Experiences of Stigma Among People with Osteoarthritis who Underwent a Total Joint Replacement of the Knee or Hip

by

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Institute of Health Policy, Management and Evaluation
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Abstract

Stigma is recognized as having an important influence on health. There is limited literature addressing the experience of stigma among people with osteoarthritis (OA). The purpose of this study was to conduct a qualitative secondary analysis of data collected from patients with end-stage OA who underwent total joint replacement (TJR) of the knee or hip at three time points using the concept of stigma. A sub-sample of 11 participants was selected for inclusion. Thematic analysis was used, and analysis drew on Major et al.'s (2018) conceptual model. Results were organized around five themes that related to people’s high valuing of independence and stoicism and how these values were disrupted by OA. This led to stigma becoming a barrier to engagement in former activities. These findings suggest that people with OA may experience stigma that impedes recovery. Therefore, clinical care should include an understanding of this phenomenon. Further research should investigate how to better address patients’ experiences of stigma in practice.
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Chapter 1
Introduction

An important relationship between stigma and health has been recognized (Major, Dovidio, Link, & Calabrese, 2017). Stigma has also been identified as a common experience among people who have a chronic illness (Charmaz, 2000). Stigma contributes to health disparities between people in disadvantaged and advantaged groups (Major et al., 2017). It has a negative impact on health at both the level of the individual, in the form of psychosocial stress, and the level of the community, through social exclusion (Major et al., 2017). Stigma leads to cognitive, affective, physiological, and behavioural responses that together can negatively influence health (Major et al., 2017). Although there are extensive bodies of research on the topic of stigma among specific groups of people including those living with mental illness or obesity, there is limited literature addressing the experience of stigma among people with osteoarthritis (OA) (Major et al., 2017). Two meta-ethnographies of literature on people’s experiences of living with OA (Smith et al., 2014a; Smith et al., 2014b) found that people had negative attitudes towards their own OA, including stigma towards their own illness and worries about how others would perceive their difficulty walking. However, studies that identified and discussed experiences of stigma or embarrassment among people with OA did not identify stigma as being a primary focus of their research (Alami et al., 2011; Chan & Chan, 2011; Gustafsson, Ponzer, Heikkila, & Ekman, 2007; Maly & Krupa, 2007; McHugh, Silman, & Luker, 2007; Parsons, Godfrey, & Jester, 2009; Caroline Sanders, Donovan, & Dieppe, 2002; C. Sanders, Donovan, & Dieppe, 2004; Tallon, Chard, & Dieppe, 2000). Since OA is a long-term and chronic condition with symptoms that can be visually perceived by others, and since experiencing stigma can have an important impact on health, it is important to examine experiences of stigma among people with OA.
1.1 Research Objective

The research objective of this thesis project was to explore and understand experiences of stigma among people undergoing total joint replacement (TJR) for OA. The research question was: *If participants describe stigma as playing a role in their illness experience, how has it played a role and what kind of stigma do they describe?*. 
Chapter 2
Background

2.1 Osteoarthritis

OA is a chronic condition that affects all tissues in a joint, specifically the cartilage, muscles, ligaments, and bone, leading to stiffness, pain, and a reduction in the range of movement of the joint (Osteoarthritis Research Society International, 2018). Most often, it occurs in older people, and risk factors include being overweight, aging, injury to joints, genetic predisposition, genetic defect in cartilage in the joints, and excessive stress to joints (National Institute of Arthritis and Musculoskeletal and Skin Diseases, 2014). It is the most common type of arthritis among Canadians. The joints that are most frequently affected by this condition are the knees, hips, spine, feet and hands (Public Health Agency of Canada, 2010).

2.1.1 Epidemiology of Osteoarthritis

Estimates of the prevalence of OA vary, ranging from 12.3% to 21.6% (Palazzo, Nguyen, Lefevre-Colau, Rannou, & Poiraudeau, 2016). The World Health Organization (World Health Organization, 2017) estimates that among people over 60 years of age worldwide, 18.0% of females and 9.6% of males have OA. Among Canadians, the prevalence of diagnosed OA in primary care among those 30 years of age or older is estimated to be 14.2% (12.4% among men and 15.6% among women) (Birtwhistle et al., 2015). The prevalence of OA is higher among women than men and increases with age, with an estimated 35.1% of those aged 80 years and older affected by OA (Birtwhistle et al., 2015).
Among Canadians, the crude prevalence rate of OA in 2015 was 13.67%, with a higher prevalence among women (16.15%) than men (11.08%) (Canadian Chronic Disease Surveillance System, 2018a). The prevalence increases with age and is consistently higher among women, with an estimated crude prevalence rate of 17.63%, 38.07%, and 55.21% among women, for age groups 50-64, 65-79, and 80+, respectively in 2015 (Canadian Chronic Disease Surveillance System, 2018b). OA tends to affect older people and is associated with comorbid conditions such as hypertension, cardiovascular disease, obesity, and diabetes (Calders & Van Ginckel, 2018). Although the prevalence of OA does increase with age, OA is not limited to older people. Younger people can develop OA as well, particularly those who are obese, and those with a previous knee or hip injury (Kroman, Roos, Bennell, Hinman, & Dobson, 2014). Thus, the epidemiology of OA suggests that the experience of stigma may differ by such characteristics as age and gender, providing another reason to study it in this population.

2.1.2 Impact of Osteoarthritis

OA has a considerable impact on people’s health-related quality of life (HRQOL) and daily living. Limitations in walking are a common difficulty for people with OA (Palazzo et al., 2016), and this condition usually includes chronic pain (Hunter, Schofield, & Callander, 2014). The Canadian Community Health Survey (CCHS) found that 34.4% of men and 39.4% of women with arthritis experienced pain that prevented them from completing activities (Public Health Agency of Canada, 2010). Pain is also a common experience; Badley et al. (Badley, Nagamuthu, Moore, & Gignac, 2015) found that among people with OA, the mean intensity of pain was 5.9 on a scale of 1 to 10, and that 70% of respondents experienced pain once a week or more. Poor health status or deteriorating health in the past year were more likely to be reported among patients with OA in Ontario than among control subjects, and using the Health Utility Index 3, patients with OA reported lower HRQOL as compared to control subjects (Tarride et al.,
Additionally, people with OA have an elevated risk of mortality (Hunter et al., 2014). A study aiming to develop a conceptual map of the personal burden of OA identified eight aspects of burden, namely, physical limitations, physical distress, physical deconditioning, psychosocial distress, financial hardship, lost productivity, fatigue, and sleep disturbances (Busija, Buchbinder, & Osborne, 2013). OA is a progressive chronic condition which leads to increasing pain and disability over time (Neogi, 2013). People struggle with the impact of having to take time off from their usual routine on account of their OA symptoms (Busija et al., 2013).

The burden of OA on the Canadian healthcare system is expected to escalate with aging and the increase in obesity in the Canadian population (Birtwhistle et al., 2015; Marshall et al., 2015). A systematic review of OA-focused cost-of-illness studies determined that the social cost of OA may be between 0.25% and 0.50% of the GDP of a country (Puig-Junoy & Ruiz Zamora, 2015). In an analysis of Ontarian data from the CCHS, Tarride et al. (Tarride et al., 2012) found that the annual direct healthcare cost of outpatient procedures, physician visits and hospitalizations was an average of $2,233 per person for patients with OA, a statistically significant amount as compared to an annual cost of $1,033 for subjects in the control group. Tarride et al. (Tarride et al., 2012) also found that compared to those without OA, patients with OA were twice as likely to receive outpatient surgery or to be hospitalized, and when hospitalized, they spent more time in hospital than those who did not have OA. In addition to direct costs, indirect costs related to OA in the context of paid work include absenteeism, presenteeism, early retirement, and unpaid caregiver time (Hunter et al., 2014; Palazzo et al., 2016).

2.1.3 Treatment of Osteoarthritis

There is currently no cure for OA. However, managing and treating this chronic condition can help to lessen pain, prevent disability and maintain functioning (Public Health Agency of
Numerous literature reviews of the effectiveness of non-pharmacological, pharmacological, and surgical treatments for hip and knee OA have been conducted. In a systematic review and evaluation of guidelines for managing OA, Nelson et al. (Nelson, Allen, Golightly, Goode, & Jordan, 2014) identified broad consistency among existing guidelines. Recommendations for non-pharmacologic modalities included the use of exercise, thermal modalities, education/self-management, weight loss, and walking aids, while recommended pharmacologic modalities included acetaminophen, paracetamol and non-steroidal anti-inflammatory drugs (NSAIDs). Joint replacement (where appropriate) was recommended as a surgical intervention. McAlindon et al. (McAlindon et al., 2014) developed guidelines for managing knee OA based on evidence in the field and expert consensus. Similar to Nelson et al. (Nelson et al., 2014), treatment modalities that were identified as being appropriate included exercise, education/self-management, weight management, strength training, and biomechanical interventions. For specific groups, appropriate treatment modalities identified included oral and topical NSAIDs, acetaminophen, duloxetine, balneotherapy, a cane, and capsaicin. McAlindon et al. (McAlindon et al., 2014) also identified intra-articular corticosteroids as being an appropriate treatment modality. However, since the publication of this review, McAlindon et al. (McAlindon et al., 2017) have found intra-articular corticosteroids to lead to more loss of cartilage volume as compared to intra-articular saline with no difference in patients’ knee pain. Additionally, in their meta-analysis of the effectiveness of NSAIDs on OA pain, da Costa et al. (da Costa et al., 2017) found diclofenac 150 mg/day to be the most effective NSAID in terms of improving pain symptoms and function. More than half of patients with OA (56.6%) in a Canadian study were prescribed NSAIDs, and one third (33%) were prescribed opioid drugs (Birtwhistle et al., 2015). TJR is one of the most effective ways to improve functioning for patients with OA whose symptoms have not sufficiently improved from using other strategies.
However, it is also estimated to be the most expensive form of treatment for OA (Palazzo et al., 2016). The number of hip and knee replacement surgeries performed in Canada has increased over time. In the period of 2014-2015, there were 51,272 hip replacement surgeries and 61,421 knee replacement surgeries performed in Canada, an increase of about 20% compared to the five years before (Canadian Institute for Health Information, 2017). Although TJR is among the most effective interventions for improving the level of functioning among patients with OA, a significant proportion of people do not return to their previous level of activity after undergoing surgery (Arnold, Walters, & Ferrar, 2016). Many patients continue to experience pain and disability even after they have undergone TJR, and struggle to return to the activities they previously engaged in. In a systematic review of OA-related hip or knee replacement studies reporting pain intensity, Beswick et al. (Beswick, Wylde, Gooberman-Hill, Blom, & Dieppe, 2012) found that the highest quality studies reviewed reported unfavourable pain outcomes among about 20% of patients after knee replacement surgery, and among more than 9% of patients who had undergone hip replacement surgery. Webster et al. (Webster et al., 2015) found that the return to usual activities among patients who had undergone TJR was highly variable and was affected by factors other than their medical outcomes. Factors influencing recovery included patients’ social context and relationships, surgical complications, co-morbidities, and life changes.

2.2 Goffman’s Theory of Stigma

According to the sociologist Erving Goffman (Goffman, 2016), stigma is a social phenomenon based on some attribute that causes a person to seem different from others and that reduces them to a tainted status. Society demarcates categories of people and determines what is perceived to be normal and natural within each of these categories. Thus, stigma is socially constructed. Goffman distinguishes between a person’s “virtual society identity,” or the expectations that we
have of them and the attributes that we assign to them, and their “actual society identity,” or the
c characteristics that they actually have (Goffman, 2016) (p. 134). Stigma, according to Goffman,
stems from the discordance between these two categories of identities and is an “undesired
differentness” (Goffman, 2016) (p. 135). A stigmatized mark is an attribute that makes a person
appear different from the majority and that discredits them as being a “normal” person. Even
people who are stigmatized have a tendency to have the same beliefs around identity as the rest
of society does. However, they may feel that they are not accepted in society in the same way
that others are. Since they are aware of what society deems to be normal, they too perceive what
makes them different and may even agree that they do not meet society’s standards for
normality. When a person sees their stigmatized characteristic as being a negative attribute, they
may experience shame and internalize the same beliefs about themselves as the non-stigmatized
majority of people hold. They may also anticipate and avoid social situations that involve non-
stigmatized people, leading to feelings of isolation, anxiety and depression, and may feel
uncertain about what others truly think about them. A stigmatized person may expect that what
they consider to be their trivial accomplishments will be exaggerated by others, and that failings
may also be attributed to their stigmatized status.

2.3 Osteoarthritis and Stigma

Streams of research about groups that face stigma have developed separately, leading to bodies
of literature addressing stigma among different groups that are unintegrated and independent of
one another (Hatzenbuehler, Phelan, & Link, 2013; Major et al., 2017). Although stigma has
been addressed extensively among many other populations, such as people living with mental
health conditions [e.g., (Brohan, Slade, Clement, & Thornicroft, 2010; Clement et al., 2015;
Livingston & Boyd, 2010; Mak, Poon, Pun, & Cheung, 2007; Parcesepe & Cabassa, 2013)],
there is only limited research exploring stigma specifically among people with OA [e.g., (Alami
et al., 2011; Chan & Chan, 2011; Gustafsson et al., 2007; Maly & Krupa, 2007; McHugh et al., 2007; Parsons et al., 2009; Caroline Sanders et al., 2002; C. Sanders et al., 2004; Smith et al., 2014a; Smith et al., 2014b; Tallon et al., 2000).}

Stigma has been identified as a common experience among people who have a chronic illness (Charmaz, 2000). Chronic conditions that become more severe over time, such as OA, can also change from being invisible to becoming progressively more visible (Charmaz, 2000). This may deepen people’s experience of stigma. In a meta-ethnography of literature on people’s experiences of living with OA, Smith et al. (Smith et al., 2014a) found that people had negative attitudes towards their own OA. They were concerned about how others would react to their OA symptoms. One of the themes related to participants’ perception of how others perceived their OA identified by Smith et al. (Smith et al., 2014a) was stigma of illness. For example, people had a negative attitude towards using a walking aid because it advertised their disability to the world and led to feelings of self-consciousness. Their self-image was also negatively affected by the physical changes that they experienced on account of their OA. Participants were worried about how others might react to seeing their physical difficulties caused by OA, as opposed to feeling hurt by the way that others had actually reacted to them. People may be hesitant to disclose their OA in a workplace setting as they perceive that doing so may expose them to stigma in the workplace in the form of loss of status, credibility, opportunities, support, or employment (Gignac & Cao, 2009). In a longitudinal study examining workplace arthritis self-disclosure, Gignac and Cao (Gignac & Cao, 2009) found that although the majority of workers with OA or inflammatory arthritis in their sample had self-disclosed their arthritis to their manager and coworkers, there was considerable variability in disclosure and not all participants chose to self-disclose.
2.4 Conceptual Model: Stigma and Health


For this thesis project, which adopted a secondary analysis approach as is further described in the Methods section (Chapter 3), the conceptual model (Figure 1) that was selected to frame the analysis was developed by Major et al. (Major et al., 2017). This model represents the main pathways and processes through which health can be affected by holding a stigmatized social status. This recently developed model expands on previous models of the relationship between stigma and health. Major et al.’s (Major et al., 2017) model begins with stigmatized marks. A stigmatized mark is an attribute that causes a person to appear different from others and that signals this difference to others (Goffman, 2016). Stigmatized marks differentiate certain individuals in society and cause them to be perceived as being ‘other’, i.e., abnormal or less valued or worthy. Which attributes are stigmatized is determined by society, specifically by members of the dominant non-stigmatized group, which executes its power to select marks and create stereotypes. Stigma is a social process by which people with stigmatized marks are differentiated, and stigmatized marks lead to four types, or processes, of stigma. These types of stigma are enacted stigma, felt stigma, internalized stigma, and anticipated stigma, and all
precipitate experiences of stress and exclusion for people who find themselves members of stigmatized groups (Major et al., 2017). Enacted stigma at an interpersonal level comprises discrimination, negative feelings and biases towards stigmatized groups of people on account of their difference. At a social structural level, it can be communicated through culture and includes norms, social conditions and institutional policies. It can lead to stress, poor coping, and exclusion from healthcare or social resources (Major et al., 2017). Felt stigma entails the perceptions that stigmatized people have of being devalued or treated unfairly on account of their socially conferred mark. It can lead to behavioural, cognitive, physiological and affective responses that negatively affect health (Major et al., 2017). Internalized stigma is a person’s acceptance of the negative feelings and beliefs related to their stigmatized status and is also referred to as self-stigma. It can develop from being exposed to cultural ideas that reinforce the stigmatized status of certain groups or as a result of one’s experience of enacted or felt stigma. It can lead to stress, social exclusion, and diminishing psychological resources. Anticipated stigma is a stigmatized person’s expectation that they will experience discrimination because of their stigmatized status. As a result of any of the three other stigma processes, people may anticipate future unfair treatment. Anticipated stigma can lead to stress, avoidance of social interactions, and exclusion (Major et al., 2017). Although this model describes and differentiates among different types of stigma and the results that they tend to be associated with, it is important to note that in reality, there is overlap among these categories and in relation to the impact that types of stigma can confer. For example, different types of stigma can lead to similar results and the effects of stigma can be experienced differently than theorized in individuals’ lives. For the purposes of this analysis, however, the four types of stigma will be discussed as discreet categories. These four types of stigma impact health through responses at the individual level, and through exclusion at the social or community level in terms of healthcare, interpersonal
relationships, education, employment, and housing. They can negatively impact affective, cognitive, behavioural, and physiological responses. These processes can also lead to disadvantages in terms of the social determinants of health (Major et al., 2017). The social determinants of health are social and economic factors that impact and influence individual and population health (Government of Canada, 2018) and their importance has become increasingly recognized (Braveman & Gottlieb, 2014). Experiencing stigma can lead people to be excluded from important social determinants including healthcare, housing, education, and employment and can increase the probability that they will face risk factors that harm health (Major et al., 2017).

In summary, stigma can have an important effect on health. People who find themselves members of stigmatized groups may be negatively impacted by their experiences of facing stigma. People with OA who have undergone TJR are an ideal group to evaluate as limited research on experiences of stigma among this population has been conducted. On account of living with OA and undergoing TJR, many have held stigmatized marks such as difficulty walking or needing to use mobility devices that visually may make them appear to be different from the social majority. Hence, the objective of this thesis project is to explore whether people who underwent a TJR of the hip or knee described stigma as playing a role in their illness experiences, and if so, the role that they described.
3.1 Qualitative Secondary Analysis

Qualitative secondary analysis is an approach that makes use of preexisting qualitative data in order to investigate new questions or to verify previous studies (Heaton, 2004). Although secondary analysis is a commonly used method in quantitative research, its application is more recent in the field of qualitative research (Heaton, 2004). Heaton (Heaton, 2004) highlights that secondary analysis is an adjunct, not an alternative, to primary research, and that little academic work has been done on the practical aspects of qualitative data re-use.

Data used for this secondary analysis came from qualitative interviews conducted in a study by Webster et al., described below (section 3.2 Original Study) (Webster et al., 2013; Webster et al., 2015). Being able to access information about the context of the primary study is an important requirement for conducting a secondary analysis (Heaton, 2004; Thorne, 1994). For this reason, two of the original co-principal investigators (AD and FW) were involved in this project. The process of secondary analysis may include the re-use of either a whole data set, or of a smaller sub-set of the material from the primary data set (Heaton, 2004). For this study, a sub-sample of participants was chosen because of the large amount of data originally collected (more details on sampling are found in section 3.6 Sampling Strategy and Size). The selection of the sub-set may be based on relevance to a specific issue, or on a particular phase of the data collection (Heaton, 2004). In this case, the sub-set was selected based on its relevance to the project’s research question, which was: *If participants describe stigma as playing a role in their illness experience, how has it played a role and what kind of stigma do they describe?*.
Curtis, Gesler, Smith and Washburn (Curtis, Gesler, Smith, & Washburn, 2000) identify some key features of qualitative samples: they are based on theoretical sampling criteria, they are small and studied intensively, they are not usually wholly pre-specified, their selection is conceptually driven, and they are designed to make analytic generalizations possible. One of the principal investigators of the original study (FW) selected a purposeful sub-sample of participants for inclusion in this secondary analysis based on the sampling criteria above (see 3.6 Sampling Strategy and Size for more detail). Transcripts were analyzed and selection continued until a point of saturation was determined in relation to the research question (Guest, Bunce, & Johnson, 2006).

Conducting a secondary analysis is only feasible if the question asked in the secondary analysis is sufficiently close to the question asked in the primary research study (Thorne, 1994). Heaton (Heaton, 2004) suggests that the re-usability of the primary data set needs to be established based on the criteria of accessibility, quality, and suitability. The criterion of accessibility was satisfied through the researcher having access to the full primary data set as well as access to two co-principal investigators from the original study (FW & AD). The quality of the original data set was high and rigour was ensured by including rich description of the data (Webster et al., 2015). Suitability, or fit, between the secondary research question and the data set is suggested to be less of a concern where the secondary analysis seeks to analyze issues that stemmed from the primary analysis of the data set (Heaton, 2004). In the case of this study, stigma was identified by the co-principal investigators as a point of interest in the primary analysis of the data set. Although none of the questions in the interview guides specifically had to do with stigma, this theme was identified based on several discussions related to answering the original study’s research question. Therefore, there was a good fit between the original data set and the research question explored through the secondary analysis.
Data analysis proceeded by way of a supplementary analysis, which is a more in-depth investigation of an issue that was identified as being interesting in the primary data post hoc but that was not fully addressed in the primary study (Heaton, 2004). The issue that was addressed was the experience of stigma among patients with OA undergoing TJR. Supplementary analysis is the most common approach to qualitative secondary analysis in the healthcare literature (Heaton, 2004). Thorne (Thorne, 1994) similarly describes the process of retrospective interpretation, wherein the primary database is used to consider new questions that were raised in the original study but not thoroughly examined.

Heaton (Heaton, 2004) notes that approaches to secondary analysis often mirror those used in the primary analysis. However, although the primary study adopted a constructivist grounded theory approach, this secondary analysis was conducted using a thematic analysis approach (described further under 3.7 Methodological Framework). It was not possible to apply a grounded theory approach in carrying out a secondary analysis as some of the core steps in using this approach include such strategies as using a theoretical sampling approach. Secondary analysis would not allow for the collection of additional primary data. Further, in a grounded theory approach, the researcher follows themes identified throughout the data collection process and looks for new cases to further develop categories in their analysis (Charmaz, 2001). In this secondary analysis, there was no mean to revise and apply the interview guide as themes were identified in the analytical process because data collection had already been completed. Therefore, a more flexible approach was needed. Adopting a different approach (thematic analysis) circumvented this limitation of attempting to use grounded theory as part of a secondary analysis project where no additional data collection was to be conducted.
3.2 Original Study

The original project was a qualitative study that adopted a constructivist grounded theory approach conducted by Drs. Fiona Webster, Aileen Davis, Anthony Perruccio, Susan Jaglal, Emil Schemitsch, and James Waddell (Webster et al., 2013; Webster et al., 2015). The aim was to explore why people with OA do or do not participate in activities after undergoing TJR. Recruitment for participation in the study took place by telephone from the practices of two orthopedic surgeons in a large Canadian city. Participants were patients with end-stage OA who were scheduled to have TJR and they were recruited by a trained research associate who was not involved in providing care. The research team used a purposive sampling approach to achieve maximum variation, and then used a theoretical sampling approach. Recruitment of participants continued until theoretical saturation was reached.

One-on-one, semi-structured interviews were conducted with patients either in their home or over the phone. Interviews were held at three time points: one month before surgery (between November 2011 and July 2012), eight months after surgery (between July 2012 and June 2013), and 18 months after surgery (between June 2013 and September 2013). In total, 29 patients participated in interviews at all three of the time points, for a total of 87 interviews. The interview guide was adapted for each of the time points to facilitate exploring experiences before and after patients’ TJR. Interviews were audio-recorded and transcribed verbatim, and then de-identified for analysis. Data analysis was based on a constructivist approach to grounded theory. Transcripts were coded individually by four members of the research team, who met monthly to discuss analyses, to develop a shared framework for their coding, and to practice reflexivity. Research team members grouped codes into categories and themes, and based on this process, a coding framework was developed and evolved as analysis progressed. Since analysis and data
collection took place concurrently, as themes were identified, they were pursued as topics of discussion with participants in subsequent interviews.

3.3 Theoretical Position

The analysis for the current thesis project adopted a constructivist theoretical position. Constructivism acknowledges the subjectivity and variety of people’s understanding of their own experiences, and highlights their complexity (Creswell, 2014). In this approach, questions tend to be open-ended and broad to allow participants to express their views and to create meaning through their answers. Participants’ perspectives are prioritized, and researchers endeavor to interpret them, while also acknowledging the influence of their own background on their interpretation (Creswell, 2014). A constructivist approach was also adopted for the original study from which this project drew its data (Webster et al., 2015).

3.4 Ethical Considerations

Ethics approval was received from the University of Toronto and an effort was made to protect participants’ privacy. As this was a secondary analysis, I was provided with access to de-identified transcripts, but not to the original interview audio recordings. Transcript files were password-protected. Participants were assigned ID numbers and all names and identifying information were withheld from transcripts.

3.5 Sampling Strategy and Size

The approach to sampling adopted in this secondary analysis was purposeful (Patton, 2002). In qualitative research, interviews continue to the point of saturation, at which point the researcher determines that no new themes are emerging in relation to the primary research question (Patton, 1990). However, data collection had already been completed prior to the commencement of this project. Thus, for this secondary analysis, a sub-sample of 11 of the 29 participants in the
original study was identified by one of the principal investigators (FW), who has expertise in qualitative research at the PhD level, as having information-rich data in relation to the concept of stigma based on the original analysis of the data. For the purposes of this thesis project, because of the large number of interviews conducted in the original study, a sub-sample of participants was chosen. Each participant included in the secondary analysis had participated in interviews at all three data collection time points and transcripts from all time points were included; thus, the total number of transcripts included in this secondary analysis was 33.

3.6 Methodological Framework

The methodological framework used in this study was thematic analysis. Thematic analysis is a widely-used and flexible approach in which themes are identified and analyzed within a set of data, and data are organized and described in detail (Braun & Clarke, 2006). Because this was a secondary analysis, it was important for a theoretically flexible framework to be used to ensure good fit between the original and secondary analysis methods. Themes are defined as patterns of meaning in data actively identified and selected by a researcher. They reflect some significant aspect of the data as linked to the research question (Braun & Clarke, 2006). Our goal was to develop a detailed description of a specific set of themes as related to the research question (Braun & Clarke, 2006). Patterns within the data were identified using a theoretical approach, which is useful in providing greater detail about a specific aspect of the data. An inductive approach to analysis, on the other hand, is more data-driven and leads to a more detailed description of the overall set of data. A theoretical approach was selected because the particular analytic interest identified prior to the start of this project specifically addressed the topic of stigma (Braun & Clarke, 2006). Themes were identified at both semantic and latent levels (Braun & Clarke, 2006). At the semantic level, themes are identified at the surface level of the data and analysis proceeds from description to interpretation. At the latent level, the researcher
goes on to identify underlying ideas that may be shaping the data (Braun & Clarke, 2006). Analysis included the process of moving from the description of what participants said to its interpretation and relating findings to existing literature on the topic, as in a semantic approach. However, the analytic process also included seeking out underlying ideas that seemed to shape what participants said, which led to an analysis that went beyond describing what participants said and included the researcher’s interpretation (Braun & Clarke, 2006). Individual open-ended interviews, the means of collecting data from participants in the case of the primary study, are recognized as an appropriate data collection method for thematic analysis (Braun & Clarke, 2006). Thematic analysis may proceed with either an inductive or deductive focus. This secondary analysis project adopted an inductive focus, wherein themes were developed based on the data rather than from an existing model or theory, to ensure that themes would be connected to the data (Patton, 1990).

### 3.7 Methodological Rigour

Methodological rigour in qualitative research refers to how thorough and appropriate the methods selected and used are (Kitto, Chesters, & Grbich, 2008). Kitto et al. (Kitto et al., 2008) detail several criteria that are helpful to determine and increase rigour: clarification, justification, procedural rigour, representativeness, interpretation, reflexivity and evaluative rigour, and transferability. The first criterion, clarification, concerns specifying the aims of the research. This criterion was met in the statement of the research question, which was: If participants describe stigma as playing a role in their illness experience, how has it played a role and what kind of stigma do they describe? Justification concerns why a qualitative approach and a given research design were chosen. For this thesis project, a qualitative approach was selected to align it with the approach used in the original project and theoretical analysis was used because a methodologically flexible approach was needed to conduct a secondary analysis. Procedural
rigour entails whether the way the research was conducted was transparently described and well-documented. This was addressed in the sections above detailing the methods of the original project from which these data were drawn, as well as the methods used for this secondary analysis thesis project. Representativeness addresses which sampling techniques were used, and this was also described in the methods section above. Interpretation concerns whether study results have been discussed in relation to a theory to explain their relevance and whether negative cases have been included. This thesis project discusses the findings in relation to a theory and a conceptual model, and the findings section includes negative cases. Reflexivity and evaluative rigour entail whether ethical aspects of research have been transparently described, whether ethics approval for the project was received, and whether the researcher has clearly discussed how their views and the methods chosen affected their data. As described above, ethics approval was received. Reflexivity, a researcher’s engagement in continuously examining and explaining their influence on their research (Dowling, 2008), was addressed by discussing codes and the relationships among them with one of the PIs of the original study (FW) as the project progressed, and by keeping a reflexive journal. Transferability concerns how helpful the findings are and whether their relevance has been discussed. This is addressed in the final chapter of this project.

### 3.8 Data Analysis

In their guide to thematic analysis, Braun and Clarke (Braun & Clarke, 2006) detail a process consisting of six phases, which was the basis for the data analysis conducted in this project:

Phase one: familiarizing oneself with the data,

Phase two: creating initial codes,

Phase three: looking for themes,

Phase four: reviewing the themes,
Phase five: naming and defining the themes, and
Phase six: writing the research report.

In the data familiarization phase, the researcher actively read all transcripts numerous times in order to ensure familiarity with and immersion in the data and took notes on preliminary ideas about the data. Two of the original study’s co-principal investigators (FW & AD) were consulted to ensure that contextual details were well-understood by this researcher. Also drawing from Saldana’s (Saldana, 2009) coding manual for qualitative researchers, interview transcripts were coded through the open-ended process of initial coding. An inductive approach to coding was used, meaning that coding did not involve organizing data into a pre-existing coding frame, and that themes were linked closely to the data (Patton, 1990). In proceeding with a secondary analysis, codes that had been developed as part of the analytical process of the original study may be removed, revised or retained (Heaton, 2004). For this secondary analysis project, the decision was made for data to be re-coded and for no codes to be retained or consulted by this researcher to ensure that the data would be approached without pre-existing ideas or categorizations. An entirely new coding framework was developed to ensure that the research question for this project could be explored appropriately. NVivo software was used to identify and gather data passages related to each code. This researcher coded the dataset independently, and then discussed the codes assigned and relationships among codes with one of the PIs of the original study (FW) to enhance reflexivity and ensure robustness of the coding process. Once the first round of coding had been completed, a second round was conducted in order to ensure that no important coding opportunities had been missed. A codebook compiling codes, their content descriptions, and a data example was created and evolved as the project progressed (Saldana, 2009). Once initial codes had been generated, they were grouped into possible themes. This list of potential themes was then reviewed to ensure they mapped onto the
coded sections of data and the overall data set. Memo-writing was used to elaborate on codes and to move towards developing conceptual categories (Bengtsson, 2016). Final themes were defined and named. Lastly, the analytical process and results were described as part of the final research report. Throughout the course of the research project, reflections on the data, ideas, and progression of the emerging analysis were documented in a research journal, which helped to guide and keep track of thinking about the analysis. Although this study involved data collected from 11 participants at three different time points, for a total of 33 transcripts, changes to their experiences of stigma over time were not considered in the analysis. A longitudinal perspective could not be adopted because the original study did not include questions about stigma in the interview guides for any of the time points. Therefore, not all participants spoke about stigma during each of their interviews, and changes among time points could not be compared.
Chapter 4
Findings

4.1 Description of Sample

The sample was comprised of 11 participants with end-stage OA, each of whom had participated in an interview at all three of the time points in the original study, for a total of 33 transcripts. Seven participants were female and four were male. Seven had undergone a knee replacement surgery and four had undergone a hip replacement surgery. Five participants were between the ages of 66 and 80, five were between the ages of 46 and 65, and one was between the ages of 30 and 45.

4.2 Summary of Findings

Figure 2 OA as disruptive to self-perception and as the catalyst for experiences of stigma
Experiencing OA was disruptive and destructive to participants’ self-perception, as illustrated in the figure above (Figure 2). This disruption to people’s self-perception led to experiences of stigma, in the forms of felt stigma, anticipated stigma, and internalized stigma. Five inter-related themes were developed around the core concept of stigma. The first theme related to participants’ self-perception as being active, independent and stoic. These three characteristics seemed to embody the values underpinning many people’s experiences. The second theme then explores how OA was disruptive to these characteristics or values and how this negatively affected participants’ self-perception. This then led to the third theme, in which participants described feelings of embarrassment over not appearing independent and their discomfort with public displays of OA. The fourth theme highlights how stigma was a barrier to engagement in former activities because participants were worried about their appearance in front of others. The fifth theme discusses how participants emphasized the importance of “normal” in their accounts of their experiences.

4.3 Theme #1: Self-perception as being active, independent and stoic

The following section sheds light on the extent to which people’s self-perception as being active, independent and stoic was influenced by and reflective of Western social values (Eckersley, 2006; Moore, Grime, Campbell, & Richardson, 2013). According to these values, being able-bodied is the norm and people have expectations around being able to do what they think that they should be able to do in the ways that they would like to. People had certain expectations of themselves in terms of both the things that they were able to do as well how they physically looked doing them, and these were driven by external factors in the form of social norms. A priority was placed on being a positive person despite facing pain and adversity.
4.3.1 Stoicism: pain tolerance and eschewing medication

It was common for participants to value stoicism (enduring pain without complaint) and to also self-identify as being a person who does not take medication. For instance, one participant commented, “I’ve never been a person who likes to take a lot of medication, that’s just never been something I like to do. So, I would probably stick it out until it’s bad before I would take something.” (Participant #015, female, 46-65 years, 2nd interview). Several participants described themselves as having high pain tolerance and therefore as not needing to take medication. However, many of the same people who said they had a high pain tolerance also admitted that they were experiencing significant pain, often to debilitating levels, as the following passage describes: “Now, as time has gone on over the last month, I’ve realized that mind over matter does not work and the hip has got progressively more painful and more uncomfortable and more debilitating.” (Participant #013, female, 66-80 years, 1st interview). In spite of the how much pain they were experiencing, some people still would not take pain medication. Some participants continued to refuse to use pain medication even when they became unable to sleep because of the pain that they were experiencing, as expressed by a participant who, when asked about the last time that she had had a regular night of sleep, replied, “Oh, probably years.” (Participant #011, female, 46-65 years, 2nd interview). Pain was often recounted as being a normal experience when participants explained that they had faced so much of it on account of their OA for a long time before their surgery. Thus, participants explained their stoic attitude and their insistence that they did not need to use medication as being the result of having learned to live with pain, as suggested by the participant who said, “Well, I’ve had pain in my knee since I’ve been 14, so I’ve just learned to live with it.” (Participant #011, female, 46-65 years, 2nd interview)
4.3.2 Stoicism: Staying positive despite facing pain and adversity

The significance assigned to stoicism was also clear among the many participants who, in spite of the health problems and pain that they were coping with, considered themselves to be positive people and highlighted the importance that they placed on having what they called a positive attitude, such as the participant who called himself “a pretty glass-half-full kind of guy.” (Participant #014, male, 46-65 years, 2nd interview) Some did acknowledge that although they identified as being positive people, because of their OA symptoms, it could feel like a struggle to remain optimistic, as the following quotation suggests: “And sometimes I feel I’m not getting better at all. I just get so deterred because … when is this going to get over? When am I going to get back to normal? Will I ever get back to normal? I keep asking these questions to myself. And it isn’t pleasant, I’ll tell you.” (Participant #004, male, 66-80 years, 2nd interview) Experiencing pain and poor or insufficient sleep made it more difficult to behave in positive ways and led to requiring even greater effort to stay true to this characteristic, as expressed by one of the participants:

I think the sleep is the one that really, really bothers me the most. Because I’m a fairly optimistic sort of person, but when you get sleep deprived, you have to watch everything you say because you don’t want to let it go over into your conversations with your husband or your grandchildren. So I’ve found that a little hard sometimes, trying to be cheerful when you’re hurting. (Participant #002, female, 66-80 years, 1st interview)

In spite of the difficulty in doing so because of the health-related challenges that they faced, participants described themselves as actively making an effort to stay hopeful and to maintain a positive outlook. One participant spoke of his decision to focus on the good instead of the bad, as he recounted, “I’m hoping to get right back to the way I was before because I’m hearing all kinds of good things from other people who have had it done. You hear bad things too but I try to just forget about that.” (Participant #004, male, 66-80 years, 1st interview). However, participants also revealed that sometimes they were unsure of their ability to stay positive in the face of
adversity and they associated this with their own internal strength, as the following quote exemplifies: “As long as I keep my mind positive then hopefully I can be strong enough to do whatever it takes to get where I want to go.” (Participant #012, female, 66-80 years, 1st interview)

4.3.3 Being active

Most of the participants in the sample described themselves as being active people and spoke frequently about this aspect of themselves. However, being active was dependent on being able-bodied, and all experienced a decline in their ability to complete physical activities because of their OA. It was common for respondents to have progressively become less active as their OA and level of pain worsened, as one participant described:

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 really bad. Now I don’t walk very far without some sort of help. (Participant #002, female, 66-80 years, 1st interview)

Participants often so strongly identified with being active people that being unable to participate in their usual activities led them to be unhappy. When asked how it felt to have given up some of their usual activities, one participant replied, “Horrible. And that was why I said to [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.” (Participant #003, female, 46-65 years, 1st interview) In spite of the difficulty in doing so, many participants still made an effort to stay active ahead of and after their joint replacement surgery. Some found that this was in fact helpful, as one participant described: “I’m a fairly active person and I found the more active I was, and it has been that way all the way through, the more active I was the better it was.” (Participant #009, female, 46-65 years, 1st interview)
4.3.4 Maintaining independence through employment

Among participants who were employed, two were working in very labour-intensive jobs and both struggled with fulfilling their regular job duties on account of their OA. However, both persevered in maintaining their jobs and would not accept that they might not be able to continue working in their chosen fields. They associated continuing employment in their chosen fields with being able to maintain independence and thus it was a highly valued part of their life. One participant described the difficulty that she was experiencing in completing her job tasks because of her OA, which finally prompted her to undergo TJR. The challenges that she was facing undermined her independence in the workplace and yet she had difficulty reaching out for help from others: “And I was just seeing that my world at work was closing and closing, like getting smaller and smaller, what my abilities were. And I’m not the kind of person who asks for help, so I was really struggling.” (Participant #011, female, 46-65 years, 2nd interview) This participant went on a leave of absence after her surgery and then returned to work on modified duties. When her long-term disability representative suggested that she retrain in another field, she refused, adamant to return to her career even though it was very physically demanding. When discussing aspects of her job that she found to be difficult, this participant was committed to finding a way to complete challenging tasks: “So, there’s going to come a time working when I’m going to have to move really significantly heavy equipment and I’m just going to have to find a way to do it.” (Participant #011, female, 46-65 years, 3rd interview) The other participant pushed herself at work even though she was aware of the detrimental effect that this was having on her health as she was determined to return to her pre-OA level of work intensity. She described her situation as one where she was doing what she felt was necessary, highlighting how much she valued being independent and being able to make her own choices:

So, I tend to not stop, but work until it’s done, and then I’ll put it up. I know that’s wrong, but it’s just kind of the way I am. So, my knee, a lot of the time, is quite swollen,
and it’s because I’m hard on it. I know I don’t even make sense when I’m talking like this, because it just sounds like I’m doing what’s wrong, which is true. But you do what you have to do. (Participant #015, female, 46-65 years, 2nd interview)

This participant’s desire to appear independent was so strong that she was willing to accept experiencing detrimental effects to her health to complete the tasks that she was able to do before her OA symptoms. As she points out, her “knee … is quite swollen, and it’s because I’m hard on it.” And yet by her continued work, in fact, she undermined her own health and ultimately her physical independence.

4.4 Theme #2: OA as disruptive to self-perception

The following section describes the ways in which living with OA was disruptive to participants’ internal self-perception as active and stoic, as much as it was to their actual functional abilities. OA was a threat to many of the characteristics that participants valued about themselves, as described in the first theme above, such as being active and feeling independent. Internalized stigma, which includes feelings of shame or guilt on account of having a stigmatized difference, and anticipated stigma, the expectation among stigmatized people of experiencing prejudice and discrimination, played a role in participants’ experience.

4.4.1 Loss of sense of independence

Participants frequently described how they went from feeling independent to having to rely on others to help them with many of the things that they used to do on their own. For instance, where previously they were able to complete chores on their own, family members often had to step in to help: “I don’t do a lot of cooking anymore. I’m not doing any of the cleaning anymore. Whenever I have to get something out of the basement or from another floor, I ask my husband to get it because stairs are just brutal.” (Participant #011, female, 46-65 years, 1st interview)

After surgery, with the number of appointments and visits from a nurse and the amount of time
dedicated to dealing with OA-related health problems, many felt it was difficult to direct their own schedule as would be their preference. One participant explained the experience of depending on others to decide what her days would look like and emphasized how it led her to feel as if her life was no longer her own: “But you still had, every other day, somebody coming in and dressing the knee. So, your life just did not seem to be your own, you were constantly waiting for a phone call to say what time they would be here.” (Participant #002, female, 66-80 years, 2nd interview) Being unable to walk without assistance and feeling afraid of falling down also limited people’s feelings of independence. One participant described being surprised at how much undergoing surgery negatively impacted his independence, rendering him “helpless”: “I was very surprised at how, I don’t know if … incapable is not the right word, how … what’s the word, sorry. You have a bit of a loss of freedom of movement that I wasn’t … and, you become a bit helpless, so I was totally not prepared for that.” (Participant #014, male, 46-65 years, 2nd interview)

4.4.2 Loss of sense of control

In addition to feeling a reduction in their sense of independence, many participants described how living with OA and undergoing joint replacement threatened their feelings of being in control of various aspects of their own life. The concept of “being in control” seemed to be something that participants highly valued and losing this ability also impacted their sense of independence.

One aspect of control that participants felt was affected was around having to deal with the healthcare system. Having to build one’s schedule around appointments and home visits made it difficult to choose how to direct one’s own day. Some participants felt out of control because they were not being listened to by their healthcare providers: “And I think there’s a feeling of
hopelessness because nobody would listen to me. I tried to leave messages on the doctor’s machine and nothing happened. And speaking with other doctors at [academic hospital] who said well that’s not us, that’s them. Nobody wants to take ownership for this and say why can’t we get this woman in and get this done?” (Participant #003, female, 46-65 years, 1st interview)

Participants also often felt as if they were not physically in control of their own body: “Taking a pain killer and just waiting until it kicks in and then start again. I mean there’s nothing much you can do, it’s just a fact of life.” (Participant #002, female, 66-80 years, 3rd interview) Some participants also expressed a feeling of having been betrayed by their own body: “I mean my body had betrayed me in a sense.” (Participant #011, female, 46-65 years, 2nd interview) Many described feeling as if their joint replacement was insecure. Sometimes they would have the impression that the joint was about to buckle, but they could not predict when this would happen and would be caught off guard by their own physical limitations: “And now I would say the worst thing that I deal with is going up or down, whether it’s a hill or whether it’s stairs, they are really bad. I still do them, I don’t stop but I have to hold onto something because a couple of times the knee just buckles on me and I’ve gone flying.” (Participant #003, female, 46-65 years, 1st interview) It was also difficult to understand what was going on within their own body as they lacked the expert knowledge of the health professionals whose care they depended on, which led to uncertainty about the extent of their own recovery, as one participant described: “Yeah, because I mean it had only just been done, and I’m not the doctor so I don’t know what’s going on inside of me or how it’s done or whatever.” (Participant #012, female, 66-80 years, 2nd interview) Ahead of their surgery, some participants voiced uncertainty about whether it would be successful. One participant felt that deciding to undergo joint replacement surgery signified a loss of control because once the procedure had been conducted, she would have minimal influence over and could not predict what her results and outcome would be: “And I have seen
people who have come in and come out looking worse than they did when they came in. And that was my biggest fear, that I would be worse off than I was. And, by saying go ahead, doing it, I was giving up any control I had over the situation.” (Participant #011, female, 46-65 years, 2nd interview) In the hospital after surgery, some participants felt out of control on account of being over-medicated by the hospital staff: “But, the fact is, when you’re overmedicated you’re not going to be getting up out of bed, you’re not going to be able to – I just felt that I wasn’t in control of my own health, care.” (Participant #011, female, 46-65 years, 2nd interview). Some participants claimed that they were in fact in control of their body and insisted that they did not let the pain that they experienced affect them, even though it was clear that living with the pain was a struggle: “The ankle starts, the knee hurts and I think it’s just you know, you’re still and quiet and it just says, okay. Yeah, at night it doesn’t really bother me, I don’t let it bother me.” (Participant #003, female, 46-65 years, 1st interview)

Participants actively tried to regain a feeling of being in control. Deciding to undergo joint replacement was a means to regain some of the control over their own life and body that living with OA had taken away: “So I saw him twice and on the second occasion, he asked me what I wanted to do about it and I said well, I have to have a knee replacement.” (Participant #003, female, 46-65 years, 1st interview) Conversely, some participants intentionally delayed scheduling their joint replacement to try to postpone its anticipated impact of reducing their ability to do the things that they wanted to do. When asked why she had waited three years to have her surgery, one participant responded, “Well I don’t really know. Well, but I’m the type to just keep going, like I don’t want anything to inhibit me from doing the things that I want to do…” (Participant #012, female, 66-80 years, 1st interview) Choosing what they felt would be the best time to undergo surgery, as opposed to simply following their doctor’s advice, was a way in which some participants exerted their control: “And I said to him, after several visits to
him, I said, you and I aren’t on the same page with this. I said I could go out and get hit by a truck tomorrow I grant you or I could die in five years. But I said I do not want to limp around like this for the next ten years. My quality of life is horrible.” (Participant #013, female, 66-80 years, 1st interview) In the hospital after surgery, some participants insisted that they should have input on the frequency and amount of medication that they were taking. Participants who described themselves as people who do not take medication often showed a desire to be in control of when and how much of the medication they would take: “And so I’m going to ask for pain medicine that I can take, just a pill as and when I need it and I can manage it myself.” (Participant #003, female, 46-65 years, 3rd interview)

4.4.3 Feeling like a burden

On account of their loss of independence due to their health problems, participants often came to feel that they had become a burden on their family, which was a negative perspective to hold. They did not want people to worry about them and were not happy to have become in need of help from others. One mother described, “Even my son who tends to be the worst one to keep in touch with me, he calls me once a week when he’s away. Sometimes with all this upset over the last few months, he’s been calling me a lot more frequently. I don’t like to worry my family.” (Participant #002, female, 66-80 years, 3rd interview) Participants did not want to become an inconvenience to their family by needing their help after undergoing TJR. Some described taking action to address their health problems sooner in the hopes of having a less burdensome impact on their family in the future: “To me, it was at the point where I just didn’t want to be in my late 70s or early 80s and have my children help me cope getting over hip surgery. It was already quite an experience.” (Participant #012, female, 66-80 years, 3rd interview)
4.5 Theme #3: Embarrassment at not appearing independent

The following section describes the embarrassment that participants experienced on account of not appearing independent because of their OA. Being able-bodied was valued by participants. Therefore, for many, the use of mobility aids, a common occurrence prior to or after joint replacement, was a particular area of embarrassment. They often highlighted public displays of having OA rather than the private experience. Participants rejected or seemed sensitive to the help offered by others, although most were grateful for it. This ambivalence toward offers of assistance seemed to contradict their feelings of independence in many instances and certainly was a barrier to the uptake of support that may have facilitated better recovery. Indeed, at times it seemed that for some participants, support from family or friends appeared to exacerbate their feelings of embarrassment. This had significant social impact on their ability to engage with others, to work, and ultimately to recover. Internalized stigma and anticipated stigma played a role in participants’ experience.

4.5.1 Concern about appearance and use of mobility aids

Needing to use a mobility aid prior to or after joint replacement surgery, a clear visual mark of their changed independence, was common among participants. Mobility aids were discussed pragmatically by some participants as a necessary part of the recovery process and were perceived by several participants as a tool that helped them to get more done than they would otherwise be able to without the added support, thus increasing their sense of independence. However, although some people spoke positively about the mobility aids or discussed them pragmatically as a necessary part of the recovery process, others had a negative attitude towards mobility aids and what they represented to them and refused to use them. Even though they were aware of their own struggles with walking and the benefit that a mobility device could provide, they refused to use one. Participants were often concerned about how OA affected their physical
appearance and did not want to appear unable in front of others. They desired to look “normal,” which for them meant not appearing to have difficulty walking, and which often meant choosing to not use a mobility device. This attitude revealed that several participants had internalized stigmatizing negative feelings and beliefs around the disability caused by OA, even though they themselves had OA, and that they were worried that others might react negatively to their appearance (anticipated stigma). One participant described her desire to be, “…able to bend your knee enough to get back onto upstairs instead of one foot at a time, to actually walk with two feet like a normal person instead of dragging the bad knee behind you,” (Participant #002, female, 66-80 years, 1st interview) suggesting that people who have difficulty walking upstairs are not normal. Another participant refused to use a cane because she had a negative perception of how it would make her look: “R: Yeah, like in 18 months when I come back in here I want to be able to tell you that I am back doing everything I would normally do without the pain. And hopefully without the limp. M: Do you use anything to help you walk? R: No. I’m very vain.” (Participant #009, female, 46-65 years, 1st interview) She was hopeful that she would be able to return to her usual activities and no longer have difficulty walking, but would not try to use a mobility aid on account of her self-described vanity, suggesting that a mobility aid would mar her appearance. The same participant intentionally did not tell the truth about her OA to her coworkers when they noticed that she was limping, and did not want to stand up at a social event because of how she might appear in the eyes of others at the gathering: “I could have got up I guess but it wouldn’t have been pretty.” (Participant #009, female, 46-65 years, 1st interview) Another participant was embarrassed about the prospect of others seeing him struggling to complete the day-to-day task of putting on his socks and shoes on account of his limited mobility. When asked about how long it had been since he could put them on without difficulty, he replied, “I don’t know, it was at least a year, if not more, because it was just embarrassing. I
had to figure out ways to do it at the gym, because I didn’t have that pull-on device at that time, I had that only after the surgery.” (Participant #014, male, 46-65 years, 2nd interview) One participant chose to not use a mobility device because of her stigmatizing view towards other people with OA who use a cane as being unable to recover and her determination to not take on the characteristics she had a negative and stigmatizing attitude towards: “And I didn’t want to be one of those people that ended up not being able to walk and having to use a cane before I got the operation. Because I think if you get to that point then it is difficult to get back to where you were.” (Participant #003, female, 46-65 years, 3rd interview) Another respondent was worried that she would end up looking like someone she knew who had undergone a hip replacement and who was now limping: “I don’t know, because you hear really good things and then you’d hear really, oh, I’m limping and I watch this lady go down the street and I’m thinking, oh my god, I know she had a hip replacement. Is that going to be me?” (Participant #009, female, 46-65 years, 3rd interview) In some cases, mobility aids were perceived to be a hindrance to the process of recovery. They were seen as an obstacle to providing muscles with the opportunity to work and to giving the body a chance to get stronger: “…I want to keep using other muscles, use my core and I don’t want to have to rely on a crutch. I want to let my body deal with it.” (Participant #003, female, 46-65 years, 1st interview) After her surgery, one participant was discouraged from using her crutches by her physiotherapist: “I was on crutches – I went to the six-week appointment on crutches, and I was told to get rid of them by the physio. She said get rid of those before you see him or he’s going to beat you with them.” (Participant #011, female, 46-65 years, 2nd interview)

4.5.2 Worry about looking older

Some participants associated the limitations caused by OA with aging and spoke about the prospect of appearing to be older in a negative way: “Going down, it’s very, very stiff and very
painful. So when I’m going down, I definitely have to hold on. And now with the ankle being so bad, I’m going down the stairs like an old lady, it’s not good. Because I don’t use a cane or anything now, I refuse to do that.” (Participant #003, female, 46-65 years, 1st interview) One participant said that to use a walker would be stupid on account of her younger age and because walkers are for those who are worse off than she is: “But the first thing to go was the walker. For me that was just stupid. M: What makes you say that? R: Well, at the time I was 49 and it was like, why am I using a walker? There’s much worse than me, I don’t need a walker.” (Participant #011, female, 46-65 years, 2nd interview) In line with internalized stigma, this participant had taken on a negative attitude around the limitations caused by OA and made a link between being older and being physically unable.

4.6 Theme #4: Stigma as a barrier to engagement in former activities

The following section describes how participants chose to isolate themselves or avoid social situations rather than appear weak or dependent. Internalized stigma and anticipated stigma played a role in participants’ experience.

4.6.1 Choosing to not participate rather than being seen as weak or dependent

Participants’ experience with stigma associated with OA had a significant impact on their willingness to engage with others and to recover, which often extended far beyond their physical limitations. Sometimes they felt left out from participating in social activities, especially those that would require them to be more active and mobile. However, at other times, they felt uncomfortable about participating in something that they had done before because they visibly had a harder time completing the activity and they worried about how the way they looked would be perceived by others. There were also times when they chose to isolate themselves rather than
to participate in social activities that they previously enjoyed albeit in a modified capacity, as in
the social event that one participant described:

Well it means I’ve missed out on things. We had one trip that we do every summer where we
would meet friends in [city] and then we’d cycle to [town] and we’d stay over and see a play
and have dinner and then we’d cycle back to [city] the next day. So I haven’t been able
to do that for two years so I kind of feel left out. One of the friends does not ride a
bike so he would just take our stuff down in the car and meet us there in [town]. And he
said, oh, you can come with me but I didn’t [sic] 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. (Participant
#003, female, 46-65 years, 1st interview)

Some participants deliberately chose to not watch sporting events that they had once enjoyed as
they felt uncomfortable about not being able to participate. One respondent described becoming
more withdrawn from social events as her physical condition worsened:

Well, you just seem more and more limited as my knee, for lack of better words,
disintegrated or deteriorated. The more it deteriorated, the less I was able to do, the more
withdrawn from activities I would become. Like, you know, my husband is a runner and
he would do races. And because I can’t participate anymore, I didn’t even want to go and
watch him. (Participant #011, female, 46-65 years, 2nd interview)

Several participants spoke about no longer being able to dance at social events as they used to:

“Well the thing we used to do a few years ago which we haven’t been able to do since the knee
started bothering me is dance. We used to dance all the time at socials and things, but we haven’t
done that because it’s very difficult.” (Participant #002, female, 66-80 years, 1st interview)

Conversely, some participants continued to maintain an active social life, even with their health
problems, and said that their experience with OA did not lessen their frequency of socializing
with others: “Oh yes, I’m social. I won’t miss any social I could possibly have been to.”
( Participant #013, female, 66-80 years, 1st interview) A few people also described adapting their
social routines so that they would not miss out on opportunities to see friends: “We still camp,
but I park my seat outside and I let people come to me. I mean the people we camp with know
that I have a problem right now and they do come and talk to me.” (Participant #002, female, 66-
80 years, 1st interview)
4.7 Theme #5: The self-defeating struggle to avoid stigma by returning to “normal”

The following section examines how participants attempted to avoid stigma by trying to return to normal, even though acceptance of their current limitations was needed in order to fully recover. It was common for participants to want to “get back” to the way things were before life was made more difficult by their OA. Stigma is about differences and returning to “normal” would mean no longer possessing the differences that made them a member of a stigmatized group and set them apart from others. However, as noted already in the example of Participant 011, avoiding situations impacted by the experience of stigma was self-defeating as engaging with others was what participants needed to do in order to return to normal. Internalized stigma, anticipated stigma, and felt stigma all played a role in participants’ experience.

4.7.1 Equating normality with independence

For many of the participants, returning to “normal” was an important goal for after their surgery, and use of the word “normal” was very common, as in the following narrative: “In general, I just think I’m going to get back to not even thinking that it’s an artificial hip and just do what I would normally do. To me, I just want to be back to normal.” (Participant #009, female, 46-65 years, 1st interview) “Normal” often referred to doing things independently again. For example, for many participants, there was also a strong desire to visually appear like a “normal” person (meaning able-bodied and independent) and to do things in the way that they “should” be done. One participant described wanting to be able to walk like a normal person and several months after surgery, another recounted experiencing felt stigma: “It’s nice that people don’t look at you and say, oh, what’s wrong? I was getting that all the time. What’s wrong that you’re dragging your leg?” (Participant #009, female, 46-65 years, 3rd interview) People also frequently spoke about wanting to get their life back, as if OA had taken their whole life away, with the inference that
this would involve them regaining a sense of independence. One participant explained, “I just went ahead. I just wanted my life back. I wanted it back so desperately. So, when this pain went away and I could walk with it, I just went for it and didn’t think about it.” (Participant #009, female, 46-65 years, 3rd interview) Similarly, another described her anticipation before her surgery: “So, this was the big hope that, as my husband would say, you would get your life back. You would get to do the things that you haven’t been able to do to your full potential because – and here I’m not yet.” (Participant #011, female, 46-65 years, 2nd interview) Living with OA and undergoing joint replacement surgery often ended up leading to a new “normal” and people had mixed reactions to this. One participant spoke about expecting to return to the way things were before, but also recognized that this was an unlikely outcome: “I expect myself to return to how I was and I have to remind myself that that is probably not going to happen.” (Participant #003, female, 46-65 years, 3rd interview) Another did not want to settle for the progress that had been made since her surgery: “I mean it’s a lot better. I’m happier. I’m just not willing to say this is as good as it gets for me.” (Participant #011, female, 46-65 years, 2nd interview) After their surgery and recovery, some participants did begin to feel independent again, and for these people, this was a source of enormous relief. At eight months after his surgery, one participant described, “Nothing from the hip, the hip is fantastic. No pain at all, and I’ve done a lot of stuff since the surgery.” (Participant #014, male, 46-65 years, 2nd interview)
5.1 Summary of Findings

The academic literature on OA has tended to focus on issues related to pain and mobility with minimal attention given to stigma. This study highlights the importance of self-identity among people with OA and specifically the values of independence, stoicism and strength that participants held and that seemed threatened by their OA. In terms of barriers to engagement in activities, it was often the stigma of disability that affected people as much as their actual disability did. The findings of this study suggest that people with OA often perceive living with OA negatively and may experience stigma on account of their health problems. This study focused on felt stigma, anticipated stigma, and internalized stigma. Few of the participants’ accounts were about enacted stigma imposed by others, but rather focused on an internalized sense of embarrassment over one’s dependence and/or fear of how they would be perceived by others.

5.2 Discussion of Findings

The emphasis that participants placed on their self-perception as being active, independent and stoic was influenced by and reflective of Western social values (Eckersley, 2006; Moore et al., 2013). Because of their OA, participants could not embody all of these values in the ways that they wanted to and that they might have been able to in the past. In their framework of influences on stigma, Pescosolido et al. (Pescosolido, Martin, Lang, & Olafsdottir, 2008) highlight the importance of the macro context, and that social context affects the stereotypes that people hold as well as their reactions to cultural beliefs. Regardless of the challenges or
difficulties that they faced, people still referred back to their desire to align themselves with
social norms and values. This was also reflective of the social context in which participants
found themselves. This context of Western culture emphasizes the importance of independence
and stoicism (Eckersley, 2006; Moore et al., 2013). Thus, participants referred back to these
socially valued characteristics. It is social values and norms that define what entails stigmatized
marks and therefore, who experiences stigma (Major et al., 2017). Therefore, stigma is not an
individual psychological characteristic, but is rather an experience dependent on and stemming
from social values. It was the interruption of meeting social norms among participants that led to
experiences of stigma.

Participants’ attachment to stoicism and their hesitation to openly discuss their pain is in line
with the findings of a review of the evidence on factors that contribute to patients’ unwillingness
to openly disclose pain in a palliative care context (Cagle & Bunting, 2017). In this review,
Cagle and Bunting (Cagle & Bunting, 2017) found that barriers to talking about pain tend to be
cognitive. They identified six beliefs that contributed to this unwillingness: stoicism, stigma,
denial, bother, fatalism, and cautiousness. Of these six factors, the ones that seemed to resonate
most with our study were stoicism and stigma. Cagle and Bunting (Cagle & Bunting, 2017)
described stoicism as being related to closing oneself off from pain, being in emotional control,
or experiencing pain without complaining. In the literature, they found that it was related to
resilience and the idea of admitting pain to others as indicating weakness. Stigma was related to
embarrassment around discussing pain. Cagle and Bunting (Cagle & Bunting, 2017) identified
stigmatizations of pain including fears of being weak, being a complainer, being an attention-
or drug-seeker, and being disapproved. Their review suggests that negative attitudes related to pain
medication could be caused by insufficient education.
Living with OA disrupted participants’ internal self-perception as being active, independent, and stoic, characteristics that participants valued about themselves. They were affected by both experiences of internalized stigma, which includes feelings of shame or guilt on account of having a stigmatized difference, and anticipated stigma, the expectation among stigmatized people of experiencing prejudice and discrimination.

One of the sub-themes was around a sense of loss of independence. As relates to this, Cott and Gignac (Cott & Gignac, 1999) conducted a qualitative study with 27 participants exploring perceptions of independence and dependence among older adults living with OA and/or osteoporosis. Participants in their study emphasized how important being independent was for them. All of the participants wanted to be able to not rely on others and perceived having to rely on others as the opposite of being independent. Half of the participants also felt that their health condition had led them to no longer be able to do what they wanted to, and discussed control, freedom and choice as being important to their sense of independence. Participants’ definition of themselves as independent depended on domains of difficulty of activities, coping efforts, assistive device use, and their relationship with people providing them with help.

As related to our sub-theme of participants’ loss of a sense of control, in her qualitative study of day-to-day experiences of people with OA and how they manage OA, one of the four main themes identified by Kee (Kee, 1998) was staying in charge. In her study, participants adjusted medication dosages as they saw fit and chose to no longer see certain health professionals to maintain their sense of control over their own lives. Similar to Kee’s (Kee, 1998) study, participants in our study valued being in control, and their self-perception was disrupted by their perceived loss of control.
One of the worries voiced by participants in our study was around feeling like a burden on their family. In line with this concern, in their systematic review of literature on people’s experience of living with hip or knee OA, Smith et al. (Smith et al., 2014a) identified five studies where participants expressed feeling like a burden on family and friends, and among these, three studies where respondents were afraid that this would worsen because of their disability in the future. Six studies also found that a role change in the family had occurred around activities of daily living, and participants were both reluctant around this change and concerned about their family’s perceptions of having to take on more responsibility.

Participants experienced embarrassment on account of not appearing independent. Since being able-bodied was valued, for many, the use of mobility aids was a particular area of embarrassment and shame and this seemed to be related to the emphasis that they placed on being independent. Participants often had a negative attitude towards public displays of having OA. Further, internalized stigma seemed to play an important role in participants’ experience and at times, participants seemed to accept and internalize negative feelings and beliefs around OA. Overall, people often had negative attitudes towards the use of walking aids and felt that they suggested poor health and age and led to stigma from others.

In their qualitative study focused on perceptions of independence and dependence among older adults living with OA and/or osteoporosis, Cott and Gignac (Cott & Gignac, 1999) found that participants had varied perspectives on the use of assistive devices. Overall, using devices was perceived as helping to maintain one’s independence. However, opinions often depended on the type of device in question. While devices used for household tasks like opening jars were perceived as being normalized, walking aids were seen as being more stigmatizing. Whereas more normalized devices were perceived as maintaining independence, mobility aids were more
often perceived as displaying dependence. Mobility devices were perceived as clearly labeling people as disabled and were found to be threatening to people’s self-identity as being independent. Some participants initially did not want to use a mobility aid because they did not want to look disabled or old, and associated this with their own vanity or pride. Participants who associated mobility aids with looking dependent were also less likely to have tried using them. Similarly, in our study, some participants refused to use mobility aids in spite of recognizing that they could have some benefits, some participants did not want others to see their disability, and some attributed refusing to use a mobility aid to their own vanity.

Smith et al. (Smith et al., 2014b) published a systematic review and meta-ethnography looking at the attitudes of people with OA towards their conservative management. They identified four studies that discussed the role of walking aids on people with OA. Sanders et al. (Caroline Sanders et al., 2002) conducted 27 qualitative interviews with people with severe hip or knee OA between the ages of 51-91 examining how they experienced symptoms of OA. Several participants expressed that they experienced stigma when using walking aids and that they were embarrassed by their disability. One participant described intentionally disguising her need of a walking aid by using an umbrella instead, and another expressed that that it was difficult to be unable to do things his peers could do. Tallon et al. (Tallon et al., 2000) explored how people with OA of the knee perceived symptoms and treatment preferences. They conducted a focus group with seven knee OA patients to inform the development of a 93-item questionnaire that aimed to collect information on symptoms, preferences, treatment experiences, and research priorities of knee OA patients. This questionnaire was completed by 112 respondents. Although the findings of the questionnaire showed that more than half of respondents used mobility aids or adaptations, in the focus group, some people identified that they did not use canes because they felt too proud to do so. Kee (Kee, 1998) conducted interviews with 20 participants with OA to
explore their daily experiences and to examine whether people in varying socioeconomic groups manage OA differently. Her study found that participants in two groups differing in socioeconomic advantage used assistive devices almost equally. Alami et al. (Alami et al., 2011) conducted a qualitative study about patient and health professional views on knee OA management with 81 patients and 29 healthcare providers. Their findings around the use of assistive devices were that as a long-term option, using canes or wheelchairs was not well-accepted because of the image that it created as well as the implication of loss of autonomy and old age. The same review (Smith et al., 2014b) found that the literature underlined the importance of counselling patients on their conservative treatment to avoid an attitude of non-compliance.

Smith et al. (Smith et al., 2014a) also conducted a systematic review and meta-ethnography of the literature around the experience of life with a knee and/or hip OA diagnosis. Of the four main concepts generated through the conduct of the meta-ethnography, one addressed the interpretation that people had of other people’s perceptions of their OA and their capability. One of the themes identified within this concept related to stigma, most often expressed in how people felt about using a mobility device. They felt that using a mobility device announced their disability and would be seen negatively by family, friends, and society. They also reference Maly and Krupa (Maly & Krupa, 2007), who conducted a phenomenological study of older adults’ experiences of knee OA. Participants in their study felt like they stood out because of mobility changes and using mobility aids, and this made them feel self-conscious.

Participants sometimes chose to not participate in their former activities rather than appear weak or dependent in front of others. It was a question of their willingness to take part, not just their physical ability to do so. At times, they chose to be entirely left out of activities because they
were unable to do some part of them, or because they were unable to do them as they could before. Participants also seemed to be affected by feelings of internalized stigma, in that they were concerned about the way that they looked in front of others.

Major et al. (Major et al., 2017) suggest that there are several dimensions that distinguish stigmatized marks from one another that are of particular importance to understanding the connection between health and stigma, as well as the experiences of stigmatized people. The first is concealability, or how easy it is to hide a stigmatized mark. Being able to conceal such a mark could lead to less discrimination and stress, but the implications of concealing a mark are not always positive. The second dimension is controllability of the stigmatized mark (Jones et al., 1984). When a mark is perceived as being more within a stigmatized person’s control, in terms of either obtaining or losing it, they tend to be held more accountable for their condition by themselves and others. The third dimension is collectivity, or the extent to which the stigmatized marks one holds are related to a collective identity as opposed to an individual identity. Perhaps participants chose to not participate in activities to ensure that they could conceal their modified capacity to participate in activities that they enjoyed before.

Participants tried to avoid stigma by attempting to return to normal. They often wanted to “get back” to the way that things were before life with OA. Returning to “normal” would mean no longer possessing the differences that made them a member of a stigmatized group and that set them apart from others. Avoiding stigma by avoiding others was self-defeating as engaging with others was a component of what participants needed to do in order to return to normal. As Webster et al. (Webster et al., 2015) point out, most post-surgical activities are not limited to the person with OA who has undergone TJR, but take place together with other people such as
family and friends. Social support and interactions with family and friends are important components of health-related quality of life among people with OA (Ethgen et al., 2004).

In his chapter on disability, normality, and power, Davis (Davis, 2016) explains that normalcy creates the problem of the person who is disabled, not the other way around. Parallel to the idea of a norm is the concept of a deviation. As this idea relates to human bodies, in a social context, a person with a disability will be considered a deviant and so will their body. Social norms therefore divide people into subpopulations of those who are normal and those who are not.

In her chapter on stigma, Coleman-Brown (Coleman-Brown, 2016) explains that stigmatization depends on social context, and that the norms within a given context determine which traits are valued. Stigmatized people lose their spot in the social hierarchy, and to avoid this, people wish to keep their place in the social majority. Coleman-Brown (Coleman-Brown, 2016) points out that stigma originates from differences, and that any difference has the potential to be stigmatized. She also notes that normality “takes on an exaggerated importance” (Coleman-Brown, 2016)(p. 153) for people who are stigmatized and seeking to be perceived as being as normal may become an important goal for them.

### 5.3 Theoretical and Conceptual Contributions

#### 5.3.1 Goffman’s Theory of Stigma

In my discussion of the themes that I have identified, I draw on Goffman’s theory of stigma, and in particular his writing about stigmatized people internalizing social biases. This is an important distinction for my research as few participants shared accounts of explicitly being stigmatized by others, but rather most often spoke about experiencing internalized stigma that arises from the internalization of social norms. Goffman writes that “Society establishes the means of categorizing persons and the complement of attributes felt to be ordinary and natural for
members of each of these categories.” (Goffman, 2016)(p. 134). For the participants in this study, being seen as independent and portraying stoicism in the face of pain seemed to be what they considered “ordinary and natural” and thus they expressed embarrassment at the OA that led to them needing assistance, including assistance from pain medication and mobility aids.

5.3.2 Major et al.’s Conceptual Model of Stigma and Health

This study highlights some of the strengths and challenges in applying conceptual models to the analysis of qualitative studies. Major et al.’s (Major et al., 2017) conceptual model describing how health can be affected by holding a stigmatized social status was applied (Figure 1 in section 2.4). This allowed me to have a framework within which to describe and explain my findings. The model begins with socially conferred marks, which are attributes that cause a person to appear different from other people and that signal this difference to others (Goffman, 2016). For participants in this study, these marks were related to holding the stigmatized status of having OA. The physically visible marks that announced their stigmatized status and differentiated them from others – including differentiating young from old with the latter being viewed negatively – included having difficulty walking or moving around and needing a mobility device. The dimensions of a mark and the characteristics of the individual and their environment can also moderate the relationship between marks and processes of stigma, influencing the stigmatization that a specific individual will experience. Participants found themselves within a context where they were not the ones who decided which types of marks would be stigmatized and stereotyped within their culture. Nonetheless, cultural beliefs were still often internalized by them and affected the way that they perceived themselves. In Major et al.’s (Major et al., 2017) model, socially assigned marks lead to four stigma processes (enacted stigma, felt stigma, internalized stigma, and anticipated stigma) that create stress and exclusion for people within stigmatized groups. For participants in our study, on account of living with OA, they described
experiencing three of these four stigma processes: felt stigma, anticipated stigma, and internalized stigma.

Although helpful in guiding analysis, this model did not entirely fit our findings. In terms of the four stigma processes identified, participants did not express experiencing enacted stigma, or discrimination and bias, because of their stigmatized mark. Future research could explicitly explore these aspects of stigma within the context of OA. The next section of Major et al.’s (Major et al., 2017) model, which entails individual-level responses and social/community exclusion that experiences of stigma lead to, represents processes that were beyond the scope of this project to identify and the impact of stigma processes and moderating factors on these responses and on exclusion could not be determined. Further, the final outcome of this model, the influence of these responses and exclusion on participants’ overall health, was not relevant to this project. Thus, Major et al.’s (Major et al., 2017) model did not entirely fit the analysis in this project. This gap may represent a particular challenge to the use of conceptual models to real-life experiences, especially when applied ad-hoc. On the other hand, it also suggests that studies could be designed according to models to better capture all their dimensions; given that qualitative research is exploratory, however, this carries the danger of imposing the researcher’s pre-conceived conceptualizations onto participants’ experiences. The impact of the framework sections that I did discuss on the overall health of participants as compared to other factors could not be determined.

5.4 OA as Disruptive to Self-perception and as the Catalyst for Experiences of Stigma

The model developed in this project (Figure 2 in section 4.2) was based on the data and themes identified through the analytical process, and illustrates how changes to participants’ self-
perception led to experiences of stigma. Participants experienced a change in their self-perception on account of their OA. Many participants identified with the characteristics of being active, independent and stoic. However, their OA disrupted their self-perception as possessing these qualities. This disruption led to feelings of stigma. Felt stigma, or the perception of being devalued or treated unfairly because of one’s socially conferred mark, was demonstrated in situations where participants perceived changes in the way that people treated them. Internalized stigma, or one’s acceptance of negative feelings and beliefs related to one’s stigmatized status, was demonstrated when participants did not want to use mobility aids or to appear weak on account of what this represented to them. Anticipated stigma, or the expectation of experiencing prejudice and discrimination, was demonstrated in situations where participants were not honest about their OA or did not want others to see their physical limitations.

5.5 Clinical Implications and Practical Contributions

The findings of this project suggest that psychosocial support might be a helpful intervention for patients with OA as experiencing stigma can have a negative impact. Patients were faced with more than just physical challenges to cope with and to work through. Understanding the extensive impact that stigma can have on patients might help clinicians to provide better care and to assist patients to better manage their condition. Earnshaw & Quinn (Earnshaw & Quinn, 2012) explored the effect that stigma can have on quality of life among people with chronic illness in healthcare settings. Their results showed that patients who experienced and internalized stigma from their healthcare providers, in turn anticipated more stigma from their healthcare workers. These patients also accessed fewer healthcare services and had a lower quality of life. Further, OA is not usually limited to a single joint, with pain in multiple joint sites being more common (Finney, Healey, Jordan, Ryan, & Dziedzic, 2016). As OA progresses, the function of one joint may negatively affect another, increasing disability (Schmitt, Vap, &
Queen, 2015). After an initial knee or hip TJR, many patients eventually require TJR of the contralateral joint (Shao et al., 2013). Therefore, even after a successful TJR in one problematic joint, the physical effects of OA may continue with trouble in another joint, and patients’ experiences of stigma may also continue. Thus, the approach that clinicians take when they speak to their patients is important and these findings may give clinicians some insight on patient experiences to inform their approach.

As outlined above, the implications of this work would be of most interest to clinicians and also to policymakers who determine what services patients should receive. However, given my relative lack of access to policymakers or clinicians, I have adopted a more traditional knowledge dissemination route of presentations at conferences and academic publications. This includes the submission of an abstract and presenting a poster at the Osteoarthritis Research Society International World Congress (OARSI) in May 2019. This annual conference attracts more than 1300 registrants from over 50 countries and reaches both clinicians and researchers. An article based on the findings of this project will be submitted to an academic journal for publication. It would also be interesting to disseminate the findings of this project to consumer groups and organizations that provide services to OA patients. The knowledge translation process entails knowledge creation, knowledge synthesis, and then the creation of knowledge products and tools (Straus & Leung, 2010). In order to move to the knowledge synthesis step, more studies directly addressing stigma and OA and directly asking people about their experiences are needed.

5.6 Strengths and Limitations

This study has a number of strengths. Analysis and interpretation included the use of both a theory and a conceptual model. It is also one of the first exploratory studies looking specifically
at stigma in this context. Results were drawn from and grounded in people’s narratives of their own experiences.

It also has several limitations. The fit of the data to a secondary research question is always a concern because data from the primary study are used to answer a question different from the secondary analysis (Heaton, 2004). This meant that specific questions designed to elicit understanding of stigma were not included in the original interview guide, even though this was the focus of this thesis project. However, although none of the questions specifically asked about stigma and there was no opportunity to probe on this topic, participants did discuss stigma and the answer to the research question is based on their responses.

One of the strengths of the original study was the longitudinal aspect and the follow-up with the same participants over time. However, this secondary analysis was unable to consider changes to participants’ experiences over time because the original study did not include questions about stigma in the interview guides.

In addition, as noted by Heaton, having “been there” is important as qualitative research emphasizes seeing and understanding the context of the lives of participants (Heaton, 2004). The original researchers are perceived as having insider knowledge and understanding of context in a way that makes others unable to analyze their data (Van den Berg, 2005). In this study, however, this was somewhat mitigated as the original co-principal investigators were involved, and this greatly enhanced the rigour of the secondary analysis.

5.7 Conclusion and Future Directions

OA is a chronic and common condition that affects many Canadians. It has a considerable impact on people’s daily living activities and HRQOL. The burden of OA on our healthcare
system and the number of hip and knee replacement surgeries performed in Canada is expected to continue to increase over time. In this study, the experience of stigma played as important a role at times as the actual physical limitations imposed by OA. People with chronic illnesses such as OA often perceive living with OA negatively and may experience stigma, which can affect many areas of their lives. I have shown how care plans for patients following TJR could benefit from the inclusion of attention to stigma and in particular internalized stigma, and how stigma may affect a patient’s willingness to engage in activities post-surgery. In addition, future research could more directly and explicitly ask patients about the role of stigma in their experiences.
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