An Anthropological Perspective on the Experiences of Osteoarthritis in the Greater Toronto Area, Canada, and South Yorkshire, England

by

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Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners. I understand that my thesis may be made electronically available to the public.

Abstract

This research studies the experience of both being diagnosed and living with osteoarthritis. I conducted this research looking to understand whether and how societal norms affected medical treatment of the disease. The research mostly focuses on the Greater Toronto Area, Canada, with a small comparative section on South Yorkshire.

Three key themes were discovered and analyzed throughout the research. The first theme is lived experiences of osteoarthritis, which focuses on the concepts of pain and loss. The second key theme is the interrelation of responsibilization, medicalization, and moralization. This involves how patients rationalize the causes of their own osteoarthritis and sometimes how these compare to others. The third theme is Doctor-Patient interactions. Participants explained their experience interacting with medical professionals about their osteoarthritis, and analysis highlights how these interactions influence the participant’s perception of their condition and their own health.

Osteoarthritis is well understood from a biological perspective; however, this is only one element in medical treatment. It is hoped in this research that the consideration of lived experiences by medical professionals will improve flaws in the communication of osteoarthritis management and treatment.

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Table of Contents

List of Figures

List of Tables

Chapter One

1 – Osteoarthritis and Public Issues Anthropology

Osteoarthritis is a chronic joint disease that affects individuals around the world, impacting both the individuals and their societies. As of 2003, the World Health Organization estimated that, across the globe, 25% of adults over the age of 65 suffer from osteoarthritis (Breedveld 2004, 4). Studies around this time approximated that 40% of all individuals over the age of 70 are afflicted specifically with osteoarthritis of the knee (Brooks 2002, 573). Osteoarthritis prevalence has since grown significantly, reaching 250 million affected individuals on a global scale in 2012 (Hunter et al. 2014, 437). Osteoarthritis prevalence is expected to steadily increase over the coming years around the world, with estimates predicting a 50% increase in cases from 2006 to 2026 (Hunter et al. 2014, 437). This may be due to an actual increase in cases, or it may be a result of refined techniques and reduced misdiagnoses. Osteoarthritis impacts a variety of elements across the globe; while the individual suffering of a patient cannot be ignored, it is also important to address the economic effects of such a prevalent, partially preventable disease. As a result, osteoarthritis is a disease in significant need of increased research. An anthropological perspective provides the opportunity to examine the human impact of osteoarthritis and attempt to capture the subjective experience in a manner not used by biomedicine. There is value in the expression of frustration or pain from each patient, and this research presents an understanding of both the science involved in managing osteoarthritis, and the ways the afflicted individuals handle it every day.

Public Anthropology is a framework named by Borofsky that examines present-day issues in a manner that is both accessible and understandable for the general public (Borofsky

2000, 9). This framework does not solely rely on experts, but instead incorporates those directly involved as well, empowering a broader base to identify and address issues (Borofsky 2000, 10). Public anthropology combines the fields of theoretical and applied anthropology, facilitating engagement with public anthropological discourse (Borofsky 2000, 9). This also serves as a reminder of anthropology's holistic roots (Borofsky 2000, 9).

Despite not being clearly articulated as "public anthropology" until Borofsky, the concept of a more applied and practical anthropology has been discussed since approximately the late 1960s. *Reinventing Anthropology* (1969) is possibly the first example of this, with Dell Hymes arguing that to survive as a discipline, anthropology must become both more responsive and responsible for political and humanly issues (Donald 1974, 858). The book is a collection of essays from anthropologists such as Hymes discussing the inherently political nature of anthropology and the necessity of accountability in the field (Donald 1974, 860). Over time, these themes have become increasingly prevalent and accepted throughout the discipline of anthropology, and can be seen reflected throughout this research in that focus is placed on participants' experience with osteoarthritis rather than the science.

The data collected in this research is applied through an interpretation of bioculturalism. Bioculturalism is an anthropological framework that studies human health through the interactions between biological, societal, and ecological factors (Wiley and Allen 2013, 8). The use of bioculturalism is important, both within the field of anthropology and in real-world application, particularly during especially intense global health crises such as the 2020 COVID-19 pandemic where disease and cultural factors interact. Biocultural anthropology incorporates theory and methodologies from all four traditional sub-fields of anthropology – biological, cultural, linguistics, and archaeology – which throughout the discipline have often remained rigidly divided (Hoke and Schell 2020, 4). Anthropology’s unofficial fifth sub-field, applied anthropology, is also integrated as bioculturalism is focused on the generation of practical knowledge regarding human health (Hoke and Schell 2020, 5). This aim is what brings the importance of biocultural anthropology beyond academia. By taking politics, economics, history, and social factors that impact the human environment and health into consideration, the use of bioculturalism in research has the potential to produce widespread benefits on a global scale (Hoke and Schell 2020, 4-5).

The burden of diseases such as osteoarthritis is typically measured through both direct and indirect financial costs; however, it is important to consider the costs of quality of life (Hunter et al. 2014, 437). This can be quantitatively measured through calculations of Quality-Adjusted Life Years (QALYs) and Disability-Adjusted Life Years (DALYs), which determines disease burden through estimation of the quality and quantity of life remaining for an afflicted individual. One QALY is equal to a gained year of hypothetical perfect health, and one DALY is equivalent to the loss of a year in perfect health (NCCID 2015, 1, 2, 4). The United States population has approximately 15 million DALYs throughout its population each year due to osteoarthritis, which is comparable to conditions such as cancer and cardiovascular disease. Over the course of a lifespan, non-obese and obese individuals with knee osteoarthritis have a mean of approximately 1.9 and 3.5 DALYs per person respectively (Hunter et al. 2014, 348). Knee osteoarthritis is included in the global top 10 non-communicable diseases for DALYs (Neogi 2013, 1148). Although these calculations highlight the importance of researching osteoarthritis from a public health standpoint, they do not showcase the actual experience of living with osteoarthritis. Without understanding the specific subjective struggles faced by individuals with osteoarthritis, it could potentially be much harder to find methods to reduce their suffering.

Osteoarthritis has significant effects on afflicted individuals, and is one of the predominant causes of physical disability for non-institutionalized elderly individuals (Breedveld 2004, 5). The main symptom of osteoarthritis is chronic pain that worsens with movement, which typically results in a loss of functionality of the joint and a reduced quality of life (Hunter et al. 2014, 437; NCCCC 2008, 6; Neogi 2013, 1145). Approximately 80% of individuals with osteoarthritis are estimated to experience loss of joint functionality, which means that the individual's range of motion in the joint decreases, limiting movement (Brooks 2002, 573; Buckwalter et al. 2004, 7; Neogi 2013, 1148). Loss of motion capabilities can have a substantial impact on the individual: osteoarthritis of the lower extremities has become the leading cause of mobility impairment of elderly individuals in the United States and amongst the top 10 causes of disability on a global scale, with 25% of afflicted individuals being unable to perform activities necessary for daily living unassisted (Brooks 2002, 573; Buckwalter et al. 2004, 7; Neogi 2013, 1145, 1148). Osteoarthritis does not typically affect solely one joint, meaning that there is an increased symptomatic burden of the disease with each additional affected joint (Neogi 2013, 1146). Alongside physical symptoms, individuals affected by osteoarthritis are also at heightened risk of experiencing a decline in mental health conditions, particularly in the form of depression or anxiety (Breedveld 2004, 5). Understanding how these symptoms affect individuals can potentially provide researchers deeper understanding of the experience of osteoarthritis.

I intend to publish my research through the peer-reviewed venue *Anthropology & Medicine*. This is an anthropological journal that focuses on medicine, health, and illness through an interdisciplinary lens (Anthropology & Medicine). *Anthropology & Medicine* examines the bridge between culture and health, with one of its main topics being chronic illness and aging. This aligns with my research, as my thesis studies how the cultural perception of osteoarthritis potentially impacts the medical treatment of the disease. Chapter 2 is formatted according to the requirements of this journal.

Chapter Two

2.1 - Introduction

This paper examines the lived experiences of individuals living with osteoarthritis in the Greater Toronto Area (GTA), and includes a comparative aspect for individuals in South Yorkshire, England. Participants' experiences are organized around three main themes: responsibility, doctor-patient relationships, and lived experiences of symptoms. These elements govern the way that patients understand their disease, and ultimately, their own bodies and experiences.

This thesis uses a lens inspired by bioculturalism, also known as a biosocial approach. In particular, this research draws from Paul Farmer, who focuses on the social contexts which shape vulnerabilities regarding disease and health. This perspective balances the tendency in bioculturalism to over-emphasize the biological aspects of health. In this thesis, a biocultural-inspired framework highlights the importance of the individuals themselves and changes the population studied in this research from ‘osteoarthritis patients’ to ‘individuals with osteoarthritis’ which highlights individuals’ perceptions and experiences. The subjective experiences of the individuals afflicted by osteoarthritis allow participants to dictate the possible gaps in the medical system regarding their disease. These interpretations do not exist in a vacuum, but are influenced by the cultural surroundings in which they live.

Surveys and interviews suggest that individuals with osteoarthritis consider their condition to be inevitable and outside of their control. Overall, the concept of ‘waiting’ was central to participants’ experiences with the medical field for their condition. They also expressed a lack of confidence in their knowledge about osteoarthritis, suggested to be due to lack of access to information. Analysis of the participants' narratives of lived experiences suggests that the enhanced limitations, framed in terms of pain and loss, from osteoarthritis were the greatest impacts on their lives. These findings suggest that there are gaps in the treatment of osteoarthritis. An increase in information flow between doctor and patient could not only improve the relationship, but also promote a sense of control for the patient through heightened comprehension of their condition and personalized treatment plans tailored to their limitations.

While participants from South Yorkshire expressed a stronger association of osteoarthritis with aging than the GTA participants, overall findings were similar for both groups.

2.2 - Background

Osteoarthritis affects millions of individuals as the most common joint disease affecting adults globally, and the most common form of disability in the Western world (Clarke et. al. 2013, 163; Michael et. al. 2010, 152; Nuovo 2007, 314; Reid and Miller 2008, 5). Osteoarthritis is also the most commonly cited reason for both hip and knee replacements, afflicting approximately 80% of patients having the procedure (Nuovo 2007, 314). There are no systemic indications of osteoarthritis, its progression does not extend beyond the joint (Nuovo 2007, 320). All synovial joints are at risk of developing osteoarthritis; however, the most commonly affected joints are those in the knees, hips, and hands (NCCCC 2008, 3).

Unlike many other diseases, osteoarthritis does not have a definitive cause. Instead, there is a wide array of both endogenous and exogenous risk factors. The former group includes age, sex, and heredity (Loeser 2011, 492; Michael et. al. 2010, 153; NCCCC 2008, 3; Neogi and Zhang 2011, 186; Nuovo 2007, 324). Exogenous risk factors, on the other hand, include elements such as joint trauma, repetitive joint microtrauma, obesity, and lifestyle (Lemintowski and Zelicof 2008, 148; Michael et. al. 2010, 153; NCCCC 2008, 3; Nuovo 2007, 314;). One's occupation can have a large effect on the development of osteoarthritis; miners, for example, have high rates of osteoarthritis in their knees and spines (Felson 2013, 12). Osteoarthritis can also be secondary, meaning that other diseases and disorders can cause osteoarthritis to develop (Michael et. al. 2010, 153).

The main symptom of osteoarthritis is persistent pain in the affected joint. In early stages of the disease the pain is typically intermittent, and occurs when the joint is in motion. As osteoarthritis progresses, the pain is likely to become fairly constant (Arden et. al. 2014, 55;

Michael et. al. 2010, 154; NCCCC 2008, 6). As chronic pain can affect numerous areas of an individual's life, such as sleep and mobility, individuals with osteoarthritis are medically considered to have a poorer quality of life compared to those without osteoarthritis (Arden et. al. 2014, 58). As the osteoarthritis progresses, the joint is likely to stiffen; the individual will lose mobility, which can have significant effects in their daily life, especially if the affected joint is weight-bearing (Michael et. al. 2010, 154-155).

Although there are no guaranteed methods to prevent osteoarthritis, there are primary and secondary interventions individuals can take to lower their risk. The strategies for the prevention of osteoarthritis are all lifestyle-based, meaning that they require regular effort over the course of the individual's lifetime. These include regular exercise and fitness to improve joint stability, and avoiding repetitive occupational strain on the joints (Nuovo 2007, 315; Nyland et. al. 2015, 4-5). As osteoarthritis also has non-modifiable risk factors such as age, gender, and genetics, it is impossible to eliminate the chance of developing the disease (Nuovo 2007, 314-315).

Patients can be diagnosed through self-reported tests, physical diagnosis, or radiographic diagnosis. A key feature of self-reported diagnosis is that they tend to focus on the individual's pain (Clarke et. al. 2013, 168). Physical diagnoses can vary depending on the medical practitioner, and can include joint inspection, and/or specialized tests (Arden et. al. 2014, 60; Michael et. al. 2010, 154-155; Nuovo 2007, 317). These methods have their limitations; the disease may be radiographically present in an individual without any reported symptoms (Neogi and Zhang 2011, 186-188). X-ray studies are the most common radiographic form used for diagnosing and monitoring the progression of osteoarthritis (Michael et. al. 2010, 155).

As there is currently no cure for osteoarthritis, the goal of treatment is to lessen the symptoms of the disease, slow its progression, and improve the individual's overall quality of life (Michael et. al. 2010, 165-156). Factors such as level of pain, level of disability, comorbidities, and clinical severity should be taken into consideration when deciding which options to pursue (Nuovo 2007, 316; Reid and Miller 2008, 7). It is generally recommended that non-pharmalogical treatment is prescribed first, with pharmacological methods and surgery available for more advanced cases (Arden et. al. 2014, 83). Patient education and information sharing is considered to be the most important aspect to treatment and the very first step. Beginning an ongoing dialogue between patient and healthcare provider not only provides clarity on the direction of the treatment plan, but provides the patient with realistic expectations (Michael et. al. 2010, 160; NCCCC 2008, 46; Wright and Goldring 2012, 81). A change in lifestyle, such as weight loss if needed, and eliminating excessive stress on the joints, is often the initial method of treatment (Michael et. al. 2010, 156). Orthopedic aids and other assistive devices can alleviate symptoms and are a non-invasive treatment (Michael et. al. 2010, 157; Nuovo 2007, 323). Physiotherapy, including exercise therapy and massage, is beneficial for improving range of motion, increasing strength, and increasing function of the joint, which can significantly improve the quality of life (Arden et. al. 2014, 85; Michael et. al. 2010, 157; Nuovo 2007, 321-322). Surgeries, the final option if the above treatments are unsuccessful, can either be joint-preserving or joint-replacement, and the latter should only be considered after the failure of the former (Michael et. al. 2010, 156, 159).

Appendix A explains this section in more detail.

2.3 - History of Osteoarthritis

Osteoarthritis has a long history that modern science has begun to piece together. There is evidence of osteoarthritis in the fossil and archaeological record that predates hominins, with the first evidence of the disease dating approximately 100 million years ago in the spine of a Comanchean dinosaur (Dequeker and Ljuyten 2008, 6; Arden et. al., 2014, 11). Osteoarthritis has been found throughout hominin history as well, one such notable example is the Neanderthal man from La Chapelle-aux-Saints (Dequeker and Luyten 2008, 6). While some have suggested that osteoarthritis is linked to bipedalism, this is unlikely as it also occurs in quadrupeds ("History of Osteoarthritis", McCoy 2015, 804).

Detailed records of joint pain from ancient Egypt depict the risks and treatments available at the time for the disease. The two main types of joint pain were what is now categorized as hip and vertebral osteoarthritis, afflicting scribes and peasants respectively ("History of Osteoarthritis"). As outlined in section 2.2, occupation is a common risk factor for osteoarthritis. Ancient Egypt is an early depiction of this causation, as scribes spent many hours a day sitting cross-legged and peasants had to repeatedly bend down and then straighten up during the course of their daily labour ("History of Osteoarthritis"). Ointments were used to relieve the joint pain.

The next known reference to joint pain is Hippocrates, who identifies gout and classifies all forms of chronic joint pain as such (Dequeker and Luyten 2008, 5). Osteoarthritis, although not named until 1890 by A.E. Garrod, was distinguished from gout in 1782 by William Heberden who noted that some individuals with joint pain in their fingers possessed nodes that had no connection with gout (Arden et. al. 2014, 11; Dequeker and Luyten 2008, 6). These nodes were later named as Heberden's nodes.

Osteoarthritis as we understand it today came into being with the invention of various technologies at the end of the 19th century. The invention of X-rays allowed for the distinction of various categories of arthritis, showcased the progression of the disease from a different perspective, and introduced a new method of diagnosing the disease (Arden et. al. 2014, 11; Dequeker and Luyten 2008, 6). In 1899, Bayer created aspirin, a medication still used today to relieve pain from osteoarthritis, as well as many other afflictions that cause pain (Arden et. al. 2014, 17). As technology and medical knowledge progress over time, our understanding of osteoarthritis will hopefully broaden, inspiring new treatments and perhaps, one day, a cure.

2.4– Context

This study examines the Greater Toronto Region (Canada), with a comparative section focusing on South Yorkshire (England). The Greater Toronto Area (GTA), is the metropolitan area with the highest population in all of Canada (Greater Toronto Area, 2020). The population of the GTA is approximately 6.4 million people, according to the 2016 Canadian census (Statistics Canada, n.d.). The Greater Toronto Area consists of 25 suburbs surrounding the city of Toronto, as well as the city itself (Greater Toronto Area, 2020). South Yorkshire is a metropolitan county in England, consisting of four districts: Barnsley, Doncaster, Rotherham, and Sheffield (South Yorkshire, 2020). The population of South Yorkshire, according to the 2011 census, is approximately 1.3 million people (Office of National Statistics, 2013). Sheffield is the largest of the districts, with the Sheffield Urban Area being the tenth largest urban region within the United Kingdom (South Yorkshire, 2020). Based on my sampling methodology, this is where the majority of my South Yorkshire participants reside.

2.5- Methods

This thesis utilized methods of an online survey, semi-structured interviews, and literature review. Data collected from the original research was qualitative in nature, and then underwent thematic analysis. More detail into the methods of this research can be seen in appendix B.

This study includes a cross-comparative component with participants located in two regions: The Greater Toronto Region (GTA) in Canada, and South Yorkshire in England. These two countries were chosen due to the similarity between their health care systems. Both nations include universal access to medical services alongside access to specialists through the use of referrals (Mackay et al. 2010, 166). The regions within these countries were chosen because the author had access to potential participants through family and friends. Out of these participants, those who chose not to be interviewed had their survey data anonymized. This aided in maintaining the accuracy of the survey responses. As a minimal-risk disease, it is unlikely that the personal connection between these participants and the author compromised the collected data.

The main method of recruitment was through snowball sampling. Social media, in particular the sites Facebook and Nextdoor, was also used to recruit participants.

The online survey was conducted through Qualtrics. Besides the consent and screening questions, participants had the option to leave any question unanswered for their comfort. Questions within the survey were a mix of demographical, medical, and experiential.

Participants were recruited for the interview portion of this research in the same manner as the survey, with the option of an interview stated on the distributed flyer. All identifying information was kept confidential, and responses to interview questions were transcribed verbatim and cleaned-up for readability. The data was then studied using thematic analysis to determine key topics present throughout responses to both the surveys and interviews. These themes were then analyzed through a biocultural lens in order to bridge the gap between the medical processes and qualitative responses. All names have been changed in this research; a list of the interviewed participants can be seen in Table 1.

Table 1: Participants Interviewed from the GTA

Pseudonym	Sex	Age Range
Lance	Male	50-59
William	Male	70-79
Michael	Male	50-59
Sarah	Female	50-59
Charles	Male	60-69
Robert	Male	70-79
Mary	Female	60-69

2.6 - Results

The number of participants for the survey was 24 from the GTA and 8 from South Yorkshire. Seven of the participants from the GTA also participated in the interview portion of the research. This section will focus on GTA participants; South Yorkshire data will be analyzed separately in section 2.11.

The demographics of the GTA participants for the survey were 16 females and 8 males. The median age range was between 60-69 for the males, 50-59 for the females, and 50-59 overall. The median diagnosis date for osteoarthritis was in the past 1-5 years, with 62.5% of participants being diagnosed under the age of 65 years and 8.3% were diagnosed over the age of 65 years. Due to ages and diagnosis date being collected in ranges, it is unknown if the other 29.2% of individuals were over the age of 65 at the time of diagnosis. It is significant to note that the majority of participants were diagnosed with osteoarthritis before the age of 65, as throughout literature the disease is often associated with an aging population. It is possible that the typical onset of osteoarthritis occurs earlier than commonly believed.

Aligning with literature, the most commonly affected joints among the participants were knees, hands, and hips. Exactly 75% of the participants received at least one biomedical test as part of their diagnosis, with most of the participants undergoing two or more diagnostic methods (See Figure 1). The three most common methods of diagnosis were X-ray (62.5%), self-reported symptoms (54.2%), and physical examination (54.2%). Only 20.8% of participants were provided with osteoarthritis prevention, either prior to initial diagnosis or to keep the diagnosed osteoarthritis from worsening. There was no correlation between diagnosis date and prevention recommendations, or between sex and prevention recommendations. Out of the participants who received recommendations, 80% involved personal responsibility through exercise.

Participants were asked to state the cause of their osteoarthritis as part of the survey (see Figure 2). The most common causes named were genetics (41.7%), age (29.2%), and joint trauma (29.2%). Five individuals listed weight as a reason for their osteoarthritis, but they all also included at least one other cause that was outside of their control (such as genetics or age). When stating the most common cause of osteoarthritis, the responses followed the same pattern. This will be examined in Section 2.8.

The most common form of recommended treatment was pharmaceuticals at 62.5%, followed by lifestyle changes (45.8%), physiotherapy (41.7%), and joint replacement surgery (41.7%) (see Figure 3). Michael[*] from the GTA stated that he felt “they were treating the symptoms not the cause”, and the statistics seem to suggest that that is often the case. As outlined in section 2.2, there is no cure for osteoarthritis, and the main function of the available medication is for pain relief. It is also surprising that less than half of the participants were recommended lifestyle changes, as it is listed throughout the literature as the first step to be taken (see section 2.2). ‘Lifestyle changes’ was the most commonly chosen treatment by participants (54.2%). Several participants decided themselves to undergo lifestyle changes without recommendation. Following lifestyle changes, participants most commonly chose physiotherapy and pharmaceuticals, which tied at 45.8% (See Figure 4). Several individuals stated that they decided not to take the prescribed medication, due to their dislike of taking pills. Only 16.7% of participants underwent joint replacement surgery and 8.3% of participants had joint preserving

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[*] All names have been changed

surgery, a significant difference from the 41.7% of participants recommended joint replacement surgery (no participants were recommended joint preserving surgery). Participants stated that they did not feel ready for surgery, with common themes of feeling too young for the procedure and the worry that the surgery will increase their symptoms.

Most participants (70.8%) stated that treatment options were only provided after complaints of symptoms, with 4.2% of participants never receiving treatment options. However, 58.3% of participants were provided treatment recommendations immediately post-diagnosis. This implies that many participants were only diagnosed after complaints of symptoms, rather than being screened for early-stage osteoarthritis. As described in section 2.2, osteoarthritis diagnosis does not require biomedical tests, and can occur through self-reported pain or physical examination, both of which could take place in a regular check-up. One potential reason for the lack of screening could be due to the average age of the participants diagnosed with osteoarthritis being much younger than stated in literature. Doctor-patient relationships are thoroughly studied within section 2.9.

Osteoarthritis affects the daily life of 75% of participants, with 4.2% of participants declining to answer. The most significant effects of osteoarthritis were stated to be limited mobility (37.5%) and pain (33.3%). Although only a third of participants directly mentioned pain, it is referenced or implied throughout all responses. This makes it difficult for the participants to exercise, and therefore difficult to prevent the osteoarthritis from worsening. The lived experience of osteoarthritis is examined more closely in section 2.10.

Participants frequently used negative word choices such as “breakdown”, “eating away”, and “fall apart” when describing their understanding of the disease. In literature, the word “breakdown” is often used in reference to the aging body. In the interviews, participants tended to use emotional language rather than accumulated knowledge. One participant, Lance from the GTA, explained that “in my mind I think of the bone as rotting, basically rotting. It’s softened up, basically decaying”. This is not physiologically accurate; osteoarthritis is a result of abnormal remodelling due to an imbalance of inflammatory mediators (Arden et. al. 2014, 39). Another participant, William, provided his understanding of osteoarthritis as: “It hurts, it eats away at things. That’s all I know. I don’t know very much about it”.

Figure 1: Method of Diagnosis for Participants in the GTA (multiple answers could be selected)

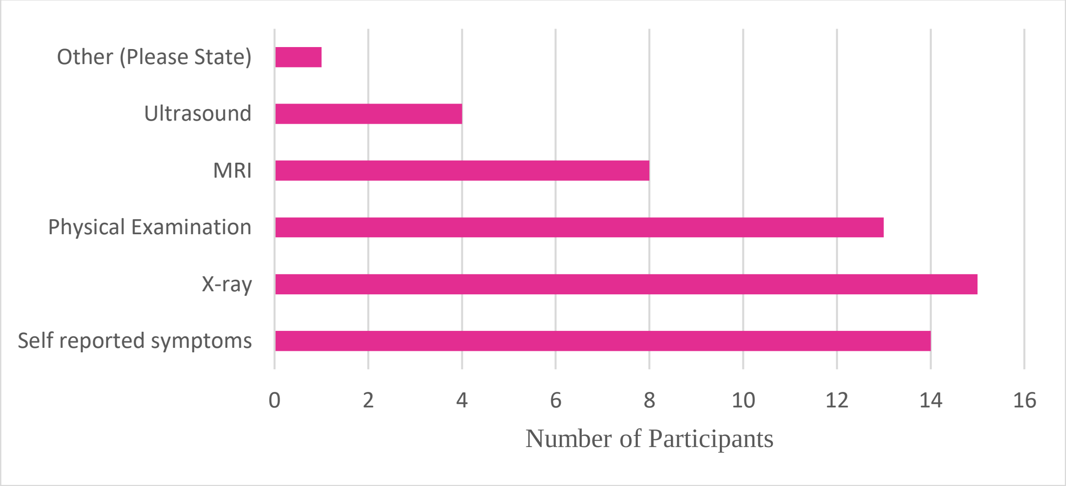


Figure 2: Cause of Osteoarthritis for Participants in the GTA (multiple answers could be selected)

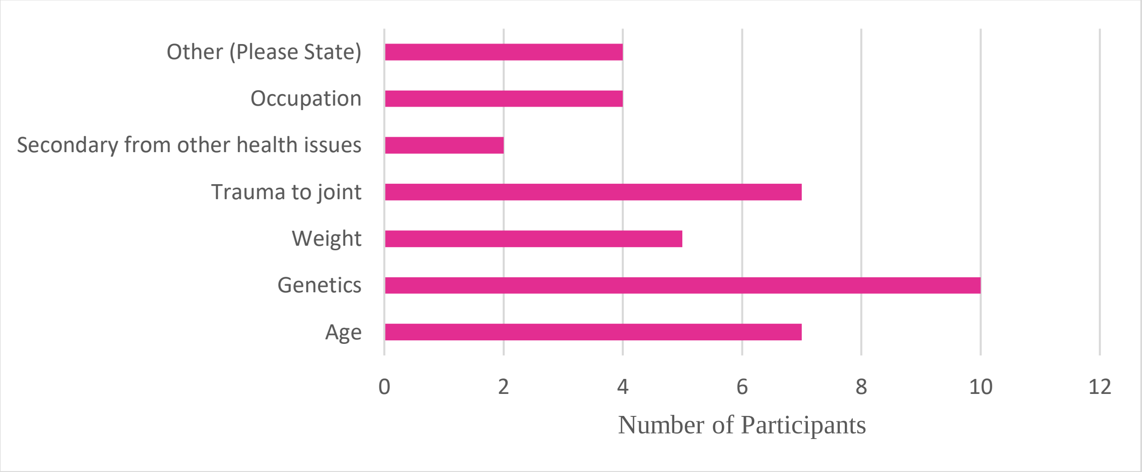


Figure 3: Recommended Methods of Treatment for Participants in the GTA (multiple answers could be selected)

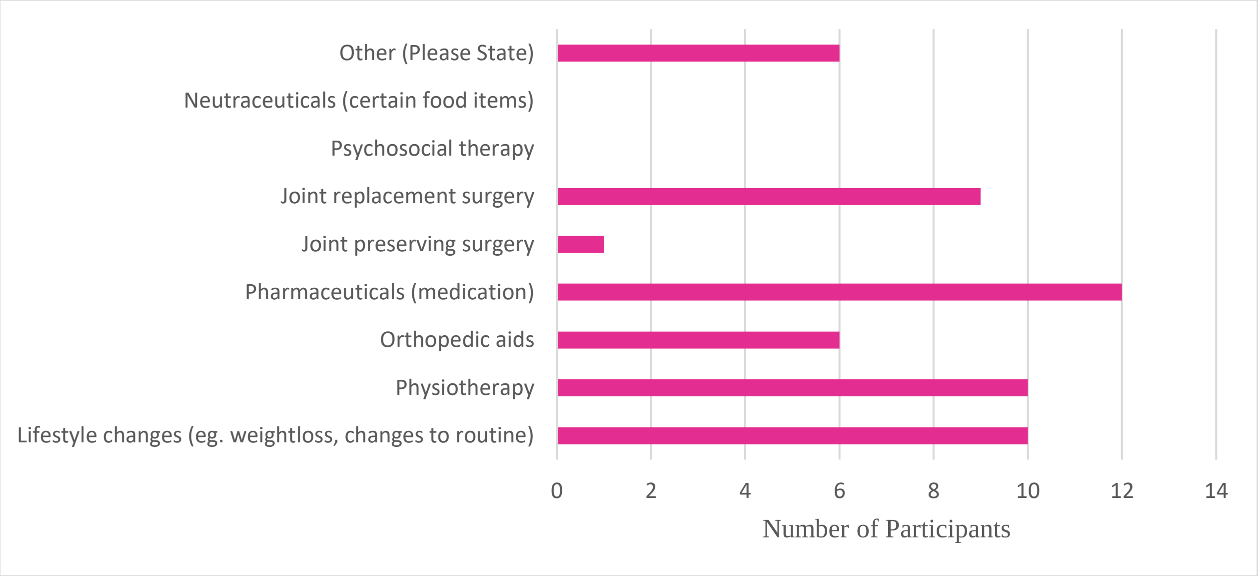
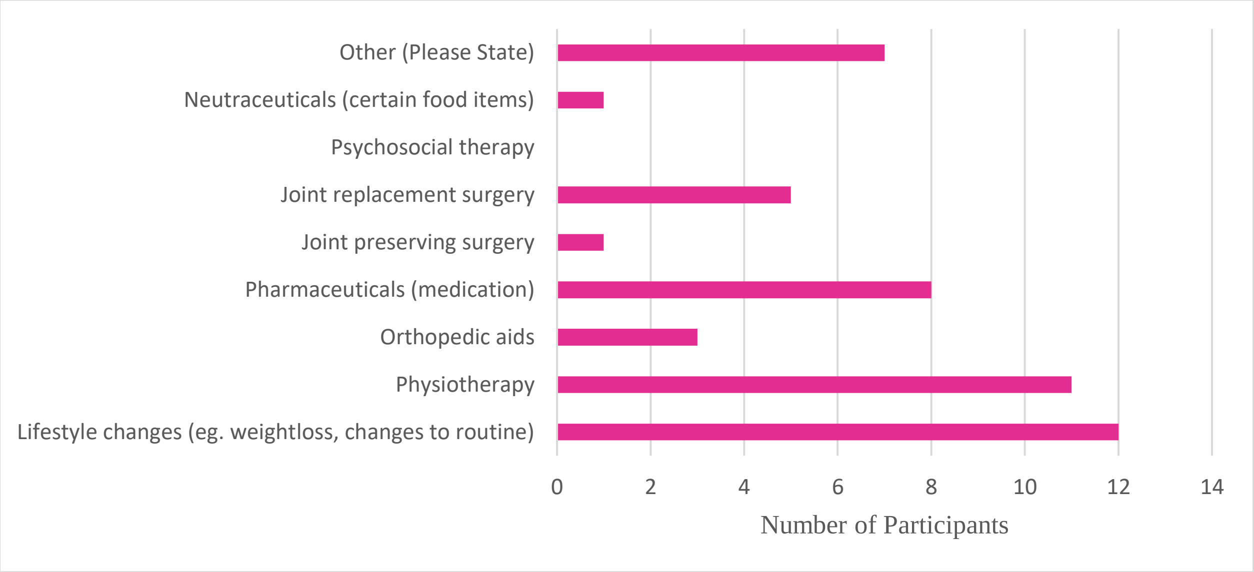


Figure 4: Chosen Methods of Treatment by Participants in the GTA (multiple answers could be selected)



2.7 – Responsibilization, Medicalization & Moralization

"In my own opinion, or assumptions I should say, it's the combination of genetics and other factors. But people who are genetically disposed to get it could bring it on more so with lifestyle. But in my case, it's just one of those things where you have the genes." – Lance, GTA

Medicalization is a process where aspects of daily living within a society are redefined as medical issues (Contino 2016, 46). This not only restricts what can be considered to be 'normal health', but also supports biological normalcy as it medically problematizes those who fall outside of the newly redefined 'norm'. Medicalized aspects of life can either be processes previously considered as 'normal', such as aging, based on aesthetics, such as physical deformities, or behaviours seen as socially deviant, such as excessive alcohol use (Zola 1976, 211). Rather than simply discussing their symptoms with their medical professional, patients have become required to disclose their habits, and stressors (Zola 1976, 210). Through the medical field's attempt to eliminate disease, risk factors have become medicalized as well. This raises the question of when an individual should be determined to need intervention (Contino 2016, 48). Participants reporting a lack of osteoarthritis prevention recommendations suggests the existence of an ethical debate. If these individuals had been given recommendations to prevent the development of the disease, it may have reduced their current pain or precluded the need for surgery. However, given the large number and variety of both extrinsic and intrinsic risk factors for osteoarthritis, a focus on preventing osteoarthritis could serve to medicalize the majority of the population. The consequences of this question can be dire: not all diagnostic procedures are risk-free, and there would be increased chance of over-diagnosis and over-treatment (Contino 2016, 48). For medicalization as a whole, the consequences extend even further. Zola considers the most powerful cost of medicalization and medical influence to be how individuals throughout the population internalize that they are in need of improvement (Zola 1976, 211).

Medicalization has expanded outside of medical systems into daily life through an emphasis on healthy living (Contino 2016, 46). This shifts the responsibility and control over health from the medical system onto the individuals themselves. In this frame, it is the individual's responsibility to avoid illness through methods such as eating well, exercising, and not smoking. This aligns societal patterns that moralize health, where health is equated with being both virtuous and socially acceptable (Rose 2001, 19). Rose (2001) calls these patterns of moralization 'responsibilization', whereby individuals' problems become reframed as moral and/or ethical problems (Rose 2000, 334). Health becomes an interaction between regulated autonomy, expertise, and the market. Regulated autonomy refers to individuals being incentivized or socialized to want to be healthy, expertise involves those who can provide guidance on how to become healthy; and the market is the setting through which individuals and experts interact (Rose 1990, 16).

As previously outlined in section 2.2, obesity is one of the leading causes of osteoarthritis. Bodies that fall outside of societal norms are often scrutinized due to an 'aesthetic' aspect to normative health whereby subjective bodily trends influence the perceived health of an individual (Jutel 2006, 2269). Weight loss by overweight individuals will often be praised and depicted as becoming healthier, even if the weight loss occurs through unhealthy means (Jutel 2006, 2269). The majority of participants in this research were recommended to either make lifestyle changes and/or begin physiotherapy, placing responsibility on the individuals to maintain their health. Several participants who were not recommended either of these treatment options decided themselves to use these methods, Michael from the GTA stated that it was his "idea to lose a bit of weight", as he felt as though he "should become healthier". Moralization of health has become normalized under the framework of 'healthy living' that medicalization has created. This is also discussed throughout *Against Health*, where the topic of health is described to be used as a method of casting moral judgements against those do not live according to our ideological positions (Metzl and Kirkland 2010).

Although weight has become moralized, obesity is not the only risk factor for osteoarthritis, and not all individuals with osteoarthritis are obese. Osteoarthritis as a whole does not seem to be moralized, unlike diseases such as HIV/AIDS and lung cancer, which places responsibility and blame on the individual for the development of the affliction (Callebaut 2016, 977). In chronic health conditions, individuals often try to explain the cause of their illness, and illnesses associated with lifestyle-based factors are those at highest likelihood for the individual to self-blame (Callebaut 2016, 966, 977).

In both the survey and the interviews, the participants were asked to describe the cause of their osteoarthritis, as well as the most common cause of osteoarthritis overall. The most commonly stated responses for the cause of their own osteoarthritis was genetics (41.7%), age (29.2%), and joint trauma (29.2%). These are all reasons outside of the participants' control. Five individuals did mention lifestyle and/or weight in their response, but never as the sole or main reason, instead favouring predetermined factors for which the individual cannot be held responsible. This does not mean to say that all, or any, of the participants caused their osteoarthritis through controllable factors, but that all of the participants distanced themselves from any responsibility for their condition.

When describing the most common cause of osteoarthritis, there was a much greater range in responses reported in the survey. Genetics was again the most commonly stated response at 25%. Besides one participant who solely stated that they did not know, the responses could be grouped into three main categories: biology, self-responsibility, and non-preventable. Within the biology category, participants stated the biological processes of inflammation and cartilage loss without providing their thoughts on what caused these processes to occur. In the self-responsibility category, reasons for other people's osteoarthritis included lifestyle, weight, and inactivity. Unlike when discussing their own condition, participants did not remove responsibility from the other individuals. The non-preventable category aligned with the responses regarding the participants' personal osteoarthritis, including genetics, aging, injury, and wear-and-tear. The self-responsibility category suggests that, as a whole, individuals do not perceive osteoarthritis as inevitable, just inevitable for themselves.

In the interviews, participants discussed the most common cause of osteoarthritis as based in the interrelationship of themselves and the world around them, often inserting themselves into their answer as seen in the quote at the beginning of this section. All individuals who mentioned lifestyle causes explicitly exempted themselves – only others are responsible for their osteoarthritis. This can be seen in a quote from Sarah in the GTA:

> "My instinct tells me that it's being overweight. Just because I see customers who are diagnosed with that and they don't have an orthopedic history and maybe that's why but I don't know. *laughs* That's me being judgy maybe, I don't know".

Sarah herself has osteoarthritis due to an orthopedic condition, bringing herself into her response. She considers orthopedic histories to be an exemption from blame; others who do not have orthopedic histories are considered more likely to be at fault for their osteoarthritis. However, there was a larger focus on the predetermined aspects of osteoarthritis. There was also a stronger focus on aging than seen in the survey responses. Participants discussed the inevitability of deterioration, describing the process of aging in terms such as “you’re starting to fall apart” and “our bodies just break down after awhile”. Osteoarthritis is depicted as a part of this deterioration which happens to us all throughout our lives.

Due to multiple narratives, there are dual strands of thought over whether osteoarthritis is moralized. Overall, the participants considered their osteoarthritis to be predetermined and outside of their control. This perspective mostly carried over when discussing the causation of osteoarthritis for other individuals. However, in discussing other individuals, participants allowed room for moralizing discourse regarding osteoarthritis. Although frameworks such as healthy living are depicted as empowering the individual through responsibility, this research suggests that individuals with osteoarthritis consider their condition to be unpreventable.

2.8 - Doctor-Patient Relationships

"It's not an issue of there not being the knowledge out there, it's about having access to the people who have that specialized knowledge" – Robert, GTA

A significant element of medical treatment is the relationship between the doctor and the patient. This relationship can actually affect the outcome of the treatment (Clarke et. al. 2013, 167). In early stages of rehabilitation or treatment, medical professionals can influence the expectations and beliefs of the individual (Redpath et. al. 2010, 802). This increases the likelihood of the individual experiencing and developing positive emotions and outlooks as related to the disease, which in turn reduces the probability of the individual developing depression or anxiety (Dibbelt et. al. 2009, 329; Redpath et. al. 2010, 802). A strong doctor-patient relationship can also improve the individual's coping skills as well as decrease pain and symptoms (Dibbelt et. al. 2009, 329). By increasing the exchange of information, the doctor is able to provide more personalized treatment tailored to the individual's needs and the patient gains a deeper understanding of what their options are and why they were prescribed. Strong doctor-patient relationships are often formed through the doctor listening to the patient and providing hope (Clarke et. al. 2013, 167).

Unfortunately, studies have shown that the areas of the medical system that individuals with chronic pain tend to consider the weakest are those relating to their relationships with their medical professionals (Dibbelt et. al. 2009, 328). Poor communication and unmet expectations are considered barriers to effective pain management by the patients (Paskins et. al. 2014, 8). Medical professionals often overestimate the amount of communicated information understood by the patient, and tend to consider a smaller percentage of the discussion to be medical jargon compared to patients' accounts (Dibbelt et. al. 2009, 330). These two factors go hand-in-hand, as it means that information is not being conveyed in language that the patient can understand. In studies, individuals have reported that when medical professionals fail to provide explanations effectively that it comes across as though the doctor does not have an interest or knowledge in the individual's condition (Paskins et. al. 2014, 7). A lack of effective communication combined with the typical long delays in receiving specialized treatment can cause patients to feel as though osteoarthritis is not a priority to their healthcare system (Paskins et. al. 2014, 1).

Doctor-patient interaction was a significant theme throughout the survey responses and the interviews. Precisely 62.5% of individuals felt as though their doctor took their symptoms seriously, with 8.3% declining to answer. The same percentage of individuals stated that their doctor explained what osteoarthritis was to them. This direct correlation highlights the importance of communication between the medical professional and the patient. Despite 62.5% of individuals having osteoarthritis explained to them, 79.2% selected their understanding to be between not well at all to moderately well (see figure 5). This shows that not only should there be a larger focus on patient education, but that medical professionals should open a dialogue to give patients the opportunity to ask questions and gain an understanding of their medical condition.

Patient comprehension may also be limited because specialized knowledge regarding osteoarthritis is not easily accessible. Robert from the GTA described his perception of this concept:

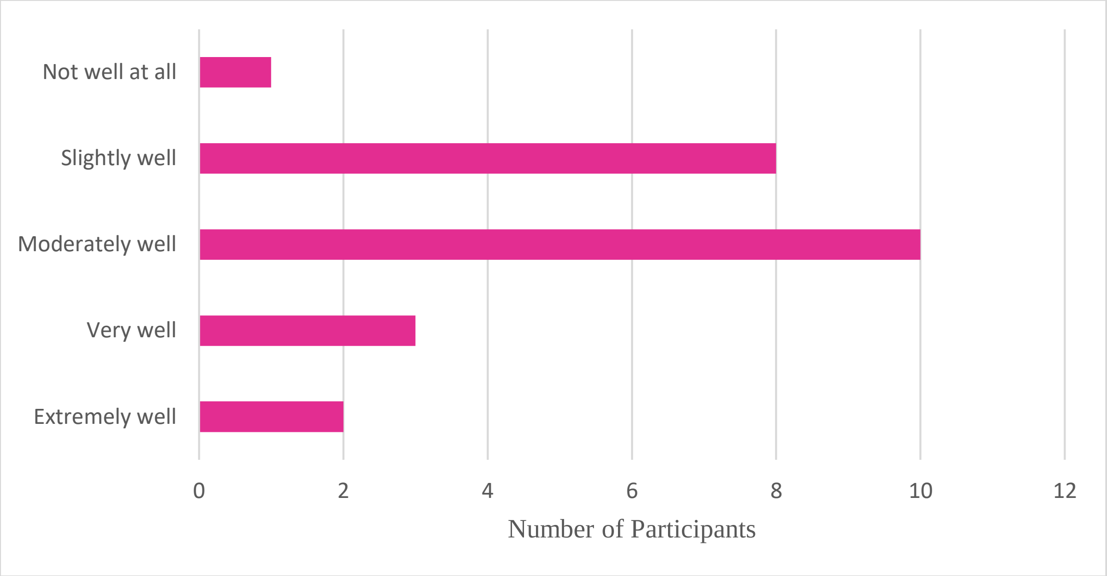
> "I don't think our GP's can deal with specialized things. You have to go to the next level, and it's difficult to get to the next level without the wait. So people go to their family doctors and get painkillers and that's it".

Long waits were mentioned repeatedly by participants throughout the interviews, as well as lack of recommendations to prevent their osteoarthritis from worsening. Overall, this led to many participants feeling as though their pain was not a priority. Lance from the GTA described how his interactions with his doctor around osteoarthritis were non-existent:

> “They confirmed that it is osteoarthritis but they never mentioned any pain medication, or any exercises, or any preventative measures. They just called to confirm that I have osteoarthritis in my hip. And that was the last time I spoke to my doctor about it. In subsequent physicals it never came up. Never”.

The theme of ‘waiting’ was not just centered around medical professionals, but around procedures as well. As prosthetics have a limited life-span, patients are often made to wait so that they do not have to undergo a second procedure to replace the prothesis, which can be traumatic for the individual. Robert from the GTA described the process as: “You could outlive your hips essentially if you lived long enough, so they stretched you out and it causes you to go through quite a painful experience while waiting for the optimal time”. Medical professionals are also not always able to correctly estimate when the patient is in need of surgery. In the case of William from the GTA, he described his experience with receiving surgery approval as: “The first doctor said I was too young. The second doctor then said I had to get both done. There was nothing left for them to fix, no cartilage at all, so they had to get fully replaced.”. In this case, age was considered to be a more significant factor compared to the state of the joint, meaning that the potential for joint-preserving surgery was lost. Strengthened relationships between doctor and patient through effective communication can significantly impact a patient’s treatment, and therefore, their life.

Figure 5: How Well Participants Understand Osteoarthritis in the GTA



2.9 – Lived Experiences of Symptoms

"… I don't really think about anything as osteoarthritis. I just think about it as pain."
– Sarah, GTA

A conceptual focus on "lived experience" treats the suffering individual as the expert; their authority is granted by their first-hand knowledge (Taylor 2001, 119). By centering the perspective of those directly affected, researchers are able to gain a deeper understanding of the issue, as well as uncover how assistance may best be received. In this section, the lived experience of individuals diagnosed with osteoarthritis is examined.

Numerous studies in medical anthropology have focused on illness in terms of definition and treatment across various cultural contexts; however, as recently as 2008, Good suggested the experience of living with illness has been largely ignored (Good 2008, 117). Previously, an experiential focus from the view of the sufferer was considered to be questionable due to its inability to be defined or assessed by the researcher (Morris 2013, 170). However, as the self is considered to be established in relation to the individual's world, Good argues in *Medicine, Rationality and Experience* that description of embodied experience provides access to the selves of the sufferers (Good 2008, 123). When studying the experience of illness, understanding the self of the sufferer is necessary as the body is often considered by the sufferer to be part of the self rather than merely a physiological state (Good 2008, 116). Good uses lived experiences of illness to demonstrate how serious health issues and other painful experiences can 'unmake' an individual's lifeworld (Good 2008, 118). Good utilises a single case study of an individual with chronic pain from Temporomandibular Joint Disorder (TMJ) to illustrate this point. The participant's narrative creates both meaning and symbolism, as well as situates the data (Good

2008, 118, 128). The participant’s lived experience of illness does not just highlight what TMJ feels likes, but how the experience of TMJ can alter an individual’s perceived world and sense of self (Good 2008, 131).

Chronic pain does not have a standard definition, but is often considered to be either any pain lasting longer than 3 or 6 months, or pain without a biomedical explanation (Morris 2013, 168). Traditionally, pain was considered by researchers to be a product of sensation; however, now it has been widely agreed upon that the process is complex and includes patient subjectivity regarding their experience (Jackson 2011, 374). Testing and understanding pain from a medical perspective is difficult, as there are no common standards or measurements (Good 2008, 125). Beyond the treatment implications, the lack of possible objectivity may have the effect of decreasing both the validity and legitimacy of the experience of chronic pain (Nichter 1995, 123). Thus, anthropological discussions of chronic pain reach beyond biomedicine to account for the numerous contexts outside of medicine in which pain is experienced (Jackson 2011, 371). One such example is Greenhalgh’s study on fibromyalgia, a musculoskeletal disorder that involves pain throughout the body and primarily afflicts women (Greenhalgh 2001, 8). Fibromyalgia is considered by Greenhalgh to be a new domain of power, and she politicizes both the disorder and women’s pain as a form of intervention for the resulting power dynamics between patient and medical provider (Greenhalgh 2001, 7, 8). In this example, scientific knowledge is considered to only be one of many truths regarding the body, and importance is placed on aspects such as selfhood, and gender norms (Greenhalgh 2001, 4, 7). While there is growing literature on chronic pain, there is a gap when focusing on the experience of osteoarthritis specifically. This study aims to fill that gap, while showing support for the aforementioned conceptual approaches by anthropologists such as Good and Greenhalgh regarding chronic pain.

Pain and loss were prominent themes that emerged throughout the data. Both of these themes are commonly seen in literature studying the experience of chronic medical conditions (Smith et. al. 2014, 445; Walker et. al. 2006, 201). Pain is the most commonly reported symptom of osteoarthritis, and its constant presence can have a significant effect on the individual's life (Smith et.al. 2014, 445). When pain is chronic, its symptoms can eventually become identical to those of both grief and depression; this is what often leads to a feeling of loss in the individual's life (Walker et. al. 2006, 201, 205). These symptoms can be emotional, such as feelings of anger and despair, social, such as difficulty maintaining relationships, or physical, such as insomnia and fatigue (Walker et. al. 2016, 205). These symptoms can be seen throughout the interviews by the participants. For example, Lance expressed sleep difficulties to be "the biggest impact of the arthritis" due to the pain he experiences when he lies down. He describes his experiences as:

> "The other things I could adjust for but sleeping I can't. Cause all my life I slept on my right side or on my stomach. I can't sleep on my stomach anymore, I can't sleep on my right side. I have to sleep either on my back or on my left side. Even on my left side it's sometimes painful. So, I typically sleep on my back all the time. And I find sleeping on my back I don't get as comfortable a sleep".

Chronic pain is described throughout literature as unpredictable (Crowe et. al. 2017, 1010, 1011; Froud et. al. 2014, 7; Toye et. al. 2013, 831). This is due to the inconsistency of pain intensity, meaning that the individuals who are suffering are unable to plan ahead due to the unpredictability of their limitations. The inconsistency of episodic chronic pain and its related limitations may create a sense of living in uncertainty (Walker et. al. 2006, 204). It can also lead to judgement and stigmatization from those who do not believe their symptoms (Froud et. al. 2014, 9). Withdrawing from activities due to the individual's limitations, or potential limitations, can damage relationships and lead to feelings of isolation (Biguet 2016, 1257; Froud et. al. 2014, 7; Toye et. al. 2013, 33; Walker et. al. 2006, 203;). Participants reported significant impacts to their daily lives through the loss of activities and the implementation of osteoarthritis-based limitations. All of the participants described their limitations in terms of "can'ts", with the strong majority listing the activities in which they can no longer partake. One participant named a modification required to continue her hobby of walking, taking routes with benches along it so that she can rest when needed. All of the other participants instead refrained from participating in activities that increased the likelihood of pain, rather than making any modifications to the activities or their lifestyles. Examples of 'lost' activities mentioned in the interviews included interests such as sports, biking, and playing musical instruments. These losses have seemingly become the norm for the participants, their limitations being held constant despite the potential fluctuation of pain. The limitations were portrayed as inherent and like second-nature to the participants, to the extent where the intensity of the pain no longer seems to dictate the limitations, but rather past experience. Lance from the GTA described his relationship with limitations as "I've gotten so used to it that I know what to avoid or when to limit myself. I know my limitations or I think I do". The normalization of limitations by the participants can be seen in this quote from Sarah from the GTA discussing how her daily life has been affected by osteoarthritis:

> "So on bad days sure it really affects all of my daily activities, but then on days where I don't feel it… *pause* I guess it does affect me daily in that there are some limitations, things I simply can't or won't do".

These quotations suggest that participants normalize their limitations, incorporating them into new patterns of everyday life. In this way, individuals seemingly do not test to see if their abilities have grown or expanded and progression is no longer an aim. Rather, it seems that the focus is instead directed towards minimizing pain.

The concept of stigmatization was not mentioned by participants in either the survey or interviews, nor was osteoarthritis considered to be stigmatized throughout literature. However, this does not mean that individuals with osteoarthritis are always free from stigma. As discussed in section 2.2, and by the participants themselves, mobility loss is a main symptom of osteoarthritis. Mobility loss is a medical issue that can be stigmatized, as often seen in wheelchair users (Cahill and Eggleston 1995, 681). Wheelchair users are commonly subjected to intrusive stares by strangers, as well as non-person treatment (Cahill and Eggleston 1995, 684-685). Non-person treatment, such as talking as though the individual is not present, intensifies when the individual is with a walking companion, as the companion is often assumed to be a caretaker (Cahill and Eggleston 1995, 685). This form of stigmatization centers around the idea that loss of mobile agency extends to other aspects of the individual’s life.

Focusing on lived experience highlights that, despite their biological origins, the chronic pain of osteoarthritis has social and psychological effects. The use of psychosocial treatment, such as therapy and support groups, can be applied to lessen these effects through strategies such as developing pain management techniques (Crowe et. al, 2017, 1005). None of the individuals in this study were recommended to pursue, nor did they pursue, psychosocial treatment. If medical professionals were trained to take individualised lived experiences into consideration, perhaps even comparably to the biological side of health, they would have an increased understanding of their patients’ individual struggles. This could allow for more personalized and appropriate treatment to be recommended.

2.10 – South Yorkshire

Osteoarthritis is the most common cause of physical disability in the United Kingdom, making the region an important population of study (NCCCC 2008, 6). As of 2008, approximately 8.5 million adults in the United Kingdom have been diagnosed with osteoarthritis (Neogi 2013, 1145). Out of this 8.5 million, approximately 2 million individuals consult with their doctors about their symptoms of osteoarthritis each year (Arthritis: The Big Picture 2002, 5). As previously mentioned, the prevalence of osteoarthritis has been increasing on a global scale, primarily due to aging populations and increased obesity (Arthritis: The Big Picture 2002, 5; Hunter et al. 2014, 437; Neogi 2013, 1145; Woolf & Pfleger 2003, 654). This is true for the United Kingdom in particular, as the region has one of the highest prevalences of obesity in the world (Arthritis: The Big Picture 2002, 5). These statistics are most likely an understatement of the burden of osteoarthritis in the United Kingdom, as approximately 6 million individuals who believe they have osteoarthritis have never discussed their condition with a medical practitioner, which was close to the number of people diagnosed with osteoarthritis at the time of the study (Arthritis: The Big Picture 2002, 4).

The economic burden of osteoarthritis seen in the United Kingdom is significant. Throughout the 1990's, approximately 70,000 total joint replacement surgeries were performed in English hospitals each year (Sanders et al. 2003, 353). In the United Kingdom in the year 1999, the cost of total joint replacement surgery was 405 million pounds, or almost 690 million Canadian dollars (Arthritis: The Big Picture 2002, 5). That same year, the cost of lost productivity was 18 billion pounds due to 206 million working days lost to arthritis-related complications throughout the United Kingdom. Musculoskeletal conditions ranked as the 2nd most common cause of lost work days for adults in the United Kingdom (Arthritis: The Big

Picture 2002, 4). In 2001, 2.4 billion pounds were given to individuals in the United Kingdom for incapacity benefit for arthritis and related conditions, as well as 98 million pounds due to severe disablement. The cost of social services care for osteoarthritis was 215 million pounds (Arthritis: The Big Picture 2002, 15). As the prevalence of osteoarthritis increases, it can only be expected that the associated costs will follow.

There were 8 research participants from South Yorkshire seven of whom were female (87.5%). The median age for male, female, and overall were 70-79 years. 25% of participants were diagnosed under the age of 65 years, 37.5% were diagnosed over the age of 65 years, and for 37.5% it is unknown whether they were senior citizens or not at the time of diagnosis. This is an older age of diagnosis compared to participants from the GTA. This could be due to chance from the limited number of participants, osteoarthritis having a stronger association with age in South Yorkshire and not being checked for in younger patients, or lower exposure to osteoarthritic risks resulting in individuals developing osteoarthritis at an older age.

The most commonly affected joints were knees, hips, and hands, which aligns with both literature and the GTA participants. As with the GTA participants, X-ray was the most common form of diagnosis, closely followed by self-reported symptoms (See Figure 6). 50% of participants received recommendations for osteoarthritis prevention, which works out to be almost the same number of participants who received recommendations as in the GTA. Three of the four individuals were recommended lifestyle changes, and three of the four individuals were recommended pharmaceuticals. There was a much stronger push for osteoarthritis medications by South Yorkshire medical professionals than was exhibited in the Canadian sample from the GTA.

This emphasis on pharmaceuticals was also depicted through the treatment recommendations to the South Yorkshire participants (See Figure 7). Every participant was recommended to use medications for their symptoms, a much higher percentage than seen in the GTA. This could possibly be due to the difference in healthcare coverage for pharmaceuticals. In the United Kingdom, prescriptions have a fixed cost of 9 GBP, approximately $15 CAD, regardless of the type or quantity of medication ("Health Insurance…"). Canada does not have a national pharmacare plan, meaning that drug coverage varies between Canadians and is often through a mix of both public and private insurance plans, with some Canadians receiving no coverage at all ("Prescription Drug…"). This should be studied further. Pharmaceuticals were also the most chosen treatment, selected by 62.5% of the South Yorkshire participants. The participants who decided against pharmaceuticals did so due to their dislike of taking medication/pills more broadly. The second most commonly recommended treatment was lifestyle changes (50%). All individuals recommended to make lifestyle changes chose to do so (See Figure 8). Three individuals (37.5%) were recommended to undergo joint replacement surgery, yet two of the individuals decided against it. This was due to not feeling ready for surgery and the fear of becoming worse-off – responses that were also seen in the GTA participants.

The most commonly stated cause of osteoarthritis in the participants was age (50%), followed by joint trauma (37.5%) and weight (25%) (See Figure 9). No individuals stated genetics, which was the most common response from the GTA participants. Aging was also stated to be the most common cause of osteoarthritis as a whole by 50% of the participants, followed by genetics and 'don't know' at 25%. There is a much stronger association between aging and osteoarthritis in South Yorkshire participants than in the GTA participants. If this extends to medical personnel, it gives evidence that the older diagnosed age of participants for the South Yorkshire participants is potentially due to this association. None of the individuals stated weight or lifestyle to be the most common cause of osteoarthritis, aligning with the GTA participants. As described in section 2. 8, these responses depict a strong sense of inevitability or lack of control when it comes to the development of osteoarthritis.

Exactly 87.5% of participants said that osteoarthritis impacts their daily life, which is slightly higher than those in the GTA. Half of the participants outright stated pain to be the most significant effect, although as with the GTA participants, all responses contained references and implications of pain. Other responses included loss of activities and limited mobility, which also aligned with the GTA sample. There were two new categories of effects that were not stated in the GTA participants: loss of balance, and mental health issues. One woman from South Yorkshire described her daily life as “the pain is constant and depressing”. The lack of mention of mental health in GTA participants is noteworthy, particularly since the number of participants in the region is three times that of the number of South Yorkshire participants. One reason for this could be that mental health is more supported, or less stigmatized, in the GTA. Another possibility is that individuals in the GTA are less willing to speak about their mental health than those in South Yorkshire.

Precisely 37.5% of South Yorkshire participants had osteoarthritis explained to them by their doctor, which is significantly lower than the GTA participants (62.5%). Despite this, the levels of understanding for osteoarthritis were reported to be roughly on par between the two regions, which was medium-low confidence in their knowledge. However, 87.5% of participants in South Yorkshire believed that their doctor took their osteoarthritis seriously, a much higher percentage than in the GTA (62.5%). It is not known why this is the case, as literature explains doctor-patient relationships to be highly reliant on education and the passage of information (see section 2.7).

Overall, South Yorkshire participants had a much stronger association between osteoarthritis and aging compared to their GTA counterparts. There was also a much stronger focus by medical professionals on the use of pharmaceuticals. These respective regions of study show considerable distance between their understandings of osteoarthritis, a disease comparably understood well scientifically. Biomedical knowledge common in the GTA region was different than in South Yorkshire, despite the fact that they were being treated and handled in broadly the same way. In groups otherwise sociologically similar, this relevant disparity reveals an opportunity for further research into the dispersals of medical knowledge in similar populations. A larger comparative study could possibly shine light into the reasonings and social norms that underlie these differences.

Figure 6: Method of Diagnosis for Participants in South Yorkshire (multiple answers could be selected)[†]

[†] The participant who chose "Other" wrote "blood tests"

Figure 7: Treatment Recommended for Participants in South Yorkshire (multiple answer could be selected)[‡]

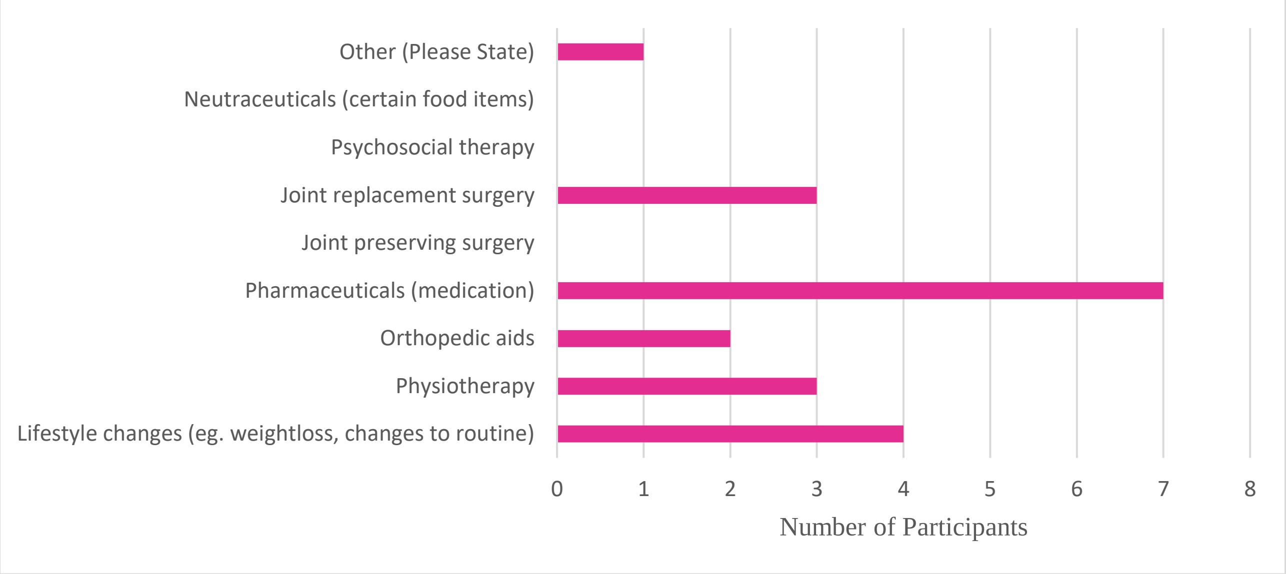
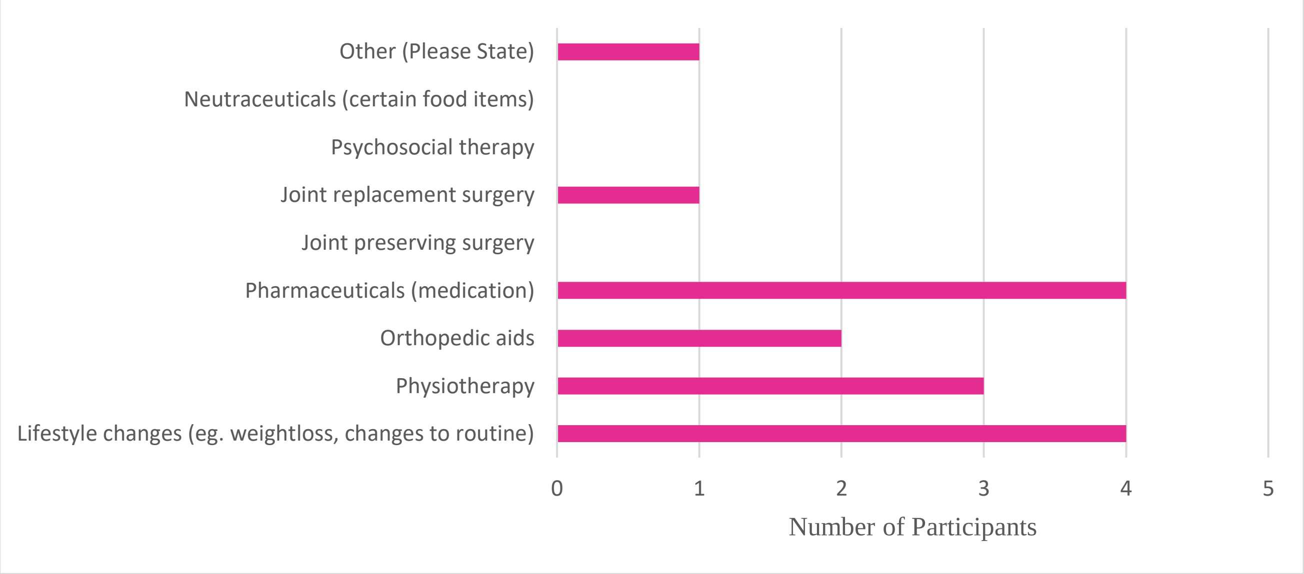


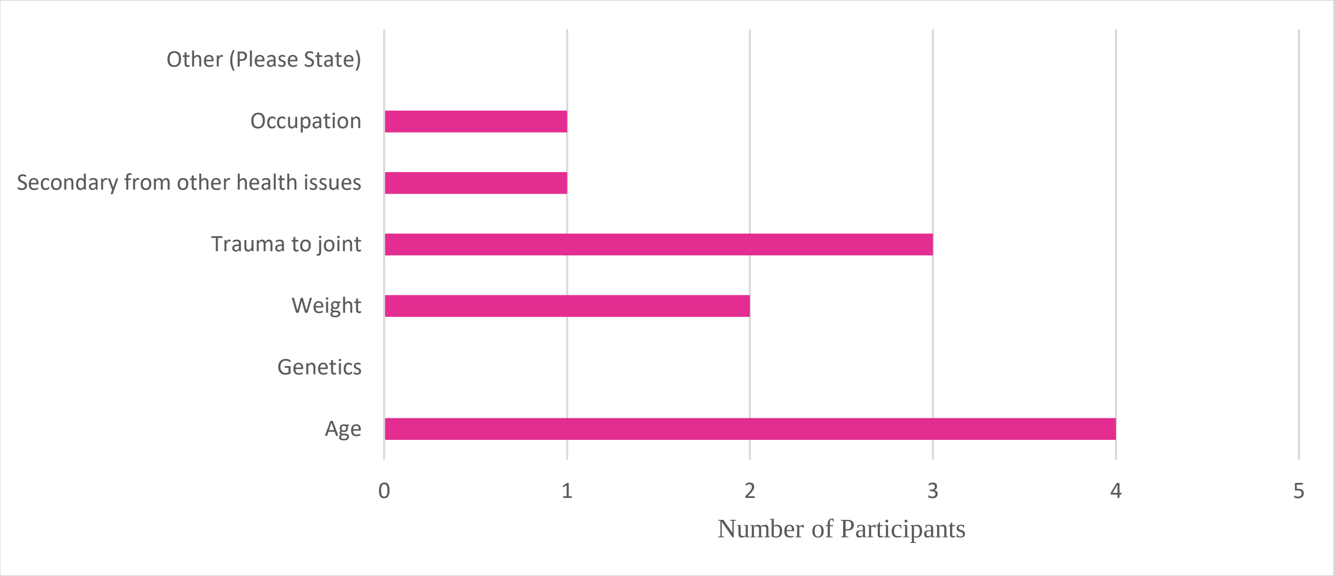
Figure 8: Treatment Chosen by Participants in South Yorkshire (multiple answers could be selected)[§]



[‡] The participant who chose "Other" wrote in "Tablets", which was counted under pharmaceuticals

[§] The participant who chose "Other" wrote in "Glucosamine", which was counted under pharmaceuticals

Figure 9: Cause of Osteoarthritis for Participants in South Yorkshire (multiple answers could be selected)



2.11 – Conclusion

This research examines the experiences of individuals with osteoarthritis in the GTA region, Canada, and South Yorkshire, England. The three main themes that emerged from the data were responsibility of illness, doctor-patient relationships, and the lived experience of osteoarthritis symptoms. The social forces observed led to individuals with osteoarthritis as seeing themselves with excess limitations in their daily lives, having no other choice than to abandon enjoyed activities due to their condition. This paper concluded with a comparison between the GTA sample and a sample of individuals from South Yorkshire, England.

The theme ‘responsibility of illness’ explored how, in general, individuals with osteoarthritis in this study prefer to consider the disease to be predetermined and inevitable, particularly in their own cases. Participants identified genetics and aging, in particular, as explanations for the cause of osteoarthritis.

The theme ‘doctor-patient relationships’ focuses on how these interactions shape not only the patient’s perspective of the medical system, but their treatment outcomes as well. Participants emphasized how detrimental and impactful the aspect of ‘waiting’ was on their health, whether in terms of receiving access to medical professionals, or receiving treatment. A strong correlation was also found between the participants’ perceived amount of information received from their doctor and how seriously they felt their doctor took their symptoms, highlighting the importance of information exchange for a strong doctor-patient relationship.

An attention to ‘lived experience’ attends to the ways in which participants are affected by pain and loss in their daily lives from osteoarthritis. Participants describe new limitations based on their past experiences with pain, rather than its current intensity. The majority of participants quit activities they used to enjoy but could no longer partake in, rather than making modifications.

This research was initially meant to be a cross-comparative study between the GTA, Canada, and South Yorkshire, England. However, complications as a result of the Covid-19 pandemic prevented the initial comparative study from proceeding as planned. The pandemic caused many potential participants to not have internet access, particularly in South Yorkshire, severely limiting the sample. Home internet is not common in the area, so individuals obtain internet access provided through public spaces such as pubs, cafes, and libraries; these spaces were closed by local governments for public safety. As a result, responses were limited in the region; still, a collection of South Yorkshire participants are compared in brief to the larger GTA group. In the South Yorkshire sample, participants relayed recommendations from their medical professionals towards pharmaceuticals to a much higher degree than that in the GTA. The South Yorkshire participants also conveyed opinions suggesting the inevitability of osteoarthritis, however, rather than genetics there was a much stronger association between the disease and aging. Further research into societal norms and perceptions would be useful to investigate why there is such a strong divide between genetics and aging between the two regions.

Osteoarthritis afflicts millions in the world but remains imperfectly addressed by medical professionals and social communities alike. While scientific investigation and pharmaceutical remedies will continue to address symptoms, further research is also required into the communication between medical professionals and patients. The gap between meaning and understanding is evidently broad; work is needed to further translate medical terminology into actionable lay speak, else patients may continue to potentially misattribute the causes of their health problems. This is the greatest identified problem among the social forces that govern how patients in this study manage their health. If medical professionals diagnosing the condition fail to take individualised lived experiences into consideration, they will continue to solve only one half of the problem. Millions live with osteoarthritis, and have the chance to do so with less pain and with more joy if they can be properly understood.

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Appendix A (Background of Osteoarthritis in Medical Literature)

Osteoarthritis affects millions of individuals as the most common joint disease affecting adults globally, and the most common form of disability in the Western world (Clarke et. al. 2013, 163; Michael et. al. 2010, 152; Nuovo 2007, 314; Reid and Miller 2008, 5). Osteoarthritis is also the most commonly cited reason for both hip and knee replacements, afflicting approximately 80% of patients having the procedure (Nuovo 2007, 314). There are no systemic indications of osteoarthritis, its progression does not extend beyond the joint (Nuovo 2007, 320). All synovial joints are at risk of developing osteoarthritis; however, the most commonly affected joints are those in the knees, hips, and hands (NCCCC 2008, 3). Osteoarthritis is due to abnormal remodelling of a bone and its surrounding articular cartilage (Arden et. al. 2014, 39). Bone remodelling occurs to keep the bone healthy, and uses catabolic and anabolic mechanisms. When there is an imbalance of these processes resulting in an overall catabolic reaction, the articular cartilage is degraded faster than it is rebuilt (Castrogiovanni et.al. 2016, 1-2; Michael et. al. 2010, 153). Osteoarthritis is considered to be an organ disease due to its effect on the joint as a whole. Alongside the loss of articular cartilage, subchondral bone sclerosis, osteophytes at the joint margin, and synovial inflammation can also often be seen (Arden et. al. 2014, 38; NCCCC 2008, 3). The cartilage that remains is thinned, roughened, inflamed, and riddled with cracks, and fissures (Castrogiovanni et.al. 2016, 2; Nuovo 2007, 316). Osteophytes are spurs of bone tissue that are covered with cartilage. They can cause the individual pain when rubbed against tendons or bone, but also assist in stabilizing the joint (Arden et. al. 2014, 45).

Unlike many other diseases, osteoarthritis does not have a definitive cause. Instead, there is a wide array of both endogenous and exogenous risk factors that increase the likelihood of developing the disease. The former group includes age, sex, and heredity (Loeser 2011, 492;

Michael et. al. 2010, 153; NCCCC 2008, 3; Neogi and Zhang 2011, 186; Nuovo 2007, 324). Age is considered to be one of the strongest risk factors, and highly interacts with sex as post-menopausal women are the most likely population to develop osteoarthritis (Arden et. al. 2014, 28; Castrogiovanni et.al. 2016, 1; Nuovo 2007, 314). However, it should be noted that the reason that the prevalence of osteoarthritis increases with age is because the condition is irreversible (Reid and Miller 2008, 5). There is no proven systemic predisposition to osteoarthritis, but rather site-specific influence has been seen. This is theorized to be due to inherited joint shape which affects the ability of the joint to handle stress (Felson 2013,12). Studies have also shown that multiple genes are likely to influence predisposition to osteoarthritis (Arden et. al. 2014, 29). Exogenous risk factors, on the other hand, include elements such as joint trauma, repetitive joint microtrauma, obesity, and lifestyle (Lemintowski and Zelicof 2008, 148; Michael et. al. 2010, 153; NCCCC 2008, 3; Nuovo 2007, 314). Obese individuals are nearly three times as likely to develop knee osteoarthritis compared to individuals with 'normal' body mass indexes (BMI) (Neogi and Zhang 2011, 186). It must be noted that these BMI classifications are American standards; that they are assumed to be applicable globally is an influence of biological normalcy. One's occupation can have a large effect on the development of osteoarthritis; miners, for example, have high rates of osteoarthritis in their knees and spines, while jackhammer operators are at increased risk of developing osteoarthritis in their elbows and wrists (Felson 2013, 12). Common occupational activities such as repeated lifting and kneeling can increase the risk of knee osteoarthritis (Nuovo 2007, 315). Injury is an exogenous risk factor that commonly occurs through high-intensity sports. Approximately 25% of individuals with knee osteoarthritis have at one point torn their anterior cruciate ligament (ACL), due to lowered joint stability and increased compressive stress across the joint (Arden et. al. 2014, 46; Felson 2013, 11). Osteoarthritis can also be secondary, meaning that other diseases and disorders can cause osteoarthritis to develop (Michael et. al. 2010, 153). The average number of comorbid chronic diseases for individuals with osteoarthritis is 8.7, with the most common being obesity, hypertension, and high cholesterol (Arden et. al. 2014, 33).

The main symptom of osteoarthritis is persistent pain in the affected joint (Arden et. al. 2014, 55; Michael et. al. 2010, 154; NCCCC 2008, 6). In early stages of the disease the pain is typically intermittent, and occurs when the joint is in motion. As the osteoarthritis progresses, the pain is likely to become fairly constant (Arden et. al. 2014, 55; Michael et. al. 2010, 154; NCCCC 2008, 6). As chronic pain can affect numerous areas of an individual's life, such as sleep and mobility, individuals with osteoarthritis are medically considered to have a significantly poorer quality of life compared to those without osteoarthritis (Arden et. al. 2014, 58). Alongside pain, the progression of osteoarthritis has deteriorating effects on the function of the joint. As the osteoarthritis progresses, the joint is likely to stiffen which decreases its range of motion (Michael et. al. 2010, 154-155). This means that the individual will lose mobility, which can have significant effects in their daily life, especially if the affected joint is weight-bearing. Without the ability to use the joint, the surrounding periarticular muscles will weaken, which causes the joint to decrease in stability (Nuovo 2007, 316). Individuals with osteoarthritis also have higher mortality rates from cardiovascular disease and gastrointestinal-related causes, the former likely due to the often-decreased ability to participate in physical activity (Arden et. al. 2014, 58). However, these relationships could be correlative rather than causal.

Although there are no guaranteed methods to prevent osteoarthritis, there are primary and secondary interventions individuals can take to lower their risk. Primary prevention stops a disease from initial development, while secondary prevention slows or ends the progression of disease (Nuovo 2007, 315). The strategies for the prevention of osteoarthritis are all lifestyle-based, meaning that they require regular effort over the course of the individual's lifetime. These include regular exercise and fitness to improve joint stability, avoiding intense competitive sports, using proper joint alignment during movements, and avoiding repetitive occupational strain on the joints (Nuovo 2007, 315; Nyland et. al. 2015, 4-5). These may not always be possible for an individual; for instance, some occupations require repetitive strain, and some individuals may have other health conditions that limit their ability to exercise. As osteoarthritis also has non-modifiable risk factors such as age, gender, and genetics, it is impossible to completely eliminate the chance of developing the disease (Nuovo 2007, 314-315).

There are various methods through which osteoarthritis can be diagnosed. Patients can be diagnosed through self-reported tests, physical diagnosis, or radiographic diagnosis. The two most commonly used standardized self-reported tests are The Western Ontario and McMaster Osteoarthritis Index (WOMAC), and the Health Assessment Questionnaire (HAQ) (Nuovo 2007, 317). A key feature of self-reported diagnosis is that they tend to focus on the individual's pain (Clarke et. al. 2013, 168). Physical diagnoses can vary depending on the medical practitioner, and can include joint inspection, range of motion tests, checking for tenderness or pain through palpitation, examining standing and walking abilities, and specialized tests such as ligament stability and gait analysis (Arden et. al. 2014, 60; Michael et. al. 2010, 154-155; Nuovo 2007, 317). Other periarticular sources of pain such as bursitis and trigger finger are often checked for simultaneously (NCCCC 2008, 32). These methods have their limitations; the disease may be radiographically present in an individual without any reported symptoms (Neogi and Zhang 2011, 186-188). X-ray studies are the most common radiographic form used for diagnosing and monitoring the progression of osteoarthritis (Michael et. al. 2010, 155). In 1957, Kellgren and

Lawrence developed a classification system for osteoarthritis that is still in use today. It divides the disease into five stages ranging from not-present to severe, and notes degrees of change on four grades which range from no change (‘normal’) to severe change (Arden et. al. 2014, 22-23). Magnetic Resonance Imaging (MRI) is also commonly used in diagnosis, as its ability to examine cartilage health allows medical practitioners to evaluate the joint as a complete organ (Arden et. al. 2014, 72; Wright and Goldring 2012, 81).

As there is currently no cure for osteoarthritis, the goal of treatment is to lessen the symptoms of the disease, slow its progression, and improve the individual’s overall quality of life (Michael et. al. 2010, 165-156). There is a large range of available treatments, and factors such as level of pain, level of disability, comorbidities, and clinical severity should be taken into consideration when deciding which options to pursue (Nuovo 2007, 316; Reid and Miller 2008, 7). It is generally recommended that non-pharmalogical treatment is prescribed first, with pharmacological methods and surgery available for more advanced cases (Arden et. al. 2014, 83). Patient education and information sharing is considered to be the most important aspect to treatment and the very first step. Beginning an ongoing dialogue between patient and healthcare provider not only provides clarity on the direction of the treatment plan, but provides the patient with realistic expectations (Michael et. al. 2010, 160; NCCCC 2008, 46; Wright and Goldring 2012, 81). Patient education aligns with psychosocial treatment, which supports self-management of osteoarthritis through the development of coping skills, resilience skills, and self-care (Nuovo 2007, 315; Nyland et. al. 2015, 4-6). A change in lifestyle, such as weight loss if needed, and eliminating excessive stress on the joints, is often the initial method of treatment (Michael et. al. 2010, 156). Orthopedic aids and other assistive devices such as shoe cushions, canes, and braces can alleviate symptoms and are a non-invasive treatment (Michael et. al. 2010, 157; Nuovo 2007, 323). Physiotherapy, including exercise therapy and massage, is beneficial for improving range of motion, increasing strength, and increasing function of the joint, which can significantly improve the quality of life (Arden et. al. 2014, 85; Michael et. al. 2010, 157; Nuovo 2007, 321-322). Pharmacological treatments for osteoarthritis are extremely common, and there are many options available. For many individuals with mild pain, acetaminophen can provide symptom relief. Acetaminophen can be used in combinations with other medications, and is both inexpensive and readily available which makes it an ideal treatment if possible (Nuovo 2007, 318; Reid and Miller 2008, 8). Another readily available medication is glucosamine; however, its results vary significantly in studies (Nuovo 2007, 320). When affected by severe osteoarthritis, patients are often prescribed Nonsteroidal Anti-Inflammatory Drugs (NSAIDs), which are the most commonly used type of drug for treating osteoarthritis around the world (Breedveld 2004, 6; Reid and Miller 2008, 8). The primary function of NSAIDs are not pain relief, but rather to suppress inflammation (Nuovo 2007, 317-318). NSAIDs, despite their popularity, are not ideal for a variety of individuals due to their extreme renal side effects. As of the year 2000, gastro-intestinal issues from NSAID use was the fourth most common medical cause of death in the U.S. (Breedveld 2004, 6). Overall, pharmalogical treatment should be used in addition to other forms of treatment rather than as a sole measure (Reid and Miller 2008, 7). Surgeries, the final option if the above treatments are unsuccessful, can either be joint-preserving or joint-replacement, and the latter should only be considered after the failure of the former (Michael et. al. 2010, 156, 159). There are a wide range of joint-preserving surgeries available, including shaving off damaged cartilage, removing inflammatory mediators (lavage), and stimulating the bone to bring stem cells to the joint surface (Michael et. al. 2010, 159-160). If a joint needs replacement, there are various options available as well. When the entire joint does not need replacement, a surface replacement (hip) or arthroscopic osteotomy (knee) can be performed instead to replace a portion of the joint (Nyland et. al. 2015, 3; Reid and Miller 2008, 11). Otherwise, the individual would undergo a total joint replacement. A difficulty of joint replacement, partial or total, is that prostheses have a life expectancy of approximately 15-20 years (Reid and Miller 2008, 12). This means that individuals can outlive their replaced joints, and will then need to undergo additional round(s) of surgery in order to maintain mobility.

Appendix B (Methodology)

This study includes a cross-comparative component with participants located in two regions: The Greater Toronto Region (GTA) in Canada, and South Yorkshire in England. The main method of recruitment was through snowball sampling. Snowball sampling is where potential participants are recruited through recommendations by previously recruited participants; the sample pool grows much like a snowball rolling down a hill, hence its name (Sedgwick 2013, 1). Snowball sampling is typically used in order to access hard-to-reach populations, often due to disempowerment or vulnerability (Baltar and Brunet 2012, 61; Sedgwick 2013, 1). In this research, snowball sampling was used as a means of accessing the South Yorkshire population. Snowball sampling was also used due to the study being limited in time and funds, as it is both cost and time effective in its application due to the lack of incentives needed and the willingness of the potential participants. The flyer and link to the online survey were distributed to family members and friends in both regions to start the sampling chain, where it was henceforth spread. Social media, in particular the sites Facebook and Nextdoor, was also used to recruit participants. However, it also should be noted that snowball sampling has the disadvantage of selection bias (Baltar and Brunet 2012, 61). This means that the recruitment of participants for this study was not completely randomized, as it was heavily influenced by the researcher's social network.

The online survey was conducted through Qualtrics and was estimated to take approximately 10 minutes of the participant's time. It was composed of 26 questions, including the obtention of consent and three screening questions. The screening questions confirmed that the participant was at least 18 years of age, resided in either the GTA or South Yorkshire (and differentiated which for analysis purposes), and had been formally diagnosed with osteoarthritis.

Besides the consent and screening questions, participants had the option to leave any question unanswered for their comfort. Participants also had the option of entering a personal code which had two purposes: the first being to link the data between the survey and the interview when applicable, and the second for if the participant wanted their data to be removed from the study. Questions within the survey were a mix of demographical, medical, and experiential. Demographical questions included personal information such as sex, age range, and which of the two populations the participant resides in. The medical questions requested information such as which of their joints are affected by osteoarthritis, how their osteoarthritis was diagnosed, and which treatments they were prescribed by their medical practitioner. The experiential questions asked participants how osteoarthritis affected their daily life, their perception of what osteoarthritis is, and how seriously they felt their osteoarthritis was taken by their medical practitioner. All data collected then underwent thematic analysis through Qualtrics to determine the various outcomes of the survey.

Participants were recruited for the interview portion of my research in the same manner as the survey, with the option of an interview stated on the distributed flyer. At the end of the survey, participants were provided the option of contacting me through email to arrange an interview. By having participants reach out to me for an interview, those who did not wish to participate in an interview could keep their identities concealed. This also prevented participants from feeling pressured into partaking in an interview. Participants had the option of being interviewed though the mediums of email, video-chatting, or through the phone. All identifying information was kept confidential; all data, both collected and transcribed, was anonymized and stored in encrypted files. The interview questions were a mix of questions that were either similar or the same as those on the survey, but with the intent of gaining experiential knowledge from the participant. The questions gave the participant the opportunity to elaborate and describe their experiences of both living with osteoarthritis, and interacting with medical professionals for their condition. Responses to interview questions were transcribed verbatim and cleaned-up for readability. The data was then studied using thematic analysis to determine key topics present throughout responses to both the surveys and interviews. These themes were then analyzed through a biocultural lens in order to bridge the gap between the medical processes and qualitative responses.

Appendix C (Reflexivity Statement)

This section focuses on the researcher's subject position in order to be transparent about potential biases due to their own background experiences and to reflect upon how the research may have been impacted.

My educational background prior to this Master's in Public Issues Anthropology at the University of Waterloo was in the sciences. In 2019 I received a Bachelor's of Science at the University of Waterloo majoring in Honours Science, with a triple minor in Anthropology, Biology, and Medical Physiology. This means that I entered this research with an understanding of osteoarthritis from a biomedical viewpoint, rather than the biocultural perspective that inspired the research. This may have resulted in underlying biases towards biomedicine, despite the care taken to center the subjective elements of the disease.

I have never personally been diagnosed with osteoarthritis, but have multiple family members who suffer from the disease. Witnessing their experiences was the initial inspiration for this thesis, and therefore may have caused biases that affected the research. Personal experience may also have affected Section 2.9 – The Lived Experiences of Symptoms, as I experience chronic joint pain in my own life from Marfan's Syndrome. Despite my scientific background, which trained me to remove myself from my research, experiencing chronic pain may have influenced how I analyzed the data for this topic.

Race, gender, and economic factors were not considered in this research due to being beyond the scope of this research. As this is a small study with a limited number of participants, I felt as though I would not be able to do justice to these important topics. Both study samples are located in countries with a national health system, meaning that all participants have some degree of access to affordable health care.