals, through occupational engagement, are able to organize their time into roles, habits, and patterns (CAOT, 1997; Kielhofner, 1995, 1997, Polatajko et al, 2007).

The sixth and last assumption is that *occupations are idiosyncratic*. This assumption indicates that the specific occupations that make up an individual’s occupational repertoire and values and importance ascribed to them is unique to that individual; individuals' perspectives on occupations are based on their personal experiences of those occupations (Polatajko et al., 2007). As Polatajko and colleagues (2007) noted: “Engagement in occupations that are situated in a person’s life and hold meaning for that individual are particularly potent, bringing validation to the person and helping them gain a sense of self” (p. 22).

### 2.4.4. An occupational perspective on the OA literature.

In the OA literature, the terms that relate to occupation most frequently used are *function* and *activity*. In many cases, they are used synonymously. The term function varies from *functional*
activities (Lingard, Katz, Wright, Wright, & Sledge, 2001; Weiss et al., 2002), functional capability (Dahm, Barnes, Harrington, Sayeed, & Berry, 2008), and physical functioning (Ballantyne et al., 2007). Function is viewed as a more objective domain and closely related to pain (Wylde, Blom et al., 2012). The use of the term “activities” also varies. For example, some activities are referred to as leisure activities, such as sports, social activities, and family vacations (Wylde, Livesey, et al., 2012). Other studies refer to activities as daily activities, which include getting dressed, cooking, and shopping (Jacobson et al., 2008). Marcinowski and colleagues (2005) described sleep as an everyday activity while ordinary activities were activities an individual is involved in, such as catching a bus or showing visitors around their gardens.

Many of the terms associated with occupation are found in the OA literature. For example all three classifications of occupations endorsed by the CAOT (1991) (self-care, leisure, and productivity), are used, although, more often the term “paid work” is used rather than productivity and the term occupation is restricted to paid work (Allaire, 2004; Andersen, Thygesen, Davidsen, & Helweg-Larsen, 2012; Franklin, Ingvarsson, Englund, & Lohmander, 2010; Gignac, 2005; Palmar, Milne, Poole, Cooper & Coggon, 2004; Sankar et al., 2013; Styron et al., 2011).

The OA literature also discusses the concept of activity limitations and suggests the loss this represents. However, the literature falls short of specifically addressing the meaning associated with activity limitations. For example, Demierre and colleagues’ (2011) discuss the social consequences of OA symptoms on their leisure and social activities described by their participants but do not explicitly discuss this in terms of meaning. Similarly, Marcinowski and colleagues (2005) when examining the psychosocial processes of individuals with knee OA who were to undergo a TKR found that pain experiences and the challenges of not being able to participate in their daily activities affected them emotionally. But again, these authors did not explicitly discuss the meaning or importance associated with the activity limitations that were experienced by their participants.
2.5. Summary

Individuals living with OA gradually develop pain, physical limitations, and functional loss and related activity limitations and loss. In the case of knee OA, when these symptoms become unmanageable through non-surgical options, a TKR is performed. The outcomes of this surgery are positive in that it results in reduced pain and increased function; yet there are many individuals who do not fully return to their pre-TKR occupations. The reason for this is poorly understood.

For the most part this literature is limited to describing the activity changes that occur and does not investigate the significance of those changes in the lives of people living with knee OA, something that, from an occupational perspective would be important to understand. Only a few studies were found that explored the occupational experiences of individuals with knee OA; these studies highlight how restricted participation in activities may negatively impact the lives and point to the importance of understanding the significance of the activities that affect the individual. None of the studies reviewed reported on the meaning and importance associated with the occupational changes experienced by the individual living with knee OA. Accordingly, it was considered important to explore the occupational experiences of individuals living with knee OA. Those individuals scheduled for a TKR were specifically chosen because it was thought that these individuals would be most likely to have had the full OA experience prior to TKR and would lend an in depth understanding of knee OA on occupational experiences.
Chapter 3
Methods

As previously stated, the purpose of the study was to explore the occupational experiences of individuals with OA in the pre-TKR period scheduled for a TKR. A qualitative approach was chosen for the present study as these types of studies are considered appropriate for investigating a broad range of experiences and have been used to conduct studies from an occupational perspective (Chaffey & Fossey, 2004; Helbig & McKay, 2003; Njelesani et al., 2012). As this research question was being formulated, the primary study investigating engagement in instrumental activities of daily living (IADLs) or in personal and social roles after a primary total hip or knee replacement was in progress. It was decided that for the purposes of the research question of interest here, a secondary analysis of a portion of the data set emanating from the primary study would be appropriate. This section begins with a brief overview of the data source for this secondary analysis.

3.1. Data source: the primary study

The primary study used a constructivist grounded theory approach guided by the work of Charmaz (2006) to explore how and why people with OA do or do not engage in instrumental activities of daily living (IADLs) or in personal and social roles after they have had a primary total hip or knee replacement. Initiated in 2011, the investigators are now in the process of completing their data analysis. The data set consists of semi-structured interviews (Appendix A) of approximately an hour to an hour and a half in duration that were conducted by a trained research assistant pre-surgery and at two post-operative time points. The interviews were audiotaped and transcribed, verbatim.

3.1.1. Participants.

The primary study included 35 participants who: (1) had a primary hip or knee replacement for OA within a year of their participation in the study, (2) were between the ages of 30 and 80 years of age at the time of the planned surgery, (3) consented to participate, and (4) were able to converse in English (to participate in the interview) (Table 2).
Table 2 Primary Study Sample

<table>
<thead>
<tr>
<th>Age groups (years)</th>
<th>Hip Male</th>
<th>Hip Female</th>
<th>Knee Male</th>
<th>Knee Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>30-45</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>46-65</td>
<td>6</td>
<td>4</td>
<td>3</td>
<td>4</td>
<td>17</td>
</tr>
<tr>
<td>66-80</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>Subtotal</td>
<td>11</td>
<td>9</td>
<td>7</td>
<td>8</td>
<td>35</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
<td>15</td>
<td></td>
<td></td>
<td>35</td>
</tr>
</tbody>
</table>

3.2. Secondary Analysis Study (Present)

The study presented in this thesis is a secondary analysis of qualitative data from the primary study. With any qualitative inquiry, it is important to understand the theoretical underpinnings; in the case of secondary analysis, it is important to understand the issues that secondary analysis brings to qualitative data. These two topics will be addressed first, and then a detailed description of the study will follow.

3.2.1. Theoretical underpinnings.

Epistemology is concerned with understanding knowledge and how it is acquired (Ritchie & Lewis, 2007), and in qualitative inquiry it is important that the epistemological stance of the researcher be made explicit. For the secondary analysis, the researcher adopted an interpretivist approach to the data. Interpretivism, as Ritchie and Lewis (2003) note, requires the researcher “to explore and understand the social world through the participants’ and their own perspectives; explanations can only be offered at the level of meaning rather than cause” (p. 23).

In other words, I accepted, as valid, the meanings participants assigned to their experiences and did not seek to investigate if these were “true” from a position of objectivity.

Entering the secondary analysis, I believed that individuals with knee OA experience symptoms such as pain, stiffness, and swelling of the knee pre-TKR. However, these experiences and how they affect a person’s participation in daily activities differ from one individual to another. How these individuals cope with the symptoms and manage their daily activities is socially organized (e.g., based on class, race, etc.). In the present study, I hoped to understand and make sense of the unique occupational experiences of individuals with knee OA scheduled for a TKR.
Ontology is defined as “the beliefs about what there is to know about the world” (Ritchie & Lewis, 2003, p. 10). My ontological assumption for the secondary analysis falls under the relativism stance, i.e., that multiple, rather than singular, realities exist (Ritchie & Lewis, 2003). The term “multiple realities” refers to the idea that “there is no single shared social reality, only a series of alternative social constructions” (Ritchie & Lewis, 2003, p. 16). Therefore, accounts of any one phenomenon (e.g., OA pain) may vary within an individual’s account as well as between several participants’ accounts in that the values and importance that are ascribed to occupations differ from one individual to another. I accepted that the views that were conveyed by the participants living with knee OA would be individually constructed.

3.2.2. Secondary analysis of qualitative data.
Secondary analysis of qualitative data has become an established approach to research (Fielding & Fielding, 2000; Heaton, 1998; Hinds, Vogel, Clarke-Steffen, 1997; Mauthner, Parry & Backett-Milburn, 1998; Parry & Mauthner, 2004; Ritchie & Lewis, 2007). A secondary analysis is a method used to analyze existing data in order to answer a research question that differs from the question posed in the original study (Heaton, 1998). Heaton (1998) described three forms of secondary analysis that are differentiated by the focus of the analysis and the nature of the original data used (Table 3). The study presented here used a secondary analysis for the purpose of examining an existing dataset in order to answer a research question that differed from the question in the original study (Hinds et al., 1997; McCall & Applebaum, 1991).

<table>
<thead>
<tr>
<th>Main focus of analysis</th>
<th>Single qualitative dataset</th>
<th>Multiple qualitative datasets</th>
<th>Mixed qualitative and quantitative datasets</th>
</tr>
</thead>
<tbody>
<tr>
<td>Additional in-depth analysis</td>
<td>1a</td>
<td>1b</td>
<td>1c</td>
</tr>
<tr>
<td>Additional subset analysis</td>
<td>2a</td>
<td>2b</td>
<td>2c</td>
</tr>
<tr>
<td>New perspective or conceptual focus</td>
<td>3a</td>
<td>3b</td>
<td>3c</td>
</tr>
</tbody>
</table>

*Note. Reproduced with permission from the editor, *Social Research Update*, Heaton (1998).*
3.2.3. Potential issues when using a secondary analysis.
Secondary analysis of qualitative data raises a number of potential issues. Heaton (1998) summarized four ethical and practical issues to consider when conducting a secondary analysis.

3.2.3.1. Compatibility of the data with secondary analysis.
One of the main concerns with conducting a secondary analysis is the compatibility of the original data with the secondary study. Specifically, the question is whether there is a “fit” between the purpose of the secondary analysis and the nature and quality of the original data. In the primary study, interviews were conducted to examine engagement in instrumental activities of daily living and the social roles of individuals with OA. The former are a subset of occupation and provide an appropriate potential data source. Social roles are described as “involving broad patterns of purposeful behavior at the level of societal involvement” (Gignac et al., 2008, p. 1656). The definition of social roles is closely related to the definition of occupation, in which the activity or set of activities are “performed with some consistency and regularity that brings structure, and is given value and meaning by individuals and a culture” (Townsend et al., 2007, p. 19). Further, the interview questions in the primary study specifically asked about “activities” that participants engaged in pre-OA and how the onset of OA influenced their participation in these activities. As discussed above, activities and occupation are closely aligned and while the terms are used distinctly in the occupational science literature, the term activity was used commonly and is equivalent to occupation within the pre-TKR literature. Accordingly, these questions had the potential to elicit details regarding occupational experiences of individuals with knee OA pre-TKR, which was the information of interest in this secondary analysis.

3.2.3.2. Position of the secondary analyst.
The second concern with secondary analysis of qualitative data identified by Heaton (1998) is whether the secondary analyst was part of the original study and also whether the secondary analyst would have access to the data of the original study. Heaton (1998) suggests that the secondary analyst requires access to the original data and access to the data would be easier if the secondary analyst was part of the original research team. In the study reported here, although I was not initially involved in the primary study I was named as part of that investigative team based on an addendum to the original study in a process vetted by the University of Toronto’s...
Research Ethics Board (REB) (Appendix B). Therefore, I had access to the data. However, I did not at any time access the entire data set, rather, I only accessed the anonymized transcripts to be used in the secondary analysis. Throughout the study I did, however, consult with the two principal investigators of the primary study: Dr. Fiona Webster and Dr. Aileen Davis who both had access to the full data set.

3.2.3.3. Reporting of original and secondary data analysis.
A third concern relates to the reporting of the original and secondary analyses. Specifically, the issue is whether extra precautions are taken to ensure that the study design, methods, and issues involved in both the original and secondary analyses are fully reported (Heaton, 1998). In the study being presented here, care was taken to ensure that the approach to inquiry, and the specific methods of analysis differed from the primary study and that the specifics of each are reported in detail, independently, thereby ensuring that the methods of the secondary analysis are distinct from those of the primary study.

3.2.3.4. Ethical issues.
A final concern raised by Heaton (1998) with respect to secondary analysis is the ethical issues of using the data. Heaton (1998) identifies two considerations in particular. First, it is suggested that consent from the participants of the original study must allow for the secondary analysis. However, this point is debated within the qualitative research community (Irwin, Bornat & Winterton, 2014). In this study, because I was named as an investigator on the primary study, this was considered a non-issue. Second, the confidentiality of participants should be maintained. In this secondary analysis, the data from the primary study were anonymized with all identifiers removed. All original data was stored on password-protected computers on an institutional network drive to which I had no access. Firewalls and security measures were in place. Hard copy records were stored in a locked cabinet in a secure location and I had access to the records when needed.

3.2.4. Participants.
Eight participant transcripts were purposively chosen by the primary investigator and research assistant of the primary study for their likelihood of containing data regarding the occupational experiences of the participants. There are a range of different approaches to purposive sampling,
designed to obtain a sample based on the research objective. Maximum variation, the sampling used here, is a sampling strategy used to choose participants to include based on phenomena, which vary widely from one another (Ritchie & Lewis, 2003). The purpose of using this sampling strategy is to understand how a phenomenon (e.g., OA pain and activity limitations, etc.) is experienced by different people, in different settings and at different times (Ritchie & Lewis, 2003).

The sample size in qualitative research is “a matter of judgment and experience in evaluating the quality of information collected against the uses to which it will be put, the particular research method and purposeful sampling strategy employed and the research product intended” (Sandelowski, 1995, p. 179). Smaller sample sizes allow the researcher to more fully examine the broader range of participants’ experiences (Russell & Gregory, 2003). Qualitative studies typically include a range of 8 to12 participants for their sample (Russell & Gregory, 2003). To date, there are no recommendations found in the qualitative literature regarding an appropriate sample size for a secondary analysis. It was determined to use eight transcripts because that is within the typical range of qualitative studies.

The specifics regarding the eight participants appear in Table 4. For the purposes of the present study it was considered that a sample of eight participant transcripts with four male and four female participants would be sufficient. Accordingly, eight participant interviews were purposively chosen using maximum variation sampling from the 15 pre-TKR transcripts of the primary study.

<table>
<thead>
<tr>
<th>Participant (pseudonym)</th>
<th>Gender</th>
<th>Age (in years)</th>
<th>Knee joint being replaced</th>
</tr>
</thead>
<tbody>
<tr>
<td>Erin</td>
<td>Female</td>
<td>46-65</td>
<td>Right knee</td>
</tr>
<tr>
<td>Portia</td>
<td>Female</td>
<td>46-65</td>
<td>Right knee</td>
</tr>
<tr>
<td>Betty</td>
<td>Female</td>
<td>46-65</td>
<td>Right knee</td>
</tr>
<tr>
<td>Clark</td>
<td>Male</td>
<td>46-65</td>
<td>Left knee</td>
</tr>
<tr>
<td>Sally</td>
<td>Female</td>
<td>66-80</td>
<td>Right knee</td>
</tr>
<tr>
<td>Sam</td>
<td>Male</td>
<td>66-80</td>
<td>Right knee</td>
</tr>
<tr>
<td>David</td>
<td>Male</td>
<td>66-80</td>
<td>Right knee</td>
</tr>
<tr>
<td>Danny</td>
<td>Male</td>
<td>66-80</td>
<td>Right knee</td>
</tr>
</tbody>
</table>

Note. Pseudonyms were assigned by the researcher to maintain participant anonymity.
3.3. Data Analysis

Braun and Clarke’s (2006) approach to thematic analysis was used to guide the analyses for the present study. As a widely used qualitative analytic method, thematic analysis is considered a useful research tool that can provide “a rich and detailed, yet complex, account of data” (p. 78). Specifically, thematic analysis is a method used to identify, analyze and report themes within a data set in a “recursive process” (Braun & Clarke, 2006, p. 81). The recursive process involves constantly moving backwards and forwards between the entire data set to find themes within the data (Braun & Clarke, 2006). The six phases of thematic analysis described by Braun and Clarke (2006) were used: (1) familiarizing yourself with the data (2) generating initial codes (3) searching for themes (4) reviewing themes (5) defining and naming themes and (6) producing a report.

3.3.1. Phase #1: Familiarizing yourself with the data.

This phase was especially important in this secondary analysis as I did not conduct the interviews so had no a priori sense of what the interviews held. I read all eight transcripts several times so I could become immersed in the data. I not only read the transcripts repeatedly but in later readings also began to search for meaning units as suggested by Braun and Clarke (2006).

3.3.2. Phase #2: Generating initial codes.

Coding is the process of deriving and developing concepts from data (Corbin & Strauss, 1990). For this phase, as I read, I assigned codes to meaning units I found in the transcripts. All codes were recorded in the margins of the transcripts. To ensure only relevant data were coded, I kept my research question in focus throughout the coding stage.

I used descriptive and “in vivo” coding. Descriptive coding summarizes, in a word or a short phrase, the basic topic of the meaning unit in the transcripts (Saldana, 2009) and entails little interpretation (Miles & Huberman, 1994). As the research question was related to the occupational experiences of individuals with knee OA scheduled for a total knee replacement, descriptive codes such as “activity loss” or “functional loss,” for example, were used to describe when participants experienced limitations with their daily activities (e.g., sleeping or walking) because of OA symptoms. In vivo coding, also called verbatim coding, refers to a word or short phrase spoken by the participants, and found in the transcripts that is used to code (Saldana,
I used this type of coding, where possible, because “sometimes, the participant says it best” (Saldana, 2009, p. 76). For example, in the initial coding phase I used this verbatim passage from one of the participants as a code, David: “I’m hoping to get back to pre-bad-knee life.” I felt this short phrase captured David’s perspective on life with a pre-TKR knee.

In the initial coding process of the eight transcripts using both descriptive and in vivo coding I generated 224 codes, which I entered into an Excel spreadsheet. I then removed codes that were not directly related to the research question (e.g., surgery scheduling experiences). This resulted in 154 codes remaining. The codes were then reviewed with my thesis supervisor.

3.3.3. Phase #3: Searching for themes.
Braun and Clarke’s (2006) third phase involves searching for themes. During this phase, I transferred all the codes from the Excel file to handwritten cue cards and began sorting the cards into like ideas. Next, I generated potential theme names that captured the emerging patterns and concepts and recorded them on the back of the cards. For example, this statement from one participant, “I was exercising at a gym and I had to quit that completely really” and this one from another participant, “I can’t play soccer anymore”, were placed under the potential theme “occupational loss” which seemed to fit meaning units from several transcripts.

Through this process, I generated 19 potential themes based on similarities in patterns and concepts. Boyatzis (1998) identifies two levels at which the themes can be identified: at a semantic (i.e., explicit) level or at a latent (i.e., interpretive) level. Whereas a semantic approach identifies themes only within the surface meanings of the data (Boyatzis, 1998), the themes identified at the latent level involve going beyond describing the data to interpreting it (Boyatzis, 1998). I used the latent approach in the present study to identify significant patterns (themes) of occupations and occupational experiences. I asked myself specific questions related to “occupation” and “meaning” as I coded the data at a latent level. For example, “What occupations are meaningful to these individuals?” and “What occupational meanings do the participants discuss?” and “What reasons do participants give for engaging or not engaging in an occupation?” All of the occupation-related questions were useful for maintaining the focus of the research question and drawing out pertinent interpretations of the data.

3.3.4. Phase #4 and #5: Reviewing themes, and defining and naming themes.
Phases #4 and #5 were combined because moving from reviewing themes to defining and
naming themes was done in an iterative fashion. I met with my thesis supervisor, on several occasions, to review the meaning units extracted from the transcripts and the emergent themes. As I reviewed these, a story seemed to be emerging from the 19 potential themes. After discussing the relationships between codes and themes based on the research question with my thesis supervisor, the themes was further reduced and grouped resulting in three broad, overarching themes, and 11 subthemes.

In this phase, I took the possible theme names that had been generated and began to write my chapter on findings as another way to understand the themes and subthemes. I realized that as I wrote that some of the subthemes were very similar to one another and therefore, collapsed them. For example, I determined that the potential subthemes (a) “You can hear it, you can feel it” and (c) “The knee started bothering me,” which I had labeled “The symptoms of OA,” were really part of the OA experience. Thus, I put these two subthemes together to form a subtheme called “Experiencing OA.” As I continued to write, I continued to refine the themes and subthemes in this manner until the title of each theme and the related subthemes seemed to capture the codes best.

I then invited the members of my PAC to review the themes and subthemes and their related meaning units. This resulted in a further refinement of the subthemes primarily to improve clarity and decrease ambiguity regarding what the meaning of the subthemes represented. For example, the potential subtheme, OA changes doing, was found to be too vague and it contained two distinct ideas so it was therefore discarded and two separate subthemes were created: Symptoms affect occupations and Occupations affect symptoms. Another example of clarifying subthemes was changing the potential subtheme OA is not alone to OA is not the only condition in order to capture the idea that OA is not the only medical condition to influence the participants’ ability to participate in occupations.

3.3.5. Phase #6: Producing the report.
This last phase involved the final analysis and write up of the report, i.e., the thesis (Braun & Clarke, 2006). As eluded under Phase #4 and #5, the writing process helped bring clarity to my thinking in particular as it related to the themes and subthemes. It also brought into focus the need for clarity around the use of occupational language.

Writing the thesis revealed the need to bring clarity to how I would use the terms that relate to occupation (e.g., activity, function, and occupation) throughout the thesis. This was
particularly important in this thesis because neither the participants of the study, nor the authors of much of the pre-TKR literature I was using were occupational scientists and so did not use occupational language in a manner consistent with practices in occupational science. For example, within the pre-TKR literature, the terms activity and function were often used interchangeably and frequently the term occupation was not used or used to mean paid work, exclusively. Further, the participants seemed to only use the term “activity” to describe their participation in a variety of occupations. Therefore, to bring clarity, the TCOP (Polatajko et al., 2007) described above, was adopted (Polatajko et al., 2007). Accordingly, for the purposes of this thesis, when citing the literature, the terms were kept as used by the authors of the various works. When discussing the relevance of that literature, the occupational language that was consistent with the TCOP (Polatajko et al., 2007), was used. Similarly, when participants describe their participation in “an activity or a set of activities that is performed with some consistency and regularity” (Polatajko et al., 2004, p. 19), these activities were considered occupations. Descriptions of activities that did not fall under this TCOP definition of occupation were considered to fit with other TCOP levels. For example, when participants talked about sitting or kneeling, these were considered actions according to TCOP and not activities nor occupations.

After the analysis was completed, the concept of occupational identity was found to be an appropriate concept for the present study but required clarification. A literature review identified occupational identity to be defined as “a composite sense of who one is and wishes to become as an occupational being generated from one’s history of occupational participation” (Kielhofner, 2002, p. 119). An occupational identity was found to be shaped by an individual’s capacities and interests, roles and relationships, obligations and routines, and by environmental context and expectations (Kielhofner, 2002; Howie, Coulter & Feldman, 2004). Kerr & Ballinger (2010) noted that an individual’s occupational identity is shaped by one’s participation in occupations and a loss of one’s identity may be a consequence of illness. The concept of occupational identity was applicable to the present study since the participants’ experiences of OA had a negative impact on their ability to participate in occupations and therefore, their identities. For example, the participants who considered themselves as “active” individuals experienced an extensive occupational loss because of knee OA that negatively impacted on their identities.

Terms such as activity, occupation and occupational identity led me to review the
literature in order to have a better understanding of these terms and incorporate them into the report.

### 3.4. Data presentation.

As is the practice in qualitative work (Anderson, 2010), direct quotations from the transcripts are presented in the findings. These quotations are presented with an assigned pseudonym so that the reader can begin to get a sense of the speaker. The pseudonyms, assigned to protect the anonymity of the participants, were chosen to reveal only the sex of the individual (see Table 4).

### 3.5. Research Rigor

To achieve research rigor, Braun & Clarke’s (2006) criteria for good thematic analysis and reflexivity were adhered to and ethical approval was obtained.

#### 3.5.1. Criteria for “good thematic analysis”.

Braun and Clarke (2006) assert that the criteria for “good thematic analysis” or research rigor, require the meticulous application of both theory and method. A checklist developed by Braun and Clarke (2006) outlines five processes and provides criteria for each process to determine whether a good thematic analysis was achieved. This checklist is used here to describe the rigor of the present study. The five processes are: transcription, coding, analysis, overall, written report.

As the present study is a secondary analysis of data, the transcription of the interviews was done as part of the primary study. The interviews were audio taped and then transcribed verbatim by a company. As part of the transcription process, the transcriptions were checked for accuracy by the research assistants of the primary study. I received these verified transcripts that were stripped of any identifying information.

The coding process involved the activity of checking one theme against another and returning back to the original data (i.e., recursive process). As described above in the discussion of thematic analysis, under Phase #3 (searching for themes), themes were closely followed in order to capture the occupational experiences of individuals with knee OA pre-TKR.

To address the analysis process, thematic analysis Phase #4 (reviewing and refining themes), and Phase #5 (defining and naming themes) were closely adhered; the data set and
codes were carefully considered to formulate themes and subthemes. The chapter on findings provides a balance between the analysis of the data and illustrative quotes from the participants, which is a main criterion for achieving rigor within the analysis process.

To achieve rigor as outlined within the overall process, ample time was allocated to complete all six phases of the thematic analysis. Each phase was reviewed at least twice to ensure that the steps were closely followed.

For the written-report process, every effort was made to maintain consistency between the methods and analysis chapters during the report-writing phase. As I was writing the report, I avoided writing an unconvincing analysis, where the themes did not appear to work, where there was too much overlap between themes or where the themes were not consistent or coherent.

3.5.2. Reflexivity.
Reflexivity refers to the assessment of the influence that the investigator’s own background, perceptions, and interests have on the qualitative research process (Ruby, 1980). Reflexive practice helps to ground the research study and enhance the understanding of the research question (Finlay, 2002). How reflexivity is generally incorporated into research varies from using reflexivity in one stage of the research to applying reflexivity throughout the research process (Finlay, 2002). The practice of reflexivity was incorporated in the present study to help examine and clarify how my perspective and position as a researcher influenced my interpretation of the participants’ accounts. Specifically, reflexivity was used to understand my own experiences and personal biases prior to conducting the present study and throughout the analysis process. To explore what I personally and professionally brought to my research study, I considered the influence of my professional background as an occupational therapist and my personal experiences with OA.

As an occupational therapist and an educator for patients preparing for a TJR at a local hospital for over eight years, I gradually developed an interest in learning more about the occupational experiences of individuals with knee OA who are scheduled for a TKR. During the pre-TKR education sessions, many patients described how their experiences of joint pain led them to want a joint replacement, they also talked about the limitations their pain put on their occupations. Over the years, I began to realize that the patients’ experiences were not just about pain but also about lost occupations and although I worked in a medical facility I began to develop an occupational perspective on their OA. In other words, I recognized that I needed to
attend to more than just the impairments that these individuals with knee OA experienced (e.g., pain); that they were also losing important doing. I began to wonder what role the occupational losses played in their experience of OA. As an occupational therapist, I presumed that everyone, including individuals with OA had the desire to engage in and find meaning in the self-care, productivity, and leisure occupations of their choice.

My own personal experiences with OA also contributed to my perspective with knee OA. Having played soccer and been a very active individual for over 22 years, I have sustained many knee injuries and have had a number of knee surgeries (none of which were a TKR) on both of my knees; therefore, I also had a standpoint as a patient. I do have OA in both my knees but they have not yet caused limitations in any of my occupations. These experiences may have affected my emotions, including empathy, which likely has influenced my interpretation of the data. My personal motivation to conduct the present study was to gain an understanding of the participants’ occupational experiences of living with OA who are scheduled for a TKR, as one day I may require a TKR myself.

Carrying out reflexive analysis is considered difficult and requires practice. Also, Finlay (2002) wrote,

Personal insights, when they arise, can be uncomfortable. In the course of methodological evaluation, researchers might be forced to come clean about certain mistakes, such as asking misguided questions or choosing the wrong strategy. . . although burdensome, as instruments of their own research, researchers need to engage in such analysis (p. 541).

To assist me in the process of reflexivity I used the “reader-response” method. This requires the reader to read for herself in the text, (Mauthner & Doucet, 2003). This is particularly important during the data analysis phase, as being explicit about the choices made when interpreting the participants’ “voices” is one way to strengthen the validity of the findings (Mauthner & Doucet, 2003, p. 418). Specifically, I placed myself, my background (e.g., professional), and my experiences, in relation to the participants’ responses. I closely examined my responses to each participant’s responses, both emotionally and intellectually, while reading the transcripts and recorded my responses in the column of the transcripts.

Having OA in my own knee joints, I had voluntarily chosen not to continue to play soccer because I did not want to accelerate the development of the OA in my knees. I realized that I had a choice to continue to play soccer but decided against it despite how important the
occupation of soccer was to me. As I read the transcripts, I realized many participants had a choice to stop participating in their occupations but chose to persevere despite their OA symptoms. I began to pay closer attention to the participants’ descriptions of the strategies they used and how some participants experienced occupational losses and activity limitations. I wrote the words, “occupational loss”, “activity limitation”, “persevere” in the column as I read the transcripts. This reader response exercise led me to identify the themes regarding occupational loss and “but mostly, I put up with it; I keep on going”.

Another example of using the reader response method was when one of the participants (Portia) described how upset she was because her OA symptoms prevented her from participating in her leisure occupation (e.g., cycling). Even though I currently do not have any OA symptoms, I felt I understood her emotional response to occupational loss. The emotional response I wrote in the column next to Portia’s description of occupational loss was “frustrated” and “angry”. This exercise facilitated the deeper understanding of the theme, occupational loss, which highlighted the participants’ occupational losses but also how those losses affected their emotional well-being. Using the reader response method, I was able to situate myself in relation to the participants’ responses, which helped to deepen my understanding of what influenced my interpretation of the data and how this occurred (Mauthner & Doucet, 2003).

Nevertheless, the fact that I have OA in my knee joints but have not yet experienced any major OA symptoms led me to realize my limited ability to fully understand the aspects of the participants’ occupational experiences. Accordingly, my interpretations of the participants’ responses about their OA experience and occupational experiences were guided by my own experiences as well as my ontological and epistemological positions (as described in detail in the methods chapter).

3.5.3. Ethical Approval.

Full approval was received from the University of Toronto’s Research Ethics Board (REB) (Appendix B). Dr. Fiona Webster and Dr. Aileen Davis, principal investigators for the primary study, both applied for an amendment to the University Health Network’s (UHN) REB (Appendix C). In particular, Dr. Helene Polatajko (thesis supervisor) and I were added as investigators to the original study. This amendment to the UNH REB application for the primary study was approved, which allowed me to conduct this secondary study.
Three major themes and 11 subthemes were identified that related to the occupational experiences of individuals with knee OA scheduled for a TKR. The first theme is living with OA: it is more than just the knee with the subthemes: *experiencing OA, symptoms affect occupations, occupations affect symptoms,* and *OA is not the only condition.* The second theme was named gradually losing my occupational identity with the subthemes: “*I am an active person*”, “*But mostly, I just put up with it; I keep on going*”, and *Occupational loss.* The third and final theme is losing too much—a “tipping point” with the subthemes: *gradual increasing occupational loss, exhausted all options,* “*I’m giving up too much,*” and “*I want my life back.*”

### 4.1. Living with OA: It is More Than Just the Knee

All the participants spoke about their symptoms of OA, but all also described that the experience of OA went beyond the symptoms. The eight participants revealed the impact of their symptoms on a myriad of everyday occupations, and the relationship between symptoms and doing went in both directions – each affecting the other. For example, the experience of pain in the knee joint limited Portia’s ability to ride her bike. However, riding her bike also affected her knee. When she rode her bike, she stated: “It [knee] would stiffen up on me” (Portia). Participants also described how living with OA involved a gradual decline over time, not being able to manage their OA symptoms and experiencing increasing occupational loss. For example, the OA symptoms led Portia to gradually stop cycling: “So the cycling was not good at all. So the doctor said you need to stop.”

Of interest, all participants described having other medical issues and previous injuries, in addition to OA, that contributed to their occupational change; in other words, for the participants, OA was not the only condition. Portia, for example, had OA in her left ankle in addition to her knee OA. These OA experiences are captured in the following four subthemes: *experiencing OA, symptoms affect occupations, occupations affect symptoms,* and *OA is not the only condition.*

#### 4.1.1. Experiencing OA.

The participants described their OA experience to include pain, swelling, and stiffness around the knee joint. Pain was a symptom that particularly stood out for them, as David described:
I’m perpetually hurting so I’m always in pain. And there’s no strength in my leg so sitting, once I get up, I get in a lot of pain.” The pain was also associated with mobility limitations of the knee joint, which David described as involving “restricted movement and a fair bit of pain [in the knee].” Portia illustrated the extent of her knee OA symptoms when she stated, 

I started to experience issues with this knee and it was getting quite bad, it was buckling on me, it was very painful, it started to be sort of swollen and inflamed, and I felt like there was sort of fluid [swelling] around it.

Although pain dominated the participants OA experience, the second and third subtheme illustrated the OA experience to also involve a two-way relationship between the participants OA symptoms and their participation in occupations.

4.1.2. Symptoms affect occupations.

The second subtheme exemplifies participants’ descriptions of how their OA symptoms affected their ability to participate in their occupations. Participants experienced symptoms while participating in a variety of occupations. To a majority of the participants, walking and sleeping were a regular part of their daily routine. When walking, Sam described: “You can hear it and feel it all the time with every step you take.”

Participants shared that sleep was an occupation that was being affected by the OA symptoms, especially pain. As Sally said: “I think that sleep is the one that really, really bothers me the most.” Sam, another participant, described how his OA symptoms affected his sleep: “It’s the right knee joint, and it keeps me awake at night.” The other occupations described by the participants as being affected by their OA symptoms included cycling, playing hockey, teaching, and running.

Aside from occupations, Sam’s OA symptoms also affected his activities, such as driving, he stated: “I can’t sit behind the wheel for half an hour because it starts to ache terrible.” In addition, Sam also experienced challenges with basic actions such as getting up from a chair and climbing the stairs because of his OA symptoms: “The biggest problem is getting out of the chair . . . going downstairs is worse than coming upstairs.” Other activities that participants described as being affected by OA symptoms included cooking, cleaning, and yard work.

These examples convey how the participants’ occupations were negatively affected by their OA symptoms. Participants indicated that not only did the OA affect their occupations but
the reverse also happened participating in occupations also affected their OA symptoms, as described in the subtheme below.

4.1.3. Occupations affect symptoms.
This subtheme shows how the relationship between OA and occupational engagement extends into much of the participants’ experiences. Specifically, the third subtheme refers to the participants’ descriptions of how engaging in everyday life activities aggravated the knee joint, thereby exacerbating the OA. Activities that aggravated the knee were many, and varied from walking and sitting in a car to work and leisure activities. When the knee joint became aggravated, most of the participants described their symptoms as involving pain and discomfort. The words used to describe the symptoms included: “throb,” “aggravated,” and “terrible.” Clark noticed that his OA symptoms worsened when he walked: “I can’t walk far without the knee starting to throb,” and Sally described her walking experience as: “I get pain all the time when I walked and everything.” For Sam, sitting in a car was a challenging experience: “I can’t sit behind the wheel for half an hour because it just starts to ache terrible.”

Work and leisure activities also aggravated the knee. Clark was a part-time teacher who felt his knee OA symptoms were aggravated by being on his feet most of the day: “When I was doing some part-time teaching and things like that, usually you’re on your feet most of the time. So, I usually found that really aggravated it [knee] a lot.” Clark also noticed his knee OA symptoms worsened when playing hockey: “I still get a lot of pain and discomfort when I play [hockey].”

4.1.4. OA is not the only condition.
This fourth subtheme refers to the participants’ descriptions of having other health-related issues or previous surgeries or injuries to other parts of their bodies that affected them, other than the knee OA. This subtheme highlights the role of previous injuries and surgeries that also influence the participants’ ability to participate in activities. As Danny said: “I had some other sickness besides that [OA in the knee].” The participants’ occupational engagement were affected by other joints (e.g., back, finger, ankle joints, etc.) as well as previous surgeries and medical illnesses. For example, Portia shared that not only did she have OA in her knee, but also “a lifelong problem with [the left] ankle” and “arthritis in [her] fingers.” She ranked her ankle to be worse than her knee OA symptoms: “Right now, the [left] ankle is worse, so the [right] knee
right now is secondary to the ankle.” Portia described having difficulty with occupational engagement in activities such as cycling and walking not only because of the OA symptoms in her knee, but also because of her ankle. However, she conveyed being more aware of the OA symptoms in her ankle than in her knee when climbing stairs: “But the knee, it bothers me, it’s just that the ankle is worse right now so the knee, I might even forget about it [knee] some days until I go up the stairs.”

Clark described not only having OA in the knee that was scheduled to be replaced but having OA in the other knee as well. Clark’s left knee was worse than his right knee, so his left knee joint was scheduled for the replacement surgery: “I have a little bit of trouble with both knees, actually, but, definitely, my left is, by far, the worst.”

Aside from having OA in her knee, Erin reported having previous injuries and surgeries to her right knee, which was being replaced: “I’ve had problems with this [right] knee since I was 14. I was in an accident” and “I’ve had nine surgeries on my right knee in total.” Erin described having also developed a syndrome she called “patellar compression syndrome” in her left knee that required surgery. Erin stated that her ability to walk was not only limited by the OA in her right knee, which was being replaced, but also by her left knee, which was recovering from an operation she had the previous year:

It’s just so much pain with walking. I’ve always had pain in this [right] knee since I was 14, and I just thought, tough it out, but it was just getting to the point that it would cause [issues with the left knee] . . . the left knee was still healing from the surgery I had in January and causing issues with that. So, it was getting to the point that I would just lurch a lot and wobble [when walking].

Sally described having a bad back prior to developing OA in her knee. Specifically, she described experiencing a poor quality of sleep that was affected not only by knee OA but also by back pain.

4.2. Gradually losing my occupational identity

Gradually losing my occupational identity is the second broad theme identified in the present study. Some participants perceived themselves as “active” individuals who really enjoyed their occupations, such as cycling (Portia) and working out at the gym (Betty). These participants closely connected their occupations with their identities. This is captured in the subtheme: “I’m
an active person” (Portia & Betty). As their OA symptoms worsened, participants described experiencing severe limitations in their ability to complete actions such as walking, or participate in occupations such as dancing. As Clark said: “I can’t walk that far without my knee really starting to throb.” David indicated: “I can’t go out and dance as much as I’d like to”. Nevertheless, participants described doing what they could and put strategies in place in order to remain engaged: “So I just try to keep going” (Portia). This is captured in the subtheme “But mostly, I just put up with it; I keep on going”; nonetheless there is eventually occupational loss – the third subtheme.

4.2.1. “I am an active person.”

The first subtheme, “I am an active person,” refers to the participants’ engagement in their occupations. These people were closely connected with their occupational identities. The onset of OA symptoms limited and, eventually, prevented them from participating in many of their occupations. Some participants viewed themselves as occupational beings, which was gleaned from their descriptions of themselves as “active.” For example, Betty enjoyed going to the gym. She viewed the cardiovascular workouts as an occupation she engaged in that helped her to stay in shape. Walking was also part of Betty’s cardiovascular workout. However, the pain and OA symptoms in her knee limited her ability to walk, which was how Betty controlled her weight:

I do a lot of walking, and that’s to keep my weight down. It’s just always what I’ve used to keep my weight down and to keep in shape. So, quite long—an average walk would be a two-hour power walk. That’s what I would usually do three times a week, and then interspersed with that I have my own cardio workouts that I do, and I would do those every other day.

Betty’s occupational identity was affected because she could no longer participate in the activities to stay in shape:

I must say, I’m an active person. I really like to keep fit and I haven’t been able to this past year, so that’s been very frustrating. So, my plans are to get back to being fit again. . . I used to really pride myself in how much I could stay in shape, but now I just can’t do any of those things.

Portia also viewed herself as an active individual and shared her personal philosophy that her overall health was maintained through staying active. Portia described taking care of herself in order to still participate in her physical activities (e.g., cycling):
I’m an active person and because I do a lot to take care of myself, because I know that even with the work I do, that daily physical activity is really one of the keys to longevity and good health.

4.2.2. “But mostly, I just put up with it; I keep on going.”
The second subtheme highlights how the participants made an effort to persevere through their OA symptoms to still participate in their occupations. Their OA symptoms led some participants to use a variety of strategies to manage the symptoms so they could continue to participate in their activities and occupations. To remain in their occupations, participants described modifying the frequency and intensity of their occupations. Other participants conveyed that their daily routines had to be restructured. In some situations, participants relied on supports, such as a knee brace or on family members, so they could still participate in the occupation.

An example of changing the intensity of an activity is expressed in Portia’s describing how she spreads out the time to complete her exercises rather than finishing them all at once: “I’m still accumulating about 40 minutes on the elliptical, but I’m spreading it out in little bursts.” Portia realized that the OA symptoms were an ongoing experience, but she was able to discern when she should stop so as not to cause further aggravation to the knee joint. Portia also shared the importance of arranging her occupational repertoire in such a way as to accommodate her OA symptoms: “So I just listen to my body and I plan my activities based on how it’s all feeling and what I think I’m capable of doing.”

The knee OA symptoms, such as pain and stiffness, also limited the frequency of participation and led some participants to restructure their occupational patterns. For example, Clark enjoyed playing hockey, and he noticed that his OA symptoms limited the frequency of his engagement. To avoid experiencing exacerbation of the OA symptoms, Clark adjusted the frequency with which he engaged in his preferred occupation:

But it just got to the point where I just found I might take a day or two to recover and then, but by the time I go out and play again, it seems kind of pointless that I’m spending all my time just getting over playing. So, for about two years now, I just play once a week.

Participants also relied on instrumental supports to help them participate in occupations or remain involved in some aspect of an occupation when their OA symptoms prevented them from participating altogether. These instrumental supports varied depending on the activity and
the limitations imposed by the OA symptoms. For example, Clark used a support to play hockey: “I still play some hockey, but I wear a knee brace,” while Sally described using a cart for walking and a bench for sitting when her OA symptoms bothered her:

Now I don’t walk very far without some sort of help. I do my walking usually in somewhere like Walmart with a shopping cart to help me walk and somewhere [a park bench] where I can quickly find somewhere to sit down if I need to.

Some participants, limited in their ability to engage in activities, spoke of relying on family and friends for assistance. For example, Sally described her camping experience:

I don’t walk around [the campground] very much. I usually let people come to me. But if we are camped far enough away from where everything is going on, my husband usually drops me off in the truck and then I don’t walk very far on the uneven ground. So we’ve had ways around it.

For Erin, the OA affected her ability to walk and train for marathons. Erin described:

“It’s just so much pain with walking.” Aside from walking, Erin was so actively engaged in training for half marathons that, despite the OA symptoms in her knee, she persisted through the pain to walk. Being able to continue to walk influenced Erin’s occupational identity; she described a sense of achievement: “Well, I wasn’t very fast. It’s [the knee] sore, it’s really sore. But at the same time, I’m happy I can still do what I did.”

4.2.3. Occupational loss.

As part of the participants’ OA experience, occupational losses occurred. This third subtheme captures the participants’ experiences of occupational losses. These examples highlighted how the participants’ identity and emotional well-being were negatively affected; participants not only experienced occupational loss but also displayed a broad range of emotions (e.g., “frustrating”) as a result of occupational loss.

For participants like Sally, OA symptoms such as pain affected sleep to the point that she no longer slept through the night: “It got bad in the last two years. I mean, it got to the stage where I can’t sleep at night.” Other participants commented on how their experiences of knee pain not only disrupted their sleep (e.g., woke up and fell back asleep) but also kept them awake during the night: “I’ll get to sleep okay, but then I’ll wake up in about three or four hours and then sometimes go back to sleep, but quite often I don’t” (Sam).
Betty enjoyed going to the gym and doing her cardiovascular workouts. Betty’s OA symptoms prevented her from participating in her gym activities and led to her occupational loss, “I really like to keep fit and I haven’t been able to [be active] this past year, so that’s been very frustrating.” Other participants, like Portia, also viewed themselves as active people. Portia described herself as an “active person”. However, the OA experience rendered her inactive as her symptoms prevented her from participating in her occupation, which was cycling. Portia, who strongly connected her cycling to her identity, exemplified this subtheme when she stated:

I haven’t been able to ride for the last two summers and that’s big for me because my work is in active transportation, so walking and cycling [are considered] as means of travelling every day and [is a] part of a healthy lifestyle. [Cycling is] what I do for a living and it’s how I live my life.

Portia’s reason for having a knee replacement appeared to be more than just her OA symptoms. She conveyed how OA symptoms also prevented her from participating in cycling trips with her friends. She was offered a car ride to the final biking destination to be with her friends but she declined: “And he [the person offering the ride] said, ‘Oh, you can come with me [in a car],’ but I did do that once when I first hurt the ankle and I couldn’t participate about five years ago, and it was just way too boring.” She associated her capacity to cycle with her occupational identity and would rather forego spending time with her friends if she did not have the ability to cycle.

Erin, a long-distance runner, had to stop running in races with her friends because of her OA symptoms. Her attitude was similar to Portia’s. She also described her desire to be a runner and a part of the races. However, the OA symptoms affected her ability to participate in her favorite sporting occupation, running. The following quote represents her unwillingness to be a spectator:

Well, I used to do a lot of races with friends. And I don’t do those anymore. I don’t even go to watch anybody because . . . I just don’t feel like going. I can’t participate and it upsets me too much to just sit and watch.

4.3. Losing too much—a “tipping point”

The third theme, losing too much—a “tipping point” refers to the participants’ experiences of extensive occupational loss, which led them to consider a TKR. Within this theme, all participants conveyed experiencing a gradual increase in occupational loss because of their
worsening OA symptoms. The options that were used by participants to remain engaged in their occupations were no longer effective. Despite the strategies that were used, participants experienced occupational loss: “And I thought I could still do the activities that I loved to do by being braced. It got to the point, in the fall, the brace wasn’t doing its job anymore” (Erin). Their occupational losses led them to the tipping point in their decision to have a TKR. The concept of the “tipping point” was taken from Erin who had longstanding back pain, but when she experienced extensive occupational loss because of her knee OA, stated: “So it was just the knee that kind of tipped the scale.” All the participants wanted to resume their previously enjoyed occupations. As Portia stated: “I would rather have it [TKR] now because I’m giving up too much stuff [occupations] and I need to get my life back.” These changes are captured in four subthemes “gradual increasing occupational loss”, “exhausted all options”, “I’m giving up too much,” and “I want my life back.”

4.3.1. Gradual increasing occupational loss.
The first subtheme, gradual increasing occupational loss, reflected that while occupational losses occurred, the process was gradual. The findings indicated that the participants made efforts to remain engaged in their occupations as long as possible, despite their OA symptoms. However, as their OA symptoms worsened over time, participants experienced a gradual occupational loss to the point that they considered undergoing a TKR.

Participants like Erin described gradual increasing occupational loss when she said: “I had slowly started giving up all of my activities I enjoyed doing.” Sally described how much she valued walking and taking her dog camping: “I did enjoy taking her [dog] camping with us and walking around and talking to other people with dogs.” However, she described experiencing occupational loss over a period of three to four years, to the point at which her OA symptoms finally prevented her from her occupation:

Well, I can’t remember exactly when it started getting really bad. But we had a dog, and I mean at one time, I would walk it two or three times a day. But towards the end of her life, it got to the stage where I couldn’t walk her. I would just watch while somebody else walked her. So over the last three or four years it’s got [sic] really bad.

By the time the participants were scheduled for their TKRs, some had already experienced extensive occupational losses. For example, before the onset of OA symptoms, Betty was able to take long, two-hour power walks: “I do a lot of walking, and that’s to keep my
weight down.” After a year of dealing with gradual worsening of her OA symptoms, walking long distances became a challenge for Betty: “I couldn’t really seem to [walk long distances]. It was just too much pain involved, and so I just backed right off. I’ve tried to do some shorter, maybe one kilometer walks, that kind of thing, but it’s quite painful.”

Some participants, like Erin, described experiencing multiple occupational losses, “I used to walk half marathons and train for those races and I used to do a lot of biking and swimming.” Portia described her gradual experience of multiple occupational losses from cycling and then walking. Portia was no longer able to cycle and resorted to walking, but, over time, walking became a challenge for her as well:

So the cycling was not good at all. So the doctor said, “You need to stop.” So that created more issues, so, then, you know, I walk a lot. I walk everywhere, but I had to cut back a little on my walking, which is not good.

4.3.2. Exhausted all options.
The second subtheme refers to the participants’ experience of discovering that all of their non-surgical options were ineffective. Many were left with no other options to manage their OA symptoms. For example, Erin stopped using her knee brace as it no longer provided her with the support she needed when she ran: “I decided not to wear the [knee] brace anymore because it wasn’t helping any, and I always had problems with it breaking down the skin.”

Different types of therapies, including massage, physiotherapy, chiropractic treatments, and naturopathic medicine, were used to manage the OA symptoms. However, these treatments, which initially provided relief for participants, gradually became ineffective. For example, Clark described his experience with physiotherapy: “I started doing physiotherapy on it [knee], but it didn’t really seem to help at all.” Sam initially felt that the naturopathic treatments were effective. However, after a few treatments he stated: “That [naturopathic treatment] does help a lot, but, last week, it just didn’t work at all and that’s the first time.”

Some participants received cortisone injections to manage their OA symptoms. However, these OA management strategies gradually became insufficient. Portia described how cortisone injections did not fully address her symptoms: “She [orthopedic surgeon] sent me for x-rays for the knee, and at that point it wasn’t too bad so [I] was doing cortisone needles . . . it was helping a little, bit but it just got progressively worse.” Like Portia, many participants felt
they had exhausted all OA management options and described experiencing extensive occupational loss.

4.3.3. “I’m giving up too much.”

The third subtheme covers a majority of participants describing their experiences of extensive occupational losses that led them to wanting their knees replaced.

Portia was the participant who used the phrase, “giving up too much,” when referring to the occupational loss of cycling, which was very important to her. This was what led her to take the TKR option. David, similarly, described the physical limitations on his knee as a result of the OA symptoms: “The summary of my knee and the impact of it on my life is really for the most part my limited motion that I have in my knee, the pain that I’m feeling.” However, David’s reason for surgery was more than just pain and other OA symptoms. David’s tipping point occurred when pain and OA symptoms severely limited his participation in the occupations that he enjoyed doing (e.g., soccer, volleyball, running, and golfing).

This subtheme also highlighted how some participants were no longer actively involved in their occupations and attributed their tipping point to their extensive occupational losses.

4.3.4. “I want my life back.”

In this fourth subtheme, participants conveyed that their consideration of a knee replacement was related to their desire to get their lives back. Many participants considered the TKR as their last option to relieve their OA symptoms in order to resume their occupations.

David’s consideration of the TKR was not only because of pain, but also because of functional loss and the loss of two occupations of importance to him, sleep and soccer. As David shared, the TKR would help “the discomfort in sleeping, the discomfort in movement, inability to walk any distances, the pain that I get through that, [and] the limit that it [knee pain] has on my favorite past time [soccer].” Clark, another participant, had put off having the surgery for years. However, the OA symptoms worsened to the point of severely limiting his ability to play hockey. Clark conveyed: “It’s just getting to the point where I’ve got to get something done because I can’t really enjoy life the way I want to with the way it is.”

Some participants discussed becoming spectators and no longer being able to participate in their occupations as key considerations for having their knees replaced. For example, Sally became a dance spectator because her OA symptoms eventually prevented her from being able
to dance with her husband. She hoped that having the TKR would help her to resume her previous occupations, such as dancing, gardening, or camping: “Well, I’m hoping that I’ll be able to do most things that I used to do.”

Participants also considered the TKR as an option to give them their “lives back.” Portia captured how she gave up many occupations and hoped that the surgery would help her reach her “pre-bad-knee” life: “I said to [the surgeon] that I really would prefer to do the knee now rather than wait and have to give up more stuff because I really just want to get my life back.” Betty was another participant who described her eagerness to have the knee replacement. Her eagerness was related to being able to resume her occupations after surgery: “So, I’m very, very thankful to be having this surgery done so that I can get back what I want to be, fully and more [of] what I used to do.”

4.4. Summary of Findings
In summary, three overarching themes were identified from the transcripts of participants telling their experiences pre-TKR surgery. The first theme, *living with OA; it is more than just the knee*, was supported by four subthemes. The first subtheme, *experiencing OA*, described the participants’ own experiences of their knee OA symptoms. The second and third indicated that the symptoms *affect occupations and occupations affect symptoms*. These two subthemes came out of participants talking about how the OA symptoms affect, and are affected by, their engagement in activities and occupations. The fourth subtheme, *OA is not the only condition*, revealed that the participants not only experienced knee OA but many also had other medical issues and previous surgeries, which affected and influenced their ability to participate in their occupations.

The second theme, *gradually losing my occupational identity*, revealed how closely connected the participants’ occupations were to their identity. Three subthemes were identified to support the second theme. The first subtheme, *I am an active person*, described how some of the participants viewed themselves as “active” and described their involvement in their occupations prior to the worsening of their OA symptoms. The second subtheme, *but mostly, I just put up with it; I keep on going*, reflects the participants’ attempts to remain engaged in the activities that they valued despite their knee OA symptoms. Nevertheless, all participants still experienced a slow and gradual loss of ability to participate, which affected their emotional well-being, which highlighted the third subtheme, *occupational loss.*
The third theme, losing too much—a “tipping point” was characterized by extensive occupational loss as participants exhausted all options to maintain their engagement in their occupations. Participants’ descriptions during this phase addressed their physical pain, but also their inability to participate in the activities that they enjoyed doing. This diminished some participants’ occupational identity. In the first subtheme, *gradually increasing occupational loss*, participants shared their experiences of increasing occupational losses to the point of becoming a spectator of the activity or being prevented from participating in the activity altogether. The second subtheme, *exhausted all options*, reflected the participants’ use of various strategies with the goal of maintaining participation in their valued activities. However, emphasis here is on how those options became ineffective. The third subtheme, *I’m giving up too much*, followed the second subtheme as, after all options had failed, participants began to experience extensive occupational loss, which led them to reach the tipping point of having a TKR. Finally, in the fourth subtheme participants conveyed the thought “*I want my life back*” because they viewed the TKR not only as an option to relieve their OA symptoms, but also to help them return to their occupations.

These three themes and the participants’ occupational experiences were identified through the use of an occupational perspective when conducting the analysis.
Chapter 5
Discussion

The purpose of the present study was to explore the occupational experiences of individuals with knee osteoarthritis (OA) who are scheduled for a total knee replacement (TKR). The present study identified three key themes: (1) living with OA: it is more than just the knee; (2) gradually losing my occupational identity; and (3) losing too much: “a tipping point”. This discussion will include an interpretation of the three themes and respective subthemes followed by a comparison of the findings of the present study to the existing literature. In particular, the interpretation of the findings revealed three overarching considerations that will be discussed in this chapter: (1) a bidirectional relationship between OA symptoms and occupation; (2) the concept of occupational identity; and (3) the relationship between the tipping point and occupational identity. Finally, the limitations of this secondary analysis as well as recommendations for future research will be reviewed. To begin, we have included a word about terminology.

5.1. Terminology

For the purpose of the present study, the taxonomic code of occupational performance’s (TCOP) definition of occupation was adopted and applied to the study findings (Polatajko et al., 2007). A close examination of the findings revealed that the study participants described their occupational performance based on three levels of the TCOP: action, activity, and occupation (Table 5). The participants did not use the term occupation; rather, they tended to use the term activities to describe all of their actions, activities, and occupations.

In the present study, the concept of occupation was differentiated from activities and actions based on the participant descriptions. For example, based on the TCOP, walking should be considered an action. However, walking was considered an occupation for some participants as they described walking to be something they enjoyed and completed on a regular, and sometimes, daily basis. The meaning and regularity characteristics that participants convey is how walking would be considered an occupation according to the TCOP.
Table 5  Descriptions of occupations used by participants based on the TCOP

<table>
<thead>
<tr>
<th>Level of Complexity</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupation</td>
<td>Cycling</td>
</tr>
<tr>
<td></td>
<td>Playing hockey</td>
</tr>
<tr>
<td></td>
<td>Playing soccer</td>
</tr>
<tr>
<td></td>
<td>Running marathons</td>
</tr>
<tr>
<td></td>
<td>Sleeping</td>
</tr>
<tr>
<td></td>
<td>Teaching</td>
</tr>
<tr>
<td></td>
<td>Walking the dog</td>
</tr>
<tr>
<td>Activity</td>
<td>Camping</td>
</tr>
<tr>
<td></td>
<td>Cardio workouts</td>
</tr>
<tr>
<td>Action</td>
<td>Kneeling</td>
</tr>
<tr>
<td></td>
<td>Sitting</td>
</tr>
</tbody>
</table>

Although not a concept within the TCOP, participants referred to the concept of “doing” along with their descriptions of their participation in occupation. This concept was found within the subtheme: “But mostly, I just put up with it; I keep on going.” According to Hammell (2001), the concept of doing includes purposeful and goal-oriented activities that provide structure for the individual; doing is synonymous with the concept of occupation.

The occupations discussed by the participants included paid work (e.g., teaching) and leisure activities (e.g., hockey, dancing, cycling, etc.), which is consistent with other pre-TKR studies (Bieleman et al., 2011; Gignac, 2005; Sankar et al., 2013; Healy et al., 2008; Jackson, Smith, Shah, Wisniewski, & Dahm, 2009; Styron et al., 2011; Wylde, Blom et al., 2007).

Interestingly, the only self-care occupation participants described in the present study, was sleep. Some pre-TKR studies have highlighted the other challenges participants experienced with their self-care occupations. Due to their OA symptoms, some participants reported difficulty with getting dressed (Jacobson et al., 2008; Parsons et al., 2009) while others had trouble bathing (Hall et al., 2008).

5.2.  Living with OA: It is more than just the knee

The first theme, living with OA: it is more than just the knee, refers to the participants’ experiences of living with OA and the way their knee OA shaped their occupational experiences. The first theme highlighted the health-related issues other than the knee OA that influenced their participation in activities. The first theme is comprised of four subthemes: (1)
experiencing OA, (2) symptoms affect occupations, (3) occupations affect symptoms, and (4) OA is not the only condition.

The first subtheme, experiencing OA, was found to be consistent with the existing literature and is well reported by many authors. Similar to the present study, the OA experience as described in the pre-TKR literature included symptoms such as intense and prolonged pain, and swelling of the knee joint (Demierre et al., 2011; Hall et al., 2008; Jacobson et al., 2008; McHugh & Luker, 2009).

The second and third subthemes revealed a bidirectional relationship between OA and occupations. Specifically, the participants’ knee OA affected their participation in occupations, which was identified within the second subtheme, symptoms affects occupations. The third subtheme, occupations affect symptoms, showed that the reverse also occurred; participating in occupations also aggravated the knee joint. A bidirectional relationship between OA and occupations was also found in a study by Bieleman and colleagues (2011). However, Bieleman and colleagues (2011) study differed from the present study as they discussed the relationship between OA and occupations, specifically work-related occupations:

There is a bidirectional relation between OA and work. On the one hand, several aspects of the physical workload have been identified as risk factors for developing knee and hip OA, for example, kneeling work positions, jumping and heavy lifting. On the other hand, people who have OA may perceive difficulties in performing work (p. 1835).

Expanding on Bieleman and colleagues’ (2011) findings, the bidirectional relationship suggested that the OA symptoms described by the participants were considered risk factors for developing joint OA. For example, aspects of the physical workload, such as kneeling, jumping, and heavy lifting, were identified as contributing factors to the development of knee and hip OA (Bieleman et al., 2011). At the same time, participants noticed that when they were working their knee OA symptoms were aggravated.

Bieleman and colleagues’ (2011) study differed from the present study in two ways. The participants of the present study did not consider the contributing factors to the development of joint OA and the occupations of the present study were not limited to work but also to leisure and self-care occupations. Even though the second and third subthemes of the present study were identified and described separately, the bidirectional relationship demonstrates that the two subthemes are connected.

The fourth subtheme, OA is not the only condition, highlights the health-related issues of
previous surgeries or injuries to other parts of the body that affect participants and their occupations. Although all participants had been admitted to the primary study because they were scheduled for a primary knee replacement, many revealed comorbidities with the OA in the knee. The participants in the present study were similar to those in most studies of knee OA, in that common inclusion criteria include individuals with joint OA who: are scheduled for a joint replacement, are over the age of 18, and are able to speak English. The sample used for the present study is similar to what is commonly found within the literature. However, a majority of the studies that have examined the pre-TKR experiences of individuals with OA did not consider other health-related issues that affected their participation in occupations (Toye et al., 2006; Gustafsson, Ponzer, Heikkila, & Ekman, 2007; Jacobson et al., 2008; McHugh & Luker, 2009; Parsons et al., 2009; Wylde et al., 2012).

Individuals with OA often have medical conditions, or co-morbidities, other than joint OA (van Dijk, et al., 2008). Comorbidity refers to having other conditions aside from a main diagnosis (Feinstein, 1970). There is evidence to show that having comorbidities alongside OA is associated with activity limitations and pain (van Dijk et al., 2008). Comorbidities found alongside OA include: diabetes, hypertension, cardiovascular disease, and obesity (Gijsen, et al., 2001; van Dijk et al., 2008). Findings from some studies have shown negative associations between joint OA and comorbidities affecting an individual’s physical functioning (Kadam & Croft, 2007), activity limitations, and pain (van Dijk et al., 2008).

As previously mentioned, studies that have examined pre-TKR experiences did not consider the impact of comorbidity in relation to one’s ability to participate in occupations. This insight is important and suggests that in addition to the knee OA, other comorbidities may also influence the participants’ pre-TKR occupational experience.

5.3. Gradually Losing My Occupational Identity

Occupational identity is a concept identified as central to the second theme, gradually losing my occupational identity. Kielhofner (2009) defined an occupational identity as a “composite sense of who one is and wishes to become as an occupational being” (p. 171). The first subtheme, “I am an active person,” found that participants closely connected their occupations with their identities. For example, Portia’s occupational identity was strongly based on being a cyclist. She cycled to work every day and regularly enjoyed bike riding trips with family and friends. Cycling was one of her occupations. For this subtheme, the participants’ strong sense of who
they were aligned with the “composite sense of who one is” part of the definition of occupational identity (Kielhofner, 2009, p. 171). The findings of the present study supported Unruh’s (2004) study that recognized that “engagement in meaningful occupations seems to be about not only creating a meaningful life but also a meaningful identity” (p.294).

The present study also supported the findings of Jacobson and colleagues’ (2008) study that their participants identified themselves as “a very active person” (p. 55). The participants’ OA symptoms have lead the participants to feel constrained and affected how they viewed themselves as they were no longer able to participate in their daily activities (Jacobson et al., 2008). However, Jacobson and colleagues (2008) did not consider the relationship between occupations and one’s identity and discussed their findings to be associated with OA symptoms and participation restrictions. Demierre and colleagues (2011) briefly discussed the concept of identity, but unlike the occupational losses experienced by the participants in the present study that had affected their identities. Demierre and colleagues’ (2011) participants felt that their identities were challenged due to the gradual dependence on others.

“But, mostly, I just put up with it; I keep on going” was the second subtheme identified from the present study to highlight how some participants made an effort to continue participating in their occupations despite their OA symptoms. This subtheme was similar to the findings of other pre-TKR studies for OA management strategies. Examples of OA management strategies identified in other studies that were used by participants within the present study included reliance on family members (Demierre et al., 2011; Parsons et al., 2009), taking rest breaks (Jacobson et al., 2008), modifying activities (e.g., decrease frequency) (Hall et al., 2008), and participating in alternative activities (Sjoling et al., 2005).

The participants in the present study used a combination of OA management strategies as has been reported in other pre-TKR studies, including cortisone injections (Jacobson et al., 2008), arthroscopic surgery, use of a knee brace, and pain medications (Hall et al., 2008), exercise (Bennell & Hinmann, 2005), alternative therapy (Williamson, Wyatt, Yein, & Melton, 2007) and physiotherapy (Lenssen, & de Bie, 2006; Mitchell et al., 2006). As the occupations played an important role to the participant’s identity, participants implemented multiple strategies to maintain participation in their meaningful occupations. An example of using multiple OA management strategies would be using pain medications while taking breaks in order to participate in their occupations.

The third subtheme, occupational loss, highlighted the participants’ occupational losses
and how those losses affected their emotional well-being. Participants in the present study experienced a broad range of emotions (e.g., frustration, annoyance, etc.). The present study supports the finding of other pre-TKR studies, which demonstrated how greatly occupational loss can affect one’s emotional well-being. Our findings supported Toye and colleagues’ (2006) study, which found participants to have felt “miserable” because their knee OA prevented them from being able to participate in their activities. Demierre and colleagues’ (2011) participants described feeling “bad” for not being able to work and to participate in their daily activities.

5.4. Losing too much: a tipping point

The final theme identified from the present study, losing too much: a tipping point, suggests that participants experienced extensive occupational loss and at some point this gradual loss affected their identity, and impacted their consideration of having a TKR. In the pre-TKR literature, participants convey their decision for a TKR to be mainly related to alleviating their OA symptoms, especially pain, and to improve function (Ballantyne et al., 2007; Fitzgerald et al., 2004; Rat et al., 2010; Rissanen, Aro, Slatis, Sintonen, & Paavolainen, 1996). In the present study, the participants’ extensive occupational loss led them to the tipping point of considering a TKR.

The findings of the first subtheme, gradual occupational loss, conveyed the participants’ gradual experience of having difficulty with participating in activities that are meaningful to them because of their knee OA symptoms. This subtheme can be interpreted in two ways. As part of the occupational loss experience, participants reported that they slowly had to give up occupations. Gustafsson and colleagues (2007) noted that participants in their study lived life with a “gradually-deteriorating body” (p. 23). Participants often referred to how strong, healthy, and able bodied they were before their OA symptoms “eventually affected the whole body” (Gustafsson et al., 2007, p. 23). The authors also noted that the OA affected “the person’s everyday life, and this [OA] process tends to be gradual” (Gustafsson et al., 2007, p. 23). The term, occupational loss was not found in the pre-TKR literature. Participants in other pre-TKR studies described their participation to be “challenged” or “limited,” or they used other terms, such as “functional limitations” or “activity limitations” (Demierre et al., 2011; Jacobson et al., 2008; McHugh & Luker, 2009; Parsons, 2008; Toye et al., 2006).

The second subtheme, exhausted all options, highlights the way participants in the present study experienced occupational loss after all their previous strategies and compensatory
techniques to manage their OA symptoms were exhausted. This finding was consistent with the OA literature. For example, Jacobson and colleagues (2008) reported that cortisone injections provided temporary relief. However, over time these treatment became ineffective and the participants described their OA conditions to have “worsened” (p. 56) Participants in the present study also used medications and alternative therapies to manage their OA symptoms, but, over time, these strategies no longer provided comfort. The present study not only found that strategies used gradually became ineffective, but also captured, through this subtheme the participants’ descriptions of exhausting all options for OA management while experiencing increasing occupational loss. The third and fourth subthemes, “I’m giving up too much” and “I want my life back,” suggest that the participants’ pre-TKR experiences involved extensive occupational loss. These two subthemes highlight the relationship between one’s occupational identity and the participant reaching the tipping point. These subthemes also suggested another reason for participants to consider undergoing a TKR, that is, they had given up too many occupations and this loss negatively affected their occupational identities.

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The participants’ OA symptoms were shown to be associated with occupational limitations and loss. A growing number of individuals with knee OA, like most participants of the present study, are becoming more active in their daily lives (Lutzner et al., 2012). For the participants, the consideration for a TKR was not only to address the OA symptoms causing occupational losses but to also maintain the goal of resuming their previously enjoyed occupations. These two subthemes correspond to the second part of Kielhofner’s (2009) definition of occupational identity, which is defined as not only “a composite of who one is” but also who an individual “wishes to become as an occupational being” (p. 171). Accordingly, participants expressed their desire to get their life back and resume their ‘active’ lives, which led to the consideration of the TKR as a means to rebuild their occupational identities.

As previously discussed, people are considered occupational beings who are searching for a sense of continuity in their occupational identities (Unruh et al., 2002). Health-changing events, such as the worsening of OA symptoms, have been shown to disrupt an individual’s occupational identity (Unruh et al., 2002). The relationship between one’s occupational identity and the tipping point lies in the participants’ hope to get his/her life back. Occupations provide another way to enable individuals to achieve their goals and allow them to demonstrate who they are and what they hope to become (Wilcock, 1993). This finding suggests that a TKR is a participant’s way to gradually rebuild the occupational identities that he/she have lost because of
their knee OA.

The participants wanted to resume actions (e.g., stair climbing and transferring out of a chair) and occupations, especially leisure occupations (e.g., playing soccer, hockey, and riding a bike). Interestingly, returning to work did not seem to be of great concern, this may be because the majority was either retired or no longer working. Aside from sleep, which was markedly affected by OA symptoms, the participants did not discuss other self-care activities unlike participants of other studies who considered getting dressed (Hall et al., 2008; Jacobson et al., 2008) and foot-care activities (Parsons et al., 2009) as important.

5.5. Limitations

The limitations of the present study are largely related to conducting a secondary analysis. Semi-structured interviews are helpful in obtaining detailed descriptions from participants. The richness of the data, as it relates to the research question, is dependent on the interviewer and the interview guide. In using a secondary analysis, I was unable to ask the participants additional questions related to the meaning behind their occupational losses. Using an occupational perspective and the lens of my own experiences, I would have pursued a different line of questioning. For example, I would have probed further into the participants’ experiences with OA and their self-care activities and the level of importance they placed on their self-care activities, in comparison to their work or leisure activities. The responses to these questions would have helped to obtain a more comprehensive understanding of the participants’ occupational experiences.

5.6. Practice Implications

The findings of the present study have several practice implications for occupational therapists (OT) as well as for other health professionals (e.g., family physicians; pre-surgery educators such as nurses) who may work with individuals with knee OA.

The findings revealed that participants living with knee OA experience significant occupational loss. OTs could address occupational loss in a number of ways. For example, to discover how the worsening of their OA symptoms has affected his or her occupational identity, the OT could ask the individual which occupations affected by OA were central over his or her lifetime and why these occupations were so meaningful (Unruh, 2004).
Alternatively, the OT could seek to minimize the occupational challenges that an individual is experiencing as a result of the knee OA. To learn more about the individual’s occupational challenges, an OT could ask the following questions:

- What does doing the occupation involve?
- Can the individual participate in the occupation and what might it be like for him or her to do so?
- Is the occupation simple or complex?
- Where does the occupation ordinarily take place?
- What steps are required for engaging in the occupation?

This information could help the therapist design and intervention that could delay participants from reaching the tipping point of considering a TKR. In addressing occupational losses it would be important to understand which changes or modifications are considered “acceptable and consistent with the values and beliefs of the individual” (Unruh, 2004, p. 294).

Alternatively, OTs could help individuals with knee OA to maintain or rebuild their occupational identities. An occupational identity is considered to be shaped by an individual’s capacities and interests, roles and relationships, obligations and routines, and by environmental context and expectations (Kielhofner, 2002; Howie et al., 2004). OTs understands that occupations hold unique meanings for individuals and are well positioned to use their professional background to address issues of occupational identity. With an OT’s help, participants should be able to either maintain their identities or build new identities (CAOT, 2008; Laliberte-Rudman, 2002). For example, the OT could provide recommendations to an individual with regard to the environment and the occupation, or the way the individual performs the occupation could be adjusted so that participation in the occupation or some part of it is still possible (Kerr & Ballinger, 2010).

The OT could also work with the individual to set realistic expectations related to the resumption of occupations post-TKR. Individuals may require reassurance regarding the safety of returning to some occupations and may have to be encouraged to reconsider returning to others. For example an individual with knee OA may wish to return to playing squash, an occupation which could damage the new knee joint. An OT’s role could be to examine the occupation with the individual, identify the risk factors for injury and consider alternative occupations that would be acceptable to the individual. Gonzalez Saenz de Tejada et al. (2010) have shown that having realistic expectations helped individuals prepare for their TJRs,
especially their expectations of achievable recovery goals and identifying the necessary support strategies to help attain these goals. On the other hand, Cross et al. (2009) have suggested that individuals with unrealistic expectations may become discouraged and fail to reach their greatest potential. It has been shown that identifying a broad range of expectations helped to prepare individuals with joint OA for surgery and make it more likely that they would achieve greater satisfaction with post-TJR outcomes (Cross et al., 2009).

Family physicians may also benefit from incorporating these findings into their practice. These findings may help them to recognize that pre-TKR OA experiences involve not only OA symptoms that contribute to pain and activity limitations, but also occupational loss. Generally, family physicians are the first health professionals whom individuals with knee OA visit when they experience OA symptoms and activity limitations. Common OA management includes prescriptions for pain medications and physiotherapy interventions (Ballantyne et al., 2007). The findings of the present study may help family physicians become more aware that the pre-TKR OA experience also includes occupational loss and that they ought to have a better understanding of key occupations in their patients’ lives (Kielhofner, 2009). If they understand the centrality of occupations in the lives of individuals with knee OA and the seriousness of occupational loss, they may consider prescribing OT for knee OA patients before extensive occupational loss occurs.

Family physicians could consider referring individuals with OA to an occupational therapist (OT) in the community (e.g., Community Care Access Centre [CCAC]). CCACs are local agencies that provide information to individuals in the community about care options. If the individual requires OT services, a family physician could make a referral and a CCAC coordinator would arrange for OT services. OT services would be an appropriate referral as the core of the OT profession is to use occupation to improve one’s health (Reilly, 1962). Further, OTs believe that occupation is considered a central source of life’s meaning (CAOT, 2002) and part of their mandate and scope of practice is to enable individuals to engage in occupations (Hammell, 2004).

The findings of the present study may also benefit pre-surgery educators by providing them with information regarding the OA experience when patients are scheduled for their TKRs. Since the findings of the present study highlight the uniqueness of each individual’s OA journey, pre-operative education should be adapted to the patient’s individual concerns (Trousdale et al., 1999; Macario, Schilling, Rubio, Bhalla, & Goodman, 2003; Demierre et al.,
2011). Pre-surgery educators would benefit from the findings of the present study to develop education and services to meet the occupational needs of individuals with knee OA and to support the maintenance or re-development of their occupational identities.

To re-build an occupational identity, both pre-surgery educators and OTs could discuss which occupations individuals with OA could participate in order to achieve a sense of accomplishment and gradually develop new yet familiar routines (Kielhofner, 2002).

5.7. Future Directions
The present study was conducted to understand the occupational experiences of individuals living with OA who were scheduled for a TKR. A number of research gaps were considered that would help to advance this underexplored area in the OA-related literature. Additional research is needed to examine how occupational identities were formed prior to the onset of knee OA due to the increasing number of aging individuals.

Conducting a primary study would be one avenue to further explore the concept of occupational identity of individuals with knee OA. Specifically, the same research topic would be used, but conducting a primary study would enable a more in-depth questioning of the participants to learn which occupations were important over each participant’s lifetime and why these occupations were meaningful. These questions could facilitate a better understanding of how and why these individuals with knee OA would struggle to maintain their occupations. This primary study would be able to highlight the issues of meaning, values, and purpose as they are experienced and expressed by individuals with knee OA through their chosen occupations.

Another research study of value to advance the pre-TKR literature is to explore the occupational experiences of individuals with hip OA or other ortho-related populations (e.g., rheumatoid arthritis, juvenile arthritis) who are scheduled for a joint replacement. Specifically, individuals who are not yet eligible for surgery would benefit from these studies as the findings may provide a means to understand their occupational experiences of living with arthritis. Understanding more about the occupational experiences of different populations would promote more effective pre- and post-surgery interventions and discharge planning.

Another avenue for study would be to examine the post-TKR occupational experiences of individuals with knee OA. The benefits of a post-TKR study would be to enable a comparison between the post-TKR occupational experiences with the pre-TKR findings of this present study. As Laliberte-Rudman (2002) noted, occupation is considered a means through
which an individuals can express who they are to themselves and to others. Conducting a post-TKR qualitative study would be beneficial for understanding the occupational choices the participants made after the TKR and how these choices allowed them to maintain an occupational identity that is acceptable and satisfying to them. Such a study could also highlight the strategies used during the post-TKR period to facilitate the participants’ resumption of their occupations as well as showing how their occupations and occupational identities were maintained or changed post-TKR.

Overall, these studies will help to enrich the occupational perspectives of individuals’ OA experiences, to further develop the concept of occupational identity and to develop interventions and rehabilitation programs to help maintain or to rebuild their occupational identities.

5.8. Conclusion

The findings from the present study suggest that occupational experiences are unique across individuals with knee OA and play a role in reshaping their occupational identity. These findings indicate that the participants’ OA experiences from the onset of OA to their decisions for a TKR were not only of pain and disability but also of occupational factors (such as occupational loss, social relationships, emotional well-being), and other factors, such as their occupational identities. This qualitative study was conducted to add to an area of the OA-related literature that is underexplored. Through the use of an occupational perspective, the present study uncovered the occupational experiences of individuals with knee OA preparing for a TKR.

As Christiansen (1999) noted: “When we build our identities through occupations, we provide ourselves with the contexts necessary for creating meaningful lives, and life meaning helps us to be well” (p. 547). Participants’ engagement in occupations throughout their lives prior to the onset of OA had shaped their occupational identities (“I am an active person”). When the participants were prevented from participating in their important occupations because of their knee OA symptoms, their occupational identities were disrupted, which appeared to have lead them to tipping point of considering a TKR.
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Appendices
APPENDIX A

<table>
<thead>
<tr>
<th>Semi-structured Interview Guide¹</th>
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<tbody>
<tr>
<td><strong>Warm-up and establishing rapport</strong></td>
</tr>
<tr>
<td>Thank person for participating, go over consent form and have them verbally agree to participate, explain process, how confidentiality and anonymity will be protected, etc.</td>
</tr>
<tr>
<td><strong>Pre-Surgery activities</strong></td>
</tr>
<tr>
<td>• Let me begin by asking you to describe for me what your daily life was like prior to developing OA? (Probes: Was this a long time ago? Did you work outside the home? Care for children? Did you like to cook? Any sports? Social life?)</td>
</tr>
<tr>
<td>• How did OA first begin to influence these things?</td>
</tr>
<tr>
<td><strong>About surgery</strong></td>
</tr>
<tr>
<td>• Describe for me what has led to your surgery? (Probe: When is it? Do you recall who you first saw i.e. family physician? What led to your referral for surgery? In general, what stands out for you about this time?)</td>
</tr>
<tr>
<td>• What are your main concerns prior to this surgery?</td>
</tr>
<tr>
<td>• What do you think your recovery will be like?</td>
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<tr>
<td>• What are you doing to manage your pain?</td>
</tr>
<tr>
<td>• What do you think about pain after surgery?</td>
</tr>
<tr>
<td>• How do you anticipate your recovery to be?</td>
</tr>
<tr>
<td><strong>Cool-Down/Wrap-up questions (all time frames)</strong></td>
</tr>
<tr>
<td>• Is there anything else I haven't asked you about that you would like to add?</td>
</tr>
<tr>
<td>• The responses you have provided may stimulate some additional questions or need for further clarification. If so, may we contact you in the future?</td>
</tr>
</tbody>
</table>

**Explain rest of the process (e.g. that they will receive summaries to review, etc.)**

*Please note: this guide only represents the main themes to be discussed with the participants and as such does not include the various probes that may also be used.*
APPENDIX B

PROTOCOL REFERENCE # 28504

January 16, 2013

Dr. Helene Polatajko
DEPT OF OCCUPATIONAL THERAPY
FACULTY OF MEDICINE

Dear Dr. Polatajko and Ms. Anna Tang,

Re: Administrative Approval of your research protocol entitled, "To understand the pre-surgery occupational experiences of individuals with osteoarthritis"

We are writing to advise you that the Office of Research Ethics (ORE) has granted administrative approval to the above-named research protocol. The level of approval is based on the following role(s) of the University of Toronto (University), as you have identified with your submission and administered under the terms and conditions of the affiliation agreement between the University and the associated TAHSN hospital:
- Graduate Student research - hospital-based only
- Storage or analysis of De-identified Personal Information (data)

This approval does not substitute for ethics approval, which has been obtained from your hospital Research Ethics Board (REB). Please note that you do not need to submit Annual Renewals, Study Completion Reports or Amendments to the ORE unless the involvement of the University changes so that ethics review is required. Please contact the ORE to determine whether a particular change to the University's involvement requires ethics review.

Best wishes for the successful completion of your research.

Yours sincerely,

Daniel Gyewu
REB Manager

OFFICE OF RESEARCH ETHICS
McMurrich Building, 12 Queen's Park Crescent West, 2nd Floor. Toronto, ON M5S 1SR Canada
Tel:+1 416 946-3273 • Fax: +1 416 946-5763 • ethics.review@utoronto.ca • http://www.research.utoronto.ca/for-researchers-administrators/ethics/
APPENDIX C

University Health Network

Date: November 7th, 2011
To: Dr. Aileen Davis

Notification of REB Initial Approval

Rm 322, 11th Floor, Main Pavilion, Toronto Western Hospital, 399 Bathurst St.
Toronto, Ontario, Canada M5T 2S8

Re: 11-0707-AE
Instrumental Activities of Daily Living and Social Roles Following Hip and Knee Replacement:
Understanding Why People's Engagement Doesn't Change

REB Review Type: Expedited
REB Initial Approval Date: November 7th, 2011
REB Expiry Date: November 7th, 2012

Documents Approved:
- Protocol
  Received on: September 19th, 2011
- Addendum to Grant Protocol
  Received on: September 19th, 2011

Documents Acknowledged:
- St. Michael's REB approval letter
  Version date: October 19th, 2011

This is an administrative approval acknowledging that the above noted study will be carried out at St. Michael's Hospital with the exception of carrying out interviews at Toronto Western Hospital with St. Michael's patients and storing data at Toronto Western Hospital. The UHN Research Ethics Board operates in compliance with the Tri-Council Policy Statement, ICH Good Clinical Practice Guidelines, Ontario Personal Health Information Protection Act (2004), Part 4 of the Natural Health Product Regulations and Part C, Division 5 of the Food and Drug Regulations of Health Canada.

Best wishes on the successful completion of your project.

Sincerely,
Anna Gagliardi, PhD.
Co-Chair, University Health Network Research Ethics Board

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There's always an answer. We'll find it.
October 19, 2011
Dr. Emil Schemitsch,
Department of Surgery, Division of Orthopaedic Surgery,
St. Michael's Hospital

Dear Dr. Schemitsch,

Re:  REB# 11-268c - Instrumental activities of daily living and social roles following hip and knee replacement: Understanding why people's engagement doesn't change

REB APPROVAL:  Original Approval Date  October 19, 2011
Annual Interval Review Date  October 19, 2012

Thank you for your application submitted on September 19, 2011. The above noted study has been reviewed through an expedited/delegated process (not by Full Board review). The views of the St. Michael's Hospital (SMH) Research Ethics Board (REB) have been documented and resolved. The REB approves the study as it is found to comply with relevant research ethics guidelines, as well as the Ontario Personal Health Information Protection Act (PHIPA), 2004. The REB hereby issues approval for the above named study for a period of 12 months from the date of this letter. Continuation beyond that date will require further review of REB approval. In addition, the following documents have been reviewed and are hereby approved:

1. Protocol
6. Study Questionnaires
7. Interview Guides

During the course of this investigation, any significant deviations from the approved protocol and/or unanticipated developments or significant adverse events should immediately be brought to the attention of the REB.

Please note that if a Clinical Trial Agreement is required, it must be submitted to the Office of Research Administration for review and approval. Any additional institutional approvals must be coordinated through the Office of Research Administration prior to initiation of this research. All drug dispensing must be coordinated through the Research Pharmacy at 416-864-5413.

Dr. Emil Schemitsch (REB# 11-268)