

How do persons living with lower back pain experience disability in their daily lives?

A qualitative study.

by

Sharli-Ann N. Esson

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Abstract and Keywords

This paper describes how persons living with lower back pain (LBP) experience disability using the International Classification of Function, Disability and Health (ICF) framework. I conducted three focus groups. Participants ages 20-65 years, living with LBP and seeking chiropractic treatment for their LBP were recruited from chiropractic clinics in Toronto, Canada. Using the World Health Organization Disability Assessment Schedule (WHODAS) questionnaire to assess disability, participants were divided into low and high disability groups. An ICF-based focus group schedule was created to explore participant experiences with disability. A qualitative thematic analysis was conducted. Twelve LBP patients participated in this study. Participants emphasized how environmental factors impacted their experiences with disability. They struggled with the invisibility of LBP and were sensitive about others' attitudes towards them. The results show a consistent feedback loop supporting the interaction between various ICF domains. My thesis highlights the importance of considering patients' perspectives when managing LBP.

Keywords: Low back pain, disability, biopsychosocial model, ICF framework

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List of Abbreviations

ICF – International Classification of Function, Disability and Health

IPA – Interpretive phenomenological analysis

LBP – Lower back pain

LDFG – Low disability focus group

HDFG – High disability focus group

TTC – Toronto Transit Commission

UOIT – University of Ontario Institute of Technology

WHO – World Health Organization

WHODAS – World Health Organization Disability Assessment Schedule

My Personal Motivation

My journey to qualitative research focusing on the experiences of persons living with lower back pain was somewhat of an unintentional or even subconscious decision. Before pursuing graduate studies in Health Sciences, I had completed a Life Science – Biology degree. However, even with this highly scientific major, I pursued a minor in Sociology. Without knowing it or acknowledging it at the time, I always had a passion for straddling the line between scientific and medical conditions and the significant socio-economic and socio-cultural implications of these conditions.

Lower back pain has always been an area of interest as I have seen firsthand how living with this non-descript and often inexplicable lower back pain has affected my mother's day-to-day activities. It plays a substantial role in many of her decision making processes from what type of bed she sleeps on, to the strategies she implements into her working environment to try to function optimally.

Once again I felt myself being compelled to investigate this issue from a sociological standpoint. When I was first introduced to qualitative research methods, I never envisioned that the experience would cause a shift in my thinking and essentially determine the path that my research would take. Qualitative research examines how individuals experience the world and is used to “explore new phenomena and capture individuals' thoughts, feelings, or interpretations of meaning and process” (Given, 2008). Qualitative inquiry seemed to be the perfect way to obtain real life experiences and appreciate the richness of experiential data. It would be remiss of me not to recognize the role of my personal connection to this research, and how it continues to shape me as a researcher seeking to produce authentic and applicable work.

Chapter One: Background

1.1 Biomedical versus Biopsychosocial model for Lower Back Pain

Lower back pain (LBP) is a prevalent disorder and a significant contributor to disability worldwide (Vos et al., 2015). The biomedical model of health has traditionally been used to guide the management of patients with LBP (Pincus et al., 2013), which is informed primarily by the identification of patho-anatomical lesions in the spine (Bishop, Thomas & Foster, 2007). This approach has led clinicians to treat LBP using physical or physiological interventions such as manipulation, mobilization, traction and massage therapy, exercise, acupuncture and medication (Waelen & Mior, 2005; Wong et al. 2016).

Although entrenched in health care, there are important limitations to the biomedical approach. The biomedical model fails to consider the relevance of psychological and social factors and in addition neglects to consider the impact of the environment on disability (Wade & Halligan, 2004). Failing to address environmental factors and their interaction with personal factors may actually promote chronic disability (Wade & Halligan, 2004).

To improve the treatment of LBP and its' associated disability, the use of a more comprehensive approach is required. The biopsychosocial model considers biomedical factors, as well as physical demands, work-related factors, emotional and cognitive factors, and socioeconomic variables (Truchon & Fillion, 2000). In this view, patient care should not merely consider and address symptom management but should involve the holistic treatment of patients (Froud et al., 2014). Therefore, it is important to understand what specific factors impact functional recovery and address them when managing patients with LBP (Cheatle, 2016; DeZutter et al., 2016).

In their systematic review of the qualitative literature, Froud et al. (2014) suggested that the social component of the biopsychosocial model was not well understood and should be included when assessing patient outcomes. The social component of the biopsychosocial model is described as the “relationships within the environment” (DeZutter et al., 2016). These include the activities people perform, the interactions they have, and the physical layout of the environment (DeZutter et al., 2016). I used the International Classification of Functioning, Disability and Health (ICF) framework (introduced into the Family of International Classifications developed by the World Health Association (WHO) in 2001) as the point of reference for gathering, analyzing and categorizing the data obtained in this study.

1.2 The ICF Model

Within the biomedical model, disability was thought of as a direct and physical consequence of a health condition. However, this view was revised by the World Health Organization (WHO) in 2002. The ICF model (Figure 1) reflects on the inherent complex relationships between an individual’s body functions and the environment in which he/she resides (WHO, 2002). The model clearly defines disability as the interaction between impaired body function, difficulty completing tasks, restrictions while participating in day-to-day situations, personal factors and the environment (WHO, 2002). Therefore, disability is significantly more complex than a health condition. Within the ICF model, body function is understood to be the physiological mechanisms within the body that allow for specific actions to be carried out (WHO, 2002). Whereas body structure refers to the anatomical components of the body. Activity refers to the completion of everyday tasks. The participation domain focuses on the involvement of an

individual in a life situation (WHO, 2002). The WHO (2002) defines environmental factors as the physical and social environment as well as people's attitudes. These factors can either facilitate or inhibit the functioning of LBP patients. Personal factors vary from one individual to the next and include an individual's basic demographic features.

I used the ICF model as the conceptual framework for my study because it uniquely captures the co-existence of the various factors associated with disability and the health condition. Also, the ICF model is useful in classifying the functioning and/or disability of persons living with LBP.

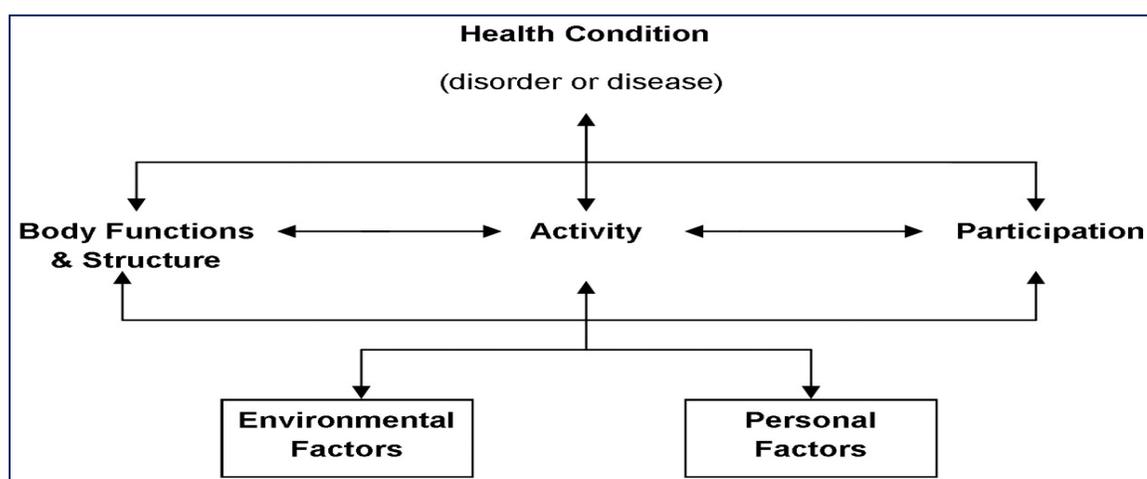


Figure 1. The International Classification of Functioning, Disability and Health (ICF) framework

1.3 Context for my Study

My study is one component of a large international collaborative project between the University of Ontario Institute of Technology (UOIT) and the ICF Research Branch - a cooperation partner within the WHO Collaborating Centre for the Family of International Classifications in Germany (at DIMDI). This collaborative project seeks to develop an ICF-based assessment tool that will allow for the standardized assessment, description, documentation and monitoring of function in LBP patients being treated with manual medicine. This tool, specifically designed for manual medicine specialists, should

be user friendly and would aid clinicians in being able to assess and systematically record the functioning and disability of LBP patients from a biopsychosocial perspective and that is respectful of the patients' environment. Therefore, my research contributes qualitative data about how persons living with LBP experience disability in everyday situations.

1.4 Review of Qualitative Literature

I conducted a review of qualitative literature to identify knowledge gaps as they relate to the use of the biopsychosocial model in patients with LBP and situate my research within the wider body of academic work on the topic. The following inclusion criteria were used to select relevant articles; (i) Published in peer-reviewed journals between January 2000 and December 2015, (ii) English language, (iii) Qualitative studies describing and interpreting adult patients' experiences with LBP, and (iv) Mixed method studies with clearly outlined qualitative analyses.

Search terms included variations and/or synonyms of: 'lower back pain, back ache, sciatica, function, disability, qualitative, focus group, and activities of daily living.' I searched PubMed, CINAHL, MEDLINE via OVID. The initial search produced 1,107 articles. After screening for relevant articles and removal of duplicate articles, 18 articles were included in qualitative synthesis. I mapped and organized the results of the review according to the domains of the ICF framework (Figure 1). Through this organization, I aimed to capture the dimensions within the framework that have been previously recorded as influences on function and disability in LBP patients. Below, I present my synthesis of the qualitative literature and show how the findings reviewed were categorized within the ICF model. The review demonstrates how each domain interacts

with the others and how they can positively or negatively influence experiences with disability.

Body function and body structure

The first domain in the model is body function and structure (Figure 1). Examples of body functions include pain, movement and psychological functions (emotional responses). On the other hand, body structure refers to the anatomical components of the body such as the brain, spine or eyes (WHO, 2002).

My review identified six papers that discussed body function. The literature clearly shows that LBP affects spine function and other non-back related functions. Snelgrove, Edwards and Lioffi (2013) reported that patients experienced stiffness and persistent sensations of pain. Participants in the study by Glenton (2003) described an inability to “walk normally” thus an uneven gait pattern. LBP patients also described moving more slowly as a result of the physical constraints associated with LBP (Crowe et al., 2010).

Snelgrove et al. (2013) reported that sleep interruption and mobility restriction were common complaints amongst LBP patients. Similarly, Vroman, Warner and Chamberlain (2009) reported that LBP was a tiring and unpredictable condition that inhibited activities and interaction with others. They also reported that LBP patients experienced emotional distress, which stemmed directly from their physical pain. These findings illustrate the relationship between physical pain, exhaustion and psychological response, which suggests that LBP patients experience multiple, simultaneous body function impediments as they conduct their lives. Additionally, LBP patients exhibited symptoms of depression and signs of anger (Smith & Osborn, 2007; Corbett, Foster &

Ong, 2007; Walker, Sofaer & Holloway, 2006). Feelings of worthlessness were described by participants as they experienced physical challenges trying to navigate everyday life (Walker et al., 2006; Lamé, Peters, Vlaeyen, Kleef & Patijn, 2005). These findings reflect upon the emotional and psychological functions which LBP patients struggle with as a result of LBP associated disability.

LBP patients struggle with numerous internal challenges in their daily lives e.g. uncertainty, worry, and fear avoidance behaviours (Corbett et al., 2007). Corbett and colleagues (2007) sought to investigate the emotional fluctuations of LBP patients and explained the predominant emotions of hope and despair which were common amongst their participants. While some tried to remain hopeful, researchers found that other LBP patients were worried and fearful of their future as the unpredictability of LBP made it hard for them to plan ahead. The study by Kawi (2014) highlighted that LBP patients were anxious about their current levels of pain and functionality.

Smith and Osborn (2007) discussed that LBP patients found their pain to be overwhelming and in turn began to project a negative self-image. They also struggled with feelings of shame and felt they had no control over their situation (Smith et al., 2007). LBP patients seemed to spend a lot of time reminiscing on their past selves (before experiencing LBP), and comparing it with their current selves. Some LBP patients attributed feelings of rage, self-loathing and negativity towards others to their experiences with LBP (Snelgrove & Lioffi, 2013). They believed that living with LBP heavily contributed to their loss of identity and diminished self-esteem (Walker et al., 2006; Holloway, Sofaer-Bennett & Walker, 2007). These findings seem to imply that although

patients were cognizant that LBP was now a consistent part of their daily lives, they were not accepting of it or receptive to its disabling impact on their lives.

There was limited discussion of other anatomical structures in previous literature. However, some studies detailed participants' accounts of increased pain in the tailbone and thigh with one respondent likening the pain to a severe dog bite (Larsen, Nielsen & Jensen, 2013; Crowe, Whitehead, Gagan, Baxter, & Panckhurst, 2010).

Activity

The activity domain focuses on the completion of daily tasks or actions (WHO, 2002). For example, LBP patients may experience difficulties with changing body positioning, looking after their health or handling stressful situations. The study by Tavafian, Gregory and Montazeri (2008) highlighted some of these challenges. They reported that Iranian women with LBP experienced increased stress levels which they attributed to their daily activities. These women believed that having to handle stress was an added burden that further contributed to the manifestation of their LBP. Another study found that the manifestation of LBP caused physical limitations which influenced basic body positioning such as posture, seated positions and rising from a seated position (Snelgrove et al., 2013).

Vroman et al (2009) found that patients with LBP wanted to feel a sense of normalcy while performing daily tasks. However, the authors reported that patients primarily sought treatment for LBP because of they were unable to engage in, and complete rudimentary tasks such as dressing one's self and driving. In many cases, patients suffered through physical pain while completing daily tasks in order to give others the impression that their pain was less severe than in actuality (Larsen et al., 2013).

Walker et al. (2006) presented further evidence of the diminished quality of life that can occur due to limitations completing tasks as a result of disability associated with LBP.

Participation

Employment, social engagement and the acquisition of goods and services all represent examples of participation (WHO, 2001). This domain considers an individual's involvement in everyday interactions and events. Researchers have argued that social and cultural pressures are likely to affect functioning and disability associated with chronic illnesses (Bury, 1982; Williams, 2000). Tavafian et al. (2008) described that female Iranian patients with LBP found it difficult to maintain active social lives while fulfilling their roles as wives and mothers. Much of what constituted an identity for these women – which included the ability to accomplish daily chores such as preparing meals, moving household items, cleaning, and maintaining the household for their children and spouse – was compromised. Similarly, Corbett et al. (2007) described that participants' marital and familial lives could be interrupted by multiple the effects of living with LBP. Crowe et al. (2010) described that physical constraints associated with LBP caused patients to be less productive. Smith and Osborn (2007) suggest that LBP patients who are unable to participate in desired events feel social isolation.

Walker et al. (2006) highlighted the theme of “loss” and its association with LBP. They elucidated multiple aspects of daily life in which LBP patients said they experienced loss. In particular, job (financial) loss was a significant contributor to patients' inability to participate in everyday situations. Job loss made it difficult to fulfill financial commitments, and placed undue strain on familial resources and relationships. As a result, social activities became less of a possibility. Negative feelings, which often

accompany the inability to earn or contribute financially, became a major instigator of social segregation (Walker et al, 2006).

Environmental Factors

The WHO (2002) describes environmental factors as physical and social settings as well as people's attitudes within these settings. Environmental factors can either enable or hinder the functioning of LBP patients. For example, having access to an efficient transit system may help to alleviate challenges associated with mobility. Kawi (2014) described how support from family, friends and healthcare personnel was of utmost importance to LBP patients and aided in facilitating their functional ability. Similarly, it was found that LBP patients experienced difficulty in clearly expressing their pain to non-LBP sufferers (Larsen et al., 2013). They also had a hard time effectively managing their levels of pain while in social settings such as the home, work and even at the clinic (Larsen et al., 2013). This was most likely because LBP patients were consistently mindful of the opinions and attitudes of others around them. They have often admitted that they try to suppress or ignore physical pain in order to maintain their positions within social groups (Larsen et al., 2013).

Attitudes and relationships are also important concepts which can be categorized with the domain of environmental factors. Snelgrove and Lioffi's (2013) qualitative systematic review summarized the experiences of chronic LBP patients. The overarching themes which emerged from their data showed the impact of chronic LBP on self; the impact of chronic LBP on relationships with family and friends; and the impact of chronic LBP on relationship with healthcare providers. Maintaining healthy family relationships was difficult because of disruptions to the family routine as a result of

patients' LBP. Marital tension and feelings of distance were also the result of disruptions to regular family activity. The relationships with family and friends were very ambivalent. Despite tension and strain, LBP patients still relied on family and friends for support and encouragement.

Snelgrove and Lioffi (2013) also highlighted a conflicting relationship between LBP patients and healthcare providers. Patients were very dependent on medical practitioners as they sought a clear diagnosis. They also tried to articulate their pain symptoms to practitioners so they could actively participate in developing their own treatment plans. They expected clinicians to find solutions for managing LBP, provide emotional support and encouragement, and assume some accountability for the success or failure of management interventions (Fu et al, 2015). However, patients reported extended waiting times for appointments and referrals. They also felt that little to no progress was being made, especially if healthcare providers had not given them an accurate diagnosis for the cause of the LBP. Patients commented that they did not always receive much needed encouragement and advice from healthcare providers (Georgy, Carr & Breen, 2009; Crowe et al, 2010; Carroll, Lis, Weiser & Torti, 2015). This often led to a loss of faith in the medical system. One study investigated what healthcare providers believed were their primary roles for assisting LBP patients. Crowe et al. (2010) found that the physiotherapists and general practitioners in their study believed their roles were to prescribe medication, refer patients to specialists as needed, and provide doctor's notes. The opposing mindsets of patients and providers highlight the apparent dissonance between those with LBP and some who manage it. Keeping these findings in mind, it

becomes more obvious why the current healthcare resources, systems and policies need to be revisited.

Hopayian et al. (2014) refers to *delegitimation* as the legitimacy of LBP being questioned or doubted by others resulting in much frustration amongst the LBP patients studied. As previously mentioned, this was likely due in to part the fact that patients did not have clear explanation about the cause of the condition. Furthermore, *delegitimation* may also have resulted from the absence of visible signs of pain, injury or disability, making it particularly difficult for others to believe that LBP sufferers' pain was real.

The attitude of others also greatly affects the overall atmosphere within which LBP patients conduct their daily lives. Holloway et al. (2009) found that participants felt that their employers were often unsympathetic and they often felt stigmatized in the workplace. Similarly, Froud et al. (2014) reported that LBP patients also felt stigmatized by co-workers who did not seem to believe the legitimacy of their LBP. Hence, LBP patients felt pressured to prove that their LBP was real and relied heavily on their healthcare providers to authenticate their diagnosis. Patients also sought validation from their clinicians that the pain they were experiencing was real. Doctor's notes served as a means of legitimizing the patients' claims in social settings as well as the workplace (Vroman et al., 2009). Pain relievers such as oral pain medications, application of topical cremes and/or heat to the back were the primary self-management strategies of LBP patients (Crowe et al., 2010; Kawi, 2014). They used these strategies frequently in order to function more effectively, especially within the workplace.

As evidenced by the findings above, environmental factors have significantly impacted the lives of LBP patients. These factors represent external influences that span

far beyond physical setting and they demonstrate how each may either positively or negatively affect functioning in LBP patients.

Personal Factors

The WHO describes personal factors as those which “may include gender, age, coping styles, social background, education, profession, past and current experience, overall behaviour pattern, character and other factors that influence how disability is experienced by the individual” (WHO, 2001, p.11). Fear is one of the personal factors that can be seen throughout the literature. Fear of movement i.e. performing prescribed therapeutic exercises is often seen in LBP patients. Although these exercises may have long-term benefits, the potential pain patients anticipate that they may experience has caused hesitation and resistance (Slade, Patel, Underwood & Keating, 2014; Verbeek, Sengers, Riemens & Haafkens, 2004).

Another study looked at the individual expectations of LBP patients being treated with chiropractic spinal manipulation or exercise. Findings showed that 80% of their participants expected improvements in their ability to carry out daily activities. More so, a crucial expectation for most patients was fully regaining their independence (Haanstra et al., 2013).

The impact of personal factors on disability is quite significant and can vary from one individual to the next. Qualitative studies have addressed some of the key personal factors that seem to impact disability in LBP patients. It has been found that age, gender and even genetic predisposition were also contributors to impairment and disability in LBP patients (Manchikanti, 2000).

Coping strategies were often discussed in the literature as pain relief was crucial to LBP patients (Verbeek et al., 2004; Crowe et al., 2010; Snelgrove et al., 2013). They often used modalities which minimized the pain and inhibited exacerbation. However, there was some apprehension about coping in the future and imminent and worsening disablement (Corbett et al., 2007).

1.5 Gaps in the knowledge

Several studies (Froud et al., 2014; Kawi, 2014; Liddle, Baxter & Gracey, 2007; Van Tulder et al., 2002) explained the value of a biopsychosocial model, but acknowledged that the model has not yet been applied in entirety. Carr and Moffett (2005) found that little attention has been given to the social aspect of the model and that more research was needed in order to design more effective interventions. My literature review suggests that previous research presents the biomedical and psychological parts of the biopsychosocial model quite well with regards to LBP. However, the social aspects have been largely neglected. More importantly, the environmental factor domain of the ICF framework shows that there is quite a lot of information that has not been investigated or acknowledged. The ICF framework has not been previously used in other studies to guide their data collection process. Therefore it is critical to situate concrete patient experiences within the all facets of the ICF model. Understanding how persons living with LBP experience disability in their daily lives is essential for ensuring that they will be treated holistically, factoring in the elements of functioning which they consider to be most important. Furthermore, it will show the importance of using this model as a lens for looking at the relationship between disability, function and LBP.

1.6 Methodological Approach

This section explores the paradigmatic and theoretical underpinnings upon which my study is based. My study employed a qualitative study design using interpretive phenomenological analysis (IPA) to investigate individuals' experiences of disability while living with LBP. Because LBP is one of the leading healthcare concerns worldwide, it is essential to acknowledge the psychosocial factors in addition to biological factors that can impact the lives of LBP patients. Therefore, obtaining the first-hand experiences and perspectives from those who are most affected by LBP is important. It is for this reason that qualitative research methods are ideal for this project. Qualitative research enables patients to share their personal experiences thereby providing a richness and deeper understanding of their perspectives on LBP.

IPA is based on the philosophical foundations of Martin Heidegger (1889-1976). IPA utilizes the subjective nature of data to create new knowledge through interpretation and in-depth understanding (Reiners, 2012). IPA offers the ability to gather candid accounts and perspectives from participants that encompass the varying experiences of LBP patients (Reid et al., 2005). The use of IPA is especially appropriate for exploring the idiosyncrasies of chronic and acute conditions such as LBP as it can explain complex and dynamic relationships by placing value on experiential data (Smith & Osborn, 2007). My research is situated within the epistemological realm of social constructivism, in which the emphasis is placed on the perceptions, values and beliefs of individuals. Social constructivism places importance on the mutualistic relationship between the researcher and the participant and through this interaction, knowledge is co-constructed (Gergen & Gergen, 2008). The ascribed meanings which come from the researcher-participant

relationship fall within the interpretivist paradigm. This paradigm demands a level of openness between the participant and the researcher as they seek to develop and articulate what it means to interact and function in the world they live in (Guba & Lincoln, 2000). Orlikowski and Baroudi (1991) argue that the purpose of interpretive research is “*to understand how members of a social group, through their participation in social processes, enact their particular realities and endow them with meaning, and to show how these meanings, beliefs and intentions of the members help to constitute their actions*” (p.13). The guiding principles within the interpretivist paradigm further help to understand LBP from the viewpoint of those who are experiencing it (Cohen, Manion & Morrison, 2000). Also, this methodological approach fits well with the use of the ICF framework and is quite complementary for exploring experiences with LBP.

1.7 Objectives

The primary objective of this study is to describe how LBP patients, seeking chiropractic care, experience functioning and disability. To address this objective, I used the domains of the ICF to frame the various patient experiences. By using this multi-dimensional model, I aimed to:

- i. present the impact of contextual factors on disability in LBP patients with varying levels of disability; and
- ii. Highlight the factors of the biopsychosocial model that are most important to LBP sufferers.

Chapter Two:

**How do persons living with lower back pain
experience disability in their daily lives?**

A qualitative study.

2.1 Introduction

Lower back pain (LBP) is a leading cause of disability worldwide (Cassidy, Carroll & Côté, 1998, Vos et al., 2015). It is one of the most prevalent chronic disorders in the population. Approximately 80% of adults will experience LBP at some point in their lives (Cassidy et al., 1998; Walker, 2000). LBP manifests itself as stiffness, tension or achiness confined between the costal margin and the inferior gluteal folds; with or without sciatica (Van Tulder, Koes & Bombardier, 2002). The pathophysiological causes of LBP are often unidentifiable. This creates challenges to the effective treatment and management of the condition, especially because patients experience LBP in different ways (Wong et al.2016).

The physical symptoms of LBP include pain or stiffness that jeopardizes an individual's ability to participate in everyday activities (Snelgrove, Edwards & Lioffi, 2013). In addition to the physical effects experienced by LBP patients, there are personal, societal and psychological ramifications associated with the condition. In some cases, asocial behavior and negative self-image are additional consequences of living with LBP (Smith & Osborn, 2007). Furthermore, increased work absenteeism, lower productivity and depressive symptoms that often accompany chronic pain, are likely to occur (Carroll et al., 1998; Nolet, Kristman, Côté, Carroll & Cassidy, 2015). Even with all that is known about LBP, there is limited qualitative data describing LBP patients' experiences with disability especially with respect to addressing all the dimensions of a biopsychosocial model.

The WHO's Framework: International Classification of Functioning, Disability and Health (ICF)

The relationship between pain and disability is complex (Turk & Flor, 1999). Disability results from the interaction between the health condition and the environment within which the person is living. In this case, the word 'environment' refers to psychosocial factors that influence how one experiences a health condition. Therefore, it is important to understand what psychosocial factors impact disability and address them when managing patients with LBP. Unlike the conventional biomedical model, evidence-based approaches that have been informed by the biopsychosocial model, better address the complexity of chronic pain. (Engel, 1980; Gatchel, Polatin & Mayer, 1995; Truchon, 2001).

The ICF model is grounded within the biopsychosocial approach to human health. According to the ICF model, disability involves impaired body function, difficulty completing tasks, and restrictions in participating in day-to-day situations (WHO, 2002). The ICF framework includes five domains to describe and understand functioning: body functions and body structures, activities, participation, environmental factors, and personal factors (see Figure 1). The ICF considers health as a complex interaction between the biological, psychological, and social dimensions of humans as they engage with their environment (WHO, 2001). The uniqueness of this model is its description of disability as experienced by patients and the multivariate perspectives it offers.

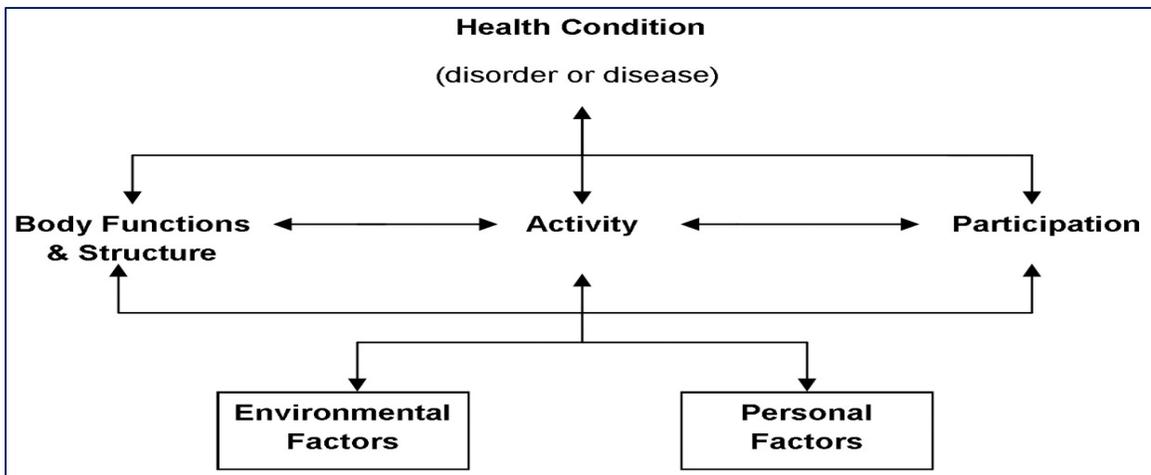


Figure 1. The International Classification of Functioning, Disability and Health (ICF) framework

According to the ICF, body function refers to the physiological function of systems within the body, including psychological behaviour and mechanisms. Body structure focuses on the body's anatomical components. The activity domain seeks to understand the execution and completion of tasks, whereas participation refers to involvement in life events and forums. Environmental factors explore the physical layout and design of the environment, the social environment and the attitudes of others in the environments where LBP patients live and conduct their daily tasks. Personal factors represent influences on functionality that are specific to the individual e.g. age, race, gender and habits.

The ICF model encompasses a wide range of factors through which the impact of functioning and disability can be explored. The objective of this research is to characterize how disability is experienced by patients with LBP. The results will be used to inform the development of an ICF assessment schedule that is tailored for manual medicine. The resultant assessment schedule will aid clinicians in understanding the needs of the patient and help them to assess and document disability and potential recovery by considering the patient's psychosocial environment.

2.2 Methods

Study Design

I used a qualitative study design to investigate LBP through the lens of human experience. I took a methodological approach involving Interpretive Phenomenological Analysis (IPA). IPA focuses on the interpretation of participants' experiences by trying to understand their subjective realities. This methodology is particularly useful for revealing complex and dynamic relationships and placing value on the subjectivity of participants' experiences (Smith & Osborn, 2007). IPA is situated within the interpretivist paradigm and appreciates the uniqueness of interpreting experiences rather than knowledge (Reiners, 2012).

Focus groups were used to collect data. Focus groups foster an atmosphere in which participants can feel comfortable sharing their experiences. There is richness in the data that arises from focus groups that is not captured in individual interviews. The data emerging from focus groups reflects the synergy between participants and explores their understanding and perceptions of the issue, which is ideal for this study (Morgan, 2008).

Participants and Recruitment

Participants were recruited from the Canadian Memorial Chiropractic College in Ontario, Canada, as well as two external chiropractic clinics in the Greater Toronto Area in Canada. Participants were eligible to participate if they met the following criteria:

- i. 20-65 years of age;
- ii. Report LBP (chronic or acute);
- iii. Currently seeking chiropractic care for their LBP.
- iv. English speaking.

Eligible participants were recruited using two strategies. First, posters were placed in all the clinics in which persons could volunteer to participate. Second, staff clinicians at the Canadian Memorial Chiropractic College introduced the study to clinic patients to gauge their interest in participating in the study and collected the contact information for those who were interested. I contacted interested patients and provided them with further information about the study and the informed consent package (Appendix A).

Focus Group Allocation

People with LBP experience varying levels of disability. Therefore, it was important to stratify participants by LBP severity. I used the World Health Organization Disability Assessment Schedule (WHODAS) (Appendix B) to stratify participants in low disability focus groups (LDFG) and high disability focus groups (HDFG). The WHODAS is a 12-item, self-administered questionnaire designed to assess difficulty experienced doing regular, everyday tasks. Studies show that the WHODAS questionnaire offers valid and reliable results for measuring disability (Von Korff et al., 2008; Silva et al., 2013).

The sample distribution of WHODAS scores was used to allocate participants to low and high disability using a pre-determined cut point. The cut point was created using the following schema. Participants with scores of 36 and below were allocated into low disability focus groups. Participants with the highest scores (above 36), were allocated to the high disability group. A score of 36 was used as the cut point because a person reporting moderate severity for all 12 questions in the questionnaire would obtain a maximum score of 36. Higher scores indicate more severe levels of disability. Similar

methods of stratification have been used in the previous studies in which other questionnaires were used (Briggs et al., 2010)

Data Collection

Three focus groups were conducted, each lasting approximately 90 minutes. The low disability focus groups consisted of 5 and 4 participants respectively. The high disability focus group included 3 participants. Each session was audio-recorded and transcribed verbatim by a professional transcriptionist.

The focus group questions were geared towards eliciting responses related to the ICF framework. With the aim of obtaining participants' experiences with disability using the ICF framework, it was important to structure the focus group interview schedule (see Appendix C) based on this framework. Further probative questions were asked to flesh out more in-depth answers to the questions in the event that what was said was not understood or required further clarification.

Analysis

The NVivo11 Software (QSR International Pty Ltd. Version 11, 2015) was used to organize and analyze the transcripts. The domains of the ICF framework were used as *a priori* themes. The focus group transcripts underwent basic thematic analysis. The data was interpreted, central themes were identified and these themes were conceptually categorized according to the domains of the ICF framework that they best fit. The primary researcher completed the initial analysis and coding of the data. Once the data was organized, it was reviewed independently by other researchers to ensure the data presented was correctly allocated into the domains of the ICF.

2.3 Results

A total of 12 participants took part in this study. Seven participants were female (58%) and five participants were male (42%). Table 1 describes the demographics of participants in the three focus groups.

| Information collected | Low disability focus group #1 [LDFG1] | Low disability focus group #2 [LDFG2] | High disability focus group [HDFG3] | Total |
|------------------------------|--|--|--|--------------|
| <u>Gender</u> | | | | |
| Male | 2 | 2 | 1 | 5 |
| Female | 3 | 2 | 2 | 7 |
| <u>Age Group</u> | | | | |
| 20-35 | 0 | 1 | 1 | 2 |
| 36-50 | 1 | 1 | 0 | 2 |
| 51-65 | 4 | 2 | 2 | 8 |
| <u>Total</u> | 5 | 4 | 3 | 12 |

Table 1. Demographic characteristics of participants in this study

Every effort was made to achieve data saturation. Purposive sampling techniques were used to recruit participants whose perspectives could effectively address the research question (van Rijnsoever, 2017; Coyne, 1997). Furthermore, probative questions were used during focus group sessions to explore deeper meanings of participants' responses to the guided questions. Also, they were used to verify that participants were not misunderstood and that accurate details were represented. In the low disability groups, more than one focus group was conducted and the repetition and reiteration of some main ideas could suggest that data saturation was approached in those groups. The high

disability group was comprised of only 25% of the sample population and the inability to conduct multiple focus groups for high disability respondents makes it difficult to determine if data saturation was reached in this group.

The experiences of disability across ICF domains

Based on the five *a priori* domains from the ICF framework, participant experiences were categorized accordingly (Table 2). The findings from the data will show both commonalities and contradictions in the low disability focus groups and the high disability focus group. The ICF conceptualizes activity and participation as two distinct categories. However, numerous researchers have argued that the domains of activity and participation within the ICF model are difficult to distinguish (Jette, Haley & Kooyoomjian, 2003; Badley, 2008; Resnik & Plow, 2009). The findings of this study suggest that the two domains bear some similarity and cannot always be used intuitively. Therefore, the domains of activity and participation have been merged and reported together to showcase individual limitations and the resulting large scale restrictions that LBP patients experience in society.

| Body Function & Body Structure | Activities & Participation | Environmental Factors | Personal Factors |
|---|---|--|---|
| <ul style="list-style-type: none"> • Pain • Sleep • Psychological/ Emotional Responses | <ul style="list-style-type: none"> • Physical tasks • Social relationships • Driving • Employment | <ul style="list-style-type: none"> • Public Resources • Weather • Healthcare • Attitudes of others | <ul style="list-style-type: none"> • Ageing • Gender • Financial Constraints • Co-morbidities • Coping |

Table 2. Emergent sub-sets from focus groups

I. Body Function and Body Structure

Participants described various challenges associated with body structure and body function. These included the exacerbation of chronic pain, difficulties sleeping, and varied emotional responses stemming from their condition.

Pain. In both the low and high disability focus groups, participants presented conflicting accounts about the location of their pain. Some participants suggested that their LBP was confined to one area – typically the small of the back, while others explained that their pain was not localized but rather travelled from one area to the next, making it difficult to predict when or where the pain would arise.

“When I first started getting the pain I would say it was somewhat localized and then it started spreading and now I can’t even tell the difference anymore because it is throughout my entire body.” Allan [HDFG3]

“My pain is normally in the same spot (points to the small of the back). It doesn’t vary very much. Mostly it is stable...” Helena [HDFG3]

However, a point of consistency among all participants was that they were unable to distinguish the origin of their pain, whether it was from a joint, muscle or bones. This finding suggests that based on the observed conflicting accounts of their LBP, participants have a high level of uncertainty about their condition. More importantly, these results offer qualitative data describing the nature, location and character of pain where previous literature has been limited (Larsen, Nielsen & Jensen, 2013; Crowe, Whitehead, Gagan, Baxter, & Panckhurst, 2010).

Sleep. Difficulty falling asleep and interrupted sleep are common experiences amongst persons living with LBP (Naughton, Ashworth & Skevington, 2007). Such findings were echoed in my study as participants in the low disability focus groups reported that falling asleep was not difficult but they struggled to sleep restfully or remain asleep. As noted in the following quote, participants reported a need to change positions to relieve their pain or discomfort.

“For me I have really rough nights sleeping so like every hour or so I have to wake up and stretch and move around. So in the morning the same thing, it is about a half an hour of stretching and moving around before I can actually function.” Corrina [LDFG1]

In contrast, participants in the high disability focus group expressed that they struggled with falling asleep, as well as restfully remaining asleep. Allan’s account clearly exemplifies these challenges.

“I would say both because it is almost impossible to find a comfortable position where you say ‘OK I am not in pain in this position so I will stay here.’ You find yourself tossing and turning all night long trying to find a position that works and usually you don’t and 9 times out of 10 the only reason you do fall asleep is from restlessness.” Allan [HDFG3]

Psychological impact. The emotional toll chronic LBP had on participants negatively impacted their motivation to perform daily activities. Depressive symptoms sometimes led to asocial behaviour as participants retreated to their homes for extended periods of time. Also, there appears to be a connection between levels of depression and difficulty sleeping. It is likely that participants exhibiting increased depressive symptoms find it

more difficult to fall asleep and are likely to awaken earlier. This lack of sleep could account for some behavioural and psychological changes that LBP patients exhibit. Snelgrove et al. (2013) found similar results in their study as they described behavioural changes such as loss of self-esteem and social isolation that resulted from feelings of depression. Both low and high disability focus group participants felt emotionally drained and disliked being dependent on others. Feelings of their frustration and anxiety associated with depending on others (and assistive devices) were threaded throughout their discussions. Participants in the high disability focus group commented on feeling overwhelmed and withdrawn and said they sometimes stayed in bed all day in an attempt to seemingly avoid the reality of their current situation:

“I stay in bed, sometimes all day which is even worse for the back pain...but if you don’t want to get out, you don’t want to get out...” Francine [HDFG3]

The feeling of withdrawing is akin to social isolation and retreating, and possibly offers participants solace from having to constantly defend or explain a condition, which many do not acknowledge, let alone understand (Ashby, Fitzgerald & Raine, 2012). In addition to the emotional responses, concentration on daily tasks varied by participant group. While low disability focus group participants did not experience any challenges with concentration or maintaining focus, the high disability focus group participants expressed a severely diminished ability to concentrate. One participant, a current student, recognized that he had to work much harder at things he used to grasp with relative ease.

“... I also have a hard time concentrating. So my concentration when it comes to studying doesn’t last more than like 10-15 minutes. So I have to study in like 10-15 minutes fighting to read and then break 5 minutes... before I would just go to

class listen and barely have to study anything or read too much now I find myself doing 10 times more work just to get one section over with.” Allan [HDFG3]

II. Activity and Participation

There were marked contrasts between the participants in the low and the high disability focus groups in their ability to engage in physical actions, which profoundly affected their social relationships, driving and employment.

Physical tasks. Participants in the low disability focus groups did not express many activity limitations. They demonstrated an awareness of what activities they were able to manage compared to those they perceived detrimental to their ability to function. Unlike the high disability participants, the low disability participants seemed to manage their pain and were able to modify rather than limit their activities. Many enjoyed cycling, yoga and swimming, but avoided high intensity exercises such as running, which they reported placed severe pressure on the back and the legs/knees.

“I went to a trampoline park with my friends...I had to completely stop because of pain in my neck, pain in my back...and I’m like well I’m going to watch you guys...because you know you can’t really do the same level as they can...” Leo [LDFG2]

Conversely, the high disability focus group participants, struggled with even elementary body movements and body positions, and faced serious exercise restrictions:

“Laying flat is very, very painful. Bending down like as the day progresses the worse I get and by the end of the day it is nearly impossible to function.” Helena [HDFG3]

Participants in the high disability focus group noted that their chiropractors recommended exercises to manage their LBP but felt that providers did not understand the challenges they faced in doing the exercises. This is example of the dissonance between LBP patients and their healthcare providers. Therefore, their ability to comply with the recommended exercise program was affected, as highlighted by Allan:

“It limits your ability to do things especially exercise. So it seems like everybody where you go for treatment recommends exercise but they kind of don’t understand that it is very hard to do things, especially when you squeeze, the pain just intensifies times 50.” Allan [HDFG3]

Also, some participants in both the low and high disability focus groups indicated that some of the problems they had with participating in activities, did not stem solely from their LBP but they were simply unaware what community group activities were available to them. Upon further probing, participants from the high disability focus group especially, were apprehensive about the cost of enrolling in such activities. Also, these participants described inability to perform certain tasks or utilize certain equipment.

“You go into these groups and if you can’t do the activities in the group that you are in, people just look at you. If you can’t do it, you feel uncomfortable in these things.” Helena [HDFG3]

The discomfort associated with other’s responses could be considered as stigmatization which Goffman (1963) defines as the process by which the response of others to an individual’s personal trait(s) causes his/her identity to be diminished and causes feelings of humiliation. The perceived stigmatization described by some participants in both the low and high disability groups appeared to be self-imposed. This

perceived stigma has also been directly linked to depressive symptoms and isolated behavior (Holloway et al., 2007).

Social relationships. Across the focus groups, participants expressed a range of experiences related to social relationships and significant differences were apparent. Most low disability focus group participants suggested that their condition did not negatively impact their social interactions. Nonetheless, certain small changes in their relationships were identified. For instance, one respondent identified a change in the interests she previously shared with friends. Implicitly, by no longer having shared interests, the participant had less in common with friends which likely put a strain on the friendship. This participant's account illustrates the strain on relationships that can occur when chronic pain becomes the primary subject of conversation. LBP sufferers may overtake conversations with their laments about pain, which could become bothersome to friends, who cannot understand this pain. This could cause friends to shy away from LBP sufferers and avoid interactions with them.

In contrast, participants in the high disability focus group described a more dramatic change in social relationships, which included loss of friends and loss of the desire to socialize. These findings appear to be quite typical of persons living with severe back pain and supports findings in previous literature (Corbett et al., 2007; Smith et al., 2007; Walker et al., 2006).

“You will probably lose all your friends, they will become tired of always having to lag behind.” Allan [HDFG3]

“I just don’t return calls if they call. I don’t think they understand, they don’t understand what you are going through.” Francine [HDFG3]

Driving. Participants in the low disability focus groups continued to drive with LBP having little to no effect on their ability to do so. One participant explained that he merely adjusted his car seat to facilitate for his back pain.

“I drive now with my seat straight up so that my back is straight. It takes a little bit getting used to...driving becomes easier and you can handle the car, it is not so slouchy and you don’t get that funny feeling when you step out.” Mason [LDFG2]

All of the participants in the high disability focus group were non-drivers. However, participants did not report that their inability to drive was specifically influenced by LBP. One participant was unable to drive due to a previous motor vehicle collision and the other participants chose not to drive for personal reasons. Previous literature suggests that there may be an association between excessive driving (prolonged sitting and exposure to whole body vibration) and LBP (Okunribido, Magnusson & Pope, 2006; Gallais & Griffin, 2006). However, little is known to what extent disability associated with LBP directly affects one’s ability to drive. Questionnaires such as the Fear-Avoidance Beliefs Questionnaire (Waddell, Newton, Henderson, Somerville & Main, 1993) query how activities such as driving can affect a person’s back pain but not vice versa. Further research is warranted to determine the significance of this finding.

Employment. The employment status of persons in the low disability focus groups varied and included retired persons, unemployed persons, students and working persons. Those

who worked were aware of their physical capabilities and sought employment within the confines of those capabilities.

“If I am looking for work I can’t really do certain physical jobs because I am not sure if it is going to tighten up...So I try to stay away from anything like that. The problem is a lot of jobs too are going to still require standing anyways.” Leo
[LDFG2]

The availability of employment opportunities for persons in the high disability focus group were considerably less than those in the low disability focus groups. At the time of the focus group session, all participants in the high disability focus group were unemployed. For one participant, it was a personal choice to become full-time caregiver for a loved one. Another participant was no longer able to keep up with the labour-intensive demands of the job and the other participant felt forced to quit her job because of compensating body movements and gait, often resulted in others accusing her of being intoxicated. The fact that the high disability group participants were unemployed and in some cases, unable to regain employment was an indication that high levels of disability associated with LBP may have serious socioeconomic impacts of LBP sufferers. High disability focus group participants expressed a desire to return to work but noted that their LBP caused diminished sitting and standing capabilities. The idea of seeking new employment was a challenge, as participants feared the reaction of potential employers once they disclosed that they lived with LBP.

“It is also hard to try and get another job...So when I go and try and get jobs I would rather be honest...When you say those kinds of things to people about how

you really are, it is like OK right away you look at their face and you're like 'I know I didn't get this job.' Allan [HDFG3]

When probed about obtaining new employment and what might assist them in the workplace, participants in the high disability focus group said that taking frequent stretch breaks and having comfortable seating would be beneficial. It was also important for employers to be empathetic towards their need for these breaks. They feared that their LBP would not be recognized and that employers might think they did not take their jobs seriously.

III. Environmental Factors

Participants described how environmental factors affected how they experience disability. Emerging from the data were findings about public resources, healthcare and the attitudes of others which represent examples of environmental factors within the ICF model.

Public resources. Communal spaces and transit were the primary public resources which participants discussed. Many of the participants in the low disability focus groups lived within the downtown core and were very aware of the community resources that were available and made maximum use of them.

"They will also fall-proof your house. So that is one of the things that you can get, you have to have a doctor referral to it but they will come in and look at your house and how you have it set-up and then do the fall prevention." Walter [LDFG1]

Participants in the high disability focus group, who also lived in downtown Toronto, were significantly less informed about community resources. They knew that

some resources could be accessed online but did not find them easily accessible because they either did not own a computer or did not consider themselves to be technologically skilled. They also said the cost of some resources was a concern.

A student in the high disability focus group described the design and accessibility of classrooms, commenting on uncomfortable seating and the need to use an assistive device during lectures. It was also noted that although campus buildings were equipped with handicapped buttons for opening doors, a large portion of them simply did not function:

“At my school I would say about 75% of the handicap buttons don’t work and if they do work maybe it is only in the summer time because in the winter they get jammed.” Allan [HDFG3]

Participants with high disability indicated that they used elevators or escalators to get to higher floors in multi-story buildings. In cases where neither were available, they relied heavily on the handrails of the stairs and were apprehensive if there were none.

“So every time I walk into a building I always like to know where the elevator is or escalator or some easier way to get up and if the last resort is the stairs then I have to kind of coach myself into doing it...” Allan [HDFG3]

The use of public transit concerned most participants. Buses and streetcars were the most frequently used modes of transportation amongst participants. They clearly expressed their experiences with both the physical components of public transportation as well as the social component of interacting with other passengers. Users of public transit facilities were from both the low disability and high disability focus groups. Respondents were particularly careful moving on and off buses and streetcars. The physical design of

the vehicles made travel difficult for participants. One participant's description of bus seats, suggested that they provided no back support but rather aggravated their pain.

“Yes their seats are really bad for people with lower back pain. It is like sitting on a metal plate.” Allan [HDFG3]

Participants elaborated on responses they received from fellow passengers, as well as the attitudes of transit operators, who did not recognize their disability. They expressed concern that bus drivers maneuvered buses in a less than smooth manner and often accelerated into traffic before they were seated or in a secure standing position.

“They will put the ramp down but they are not going to put it down for someone who ‘looks good’... The buses themselves dodge or [drivers] hit the brakes really fast, I mean if you are standing or even if you are sitting it is hard but if you are standing it jostles you terribly.” Corrina [LDFG1]

Participants also described experiences with other transit users of the Toronto Transit Commission (TTC), ranging from helpful by offering a seat to dismissive. The TTC has implemented strategies in accordance with the Accessibility for Ontarians with Disabilities Act 2005 (AODA), to circumnavigate some of the challenges persons with disabilities may encounter. This includes a policy which states that “A customer with a disability occupying a priority seat is not required to move for another customer with a disability” (<http://www.ttc.ca>). Despite the TTC's efforts to improve access and accommodation for persons with disabilities (<http://www.ttc.ca>), participants' experiences suggest a lack of awareness of such strategies. This lack of awareness could explain some of the unpleasant interactions disabled persons have had to endure.

Continued ignorance of TTC policies will likely prolong some of the unfortunate responses towards persons living with invisible disabilities.

A participant in the high disability focus group described an instance where she was asked by another passenger to give up the accessible seats on public transit to someone who appeared to need it. Participants experience feelings of frustration as their disability continues to go unnoticed unless described to others. Even then, non-LBP sufferers could not appreciate the suffering and functional impairment of LBP. Whether through interactions with family members or with persons on a bus, LBP sufferers often encounter others' disbelief of their disability – if they appear fine on the outside, they must be fine on the inside too. Since they “look good” and appear to be able-bodied and fully functional, their pain is not viewed as legitimate. This affected the ways in which they were treated by society at large. Embedded within each discussion was the notion of LBP's invisibility to others. Matthews (1994) describes an invisible disability as one which is hidden, and not immediately recognizable by an observer. It only becomes evident in unusual circumstances or if disclosed by the sufferer (Matthews, 1994). Invisibility often occurs in the presence of chronic illnesses and my data is consistent with this as participants described many instances of LBP invisibility. Because LBP is not easily discernable, the concept of invisibility could be seen across the domains of the ICF model. The overall effects of an invisible disability are varied (Davis, 2005). Invisibility may allow a disabled person to assimilate into social settings without alerting others to their disability or subjecting themselves to further scrutiny. Conversely, the inability of others to identify an invisible disability means that disabled persons are often disbelieved and the authenticity of their disability is questioned (Davis, 2005).

Weather. The effect of weather was only mentioned by participants in the low disability focus groups. They explained that it was not cold temperatures that bothered them but rather, they experienced more pain on damp or humid days. They suggested it was the moisture in the air that aggravated their pain.

“One thing I do want to mention and I am wondering if anyone else feels this I always feel that on days like this when it is damp, there is a lot of humidity or dampness in the air that it seems to affect me more... Or in the summer the humidity really, if there is a lot of humidity in the air.” Wendy [LDFG2]

Additionally, since living with LBP, one participant shared that she has become more conscious of impending weather conditions before venturing out.

“We are getting into winter and if there is icy sidewalks and steps... something I wouldn't have thought about before; even a couple of years ago. I just would have put on good boots and gone.” Hilary [LDFG1]

The belief that weather can affect pain manifestation is a perception that has been held for years. While there appears to be no evidence to affirm or refute such a belief, the Thomas theorem offers insight to how perceptions can shape an individual's reality; “If men define situations as real, they are real in their consequences (Thomas & Thomas, 1928).” Likewise, qualitative research understands that people's beliefs and perceptions have real consequences for their actions and behaviours. Irrespective of the weather actually affecting pain, respondents believed that it did and, hence, were bracing themselves for rainy months and the likelihood that they would not be venturing out as much.

Healthcare. All participants briefly discussed their experiences with their primary healthcare providers. They sought treatment from general practitioners and chiropractors. Participants in both low and high disability focus groups were pleased with the treatment they received in the chiropractic clinic. A few participants explained in detail the empathetic nature of their chiropractor and shared some of the advice they received that they found beneficial.

“Actually my chiropractor now is actually having me...stand straight and you move your hips forward, like a tilt kind of thing, and that’s how you walk and it’s amazing. The pain is much less over a fairly long period of time you can actually walk properly.” Mallory [LDFG2]

“I do like when the chiropractor does work on me. Basically they stretch it out first and then put menthol or whatever stuff they put on it. Like this morning I was there and I find that I can move around a lot better once they do that.” Helena [HDFG3]

In addition to chiropractic treatments, participants in the low disability focus groups seemed to be actively involved in their care and encouraged correspondence between all the professionals treating them including the fitness expert at the gym to ensure that the exercises being performed were not strenuous or detrimental in any way. This observation supports previous literature which highlighted patients’ desire to be actively involved in their own treatment plans (Fu et al., 2015). It is also consistent with the idea of complying with exercise recommendation previously noted in the activity and participation domains and highlights how the domains are interconnected rather than uniquely isolated.

“If anything, I think I am stronger now and in particular, my back is a lot stronger because the great thing is I now have a feedback loop going between the guys at the chiro clinic and my trainer and the guys here are going “he needs to work more on this” and “you probably don’t want him doing this” and so there is a collaboration.” Walter [LDFG1]

High disability focus group participants were mindful of what they were feeling so they could appropriately articulate it to their chiropractors. Participants also said that their chiropractors made suggestions about strategies or equipment they might use to cope with various everyday challenges.

Some assistive devices were also used to help improve functioning. However, all participants in the high disability focus group were adamant about only using these devices temporarily as they strived to maintain their independence. They refused to use some devices altogether such as wheelchairs and walkers.

“I can do without any of those devices I am better off because once you start using them it is a crutch and basically your muscles and whatever further deteriorates because you are not using them... My independence with that is no good.” Helena [HDFG3]

Some assistive devices - such as wheelchairs and walkers were perceived to be symbolic of disablement. Participants also expressed that they did not want to announce their disability to others. This is consistent with previous studies that indicated that persons with disabilities often abandoned the use of assistive devices to avoid the judgement of others and prevent potential social exclusion, which they presumed would

occur with the use of such devices (Pape, Kim & Weiner, 2002; Shinohara & Wobbrock, 2011).

Although participants lamented that persons did not recognize their disability, they were concerned about appearing disabled and the accompanying perceived loss of social status. This contradiction seems to be the internal battle that LBP patients struggle with as they try to maintain levels of normalcy and independence while realizing that living with LBP may not allow for that. Cummings and colleagues (2017) found similar findings concluding that interventions for back pain patients should facilitate them asking for help for their diminished capability, while having a sense of self-sufficiency and self-worth.

A unique and interesting finding about healthcare was the opportunity for socializing that going to the chiropractic clinic offers. Some participants did not have healthy social lives and seemed to appreciate the friendly environment in the clinics. They often treated their chiropractic appointments as a part of their social calendar.

“Some people that go to the bar and they drink and try to get rid of their stress which actually makes things worse and to socialize. Believe it or not...I actually get a bit of a high in coming in from my treatment. So I am getting the medical help and it is also a social structure too.” Mason [LDFG2]

Healthcare played an integral role in participants' lives. They expressed the benefits of obtaining chiropractic treatments but it was quite surprising that the social component of going to the clinics seemed to play a role in their decision to attend. This finding could be the result of chiropractors acknowledging their pain and disability, which validates their feelings and experiences unlike some interactions with friends and family. Results from

Fu et al. (2015) corroborate that LBP patients seek support and encouragement from their healthcare providers, thus it is not difficult to see how LBP patients could feel a sense of social fulfillment through these interactions. With this in mind, the importance of addressing the social aspect of the biopsychosocial model is again reinforced.

Attitudes of others. The attitudes of friends, family and the general community were important to all participants. However, there was a disparity between the participants in low disability focus groups and high disability focus group. Participants in the low disability focus groups conveyed varying experiences about the attitudes of family members and community members. Some participants maintained healthy family and social relationships that did not much differ from a time when they did not have LBP.

“Yes mine hasn’t affected things that much with getting together with friends and that, so I am lucky ...” Wendy [LDFG2]

Unfortunately, not all participants had similar experiences. Some participants felt that family members had other concerns so they chose not to discuss their LBP. In this regard, the disinterest of family members caused feelings of marginalization. Some participants seemed to internalize the doubt others expressed about the seriousness of their LBP. Some of these feelings might have been self-imposed as some participants were extremely insecure about their LBP. This finding supports previous work by Smith and Osborn (2007) who found that social situations often intensified the psychological dilemma faced by LBP patients as they became self-conscious and were fearful of the judgement of others. As such, patients became socially isolated and had no desire to interact in public forums.

“...much like you are at the dining room table with your family there is always other people’s issues that are more important and more pressing kind of thing, than just ‘oh, you just have lower back pain’ whatever!” Val [LDFG1]

Some participants indicated that their lack of family relationship came from personal decisions and previous family turmoil, not stemming directly from living with LBP. Conversely, participants in the high disability focus group saw living with LBP as the reason why they experienced personal strife from day to day. They believed LBP led to the decline of relationships and that friends and family did not understand what living with LBP was like. Family and friends were often unsympathetic about participants’ expressions of pain, and would often steer conversations in a different direction or even distance themselves.

“I find that people say they will be there for you, they are your friends or whatever and even family and all of a sudden there will be days or times when I need somebody for even emotional support or physical support to do something and everybody is busy or they don’t want to come or they don’t want to hear about it.” Helena [HDFG3]

“I mean I had work friends but only at work. Once you leave work they go home you know and didn’t really have time to talk...My friends are not interested in what I want to do ok so I would like to see people more interested in what I want to do and I will join them.” Corrina [LDFG1]

High disability focus group participants implied that their LBP was in part or wholly responsible for their inability to work or effectively function in social settings. These participants seemed to be more conscious of their disability when in the presence

of non-back pain sufferers and worried about how they were perceived by others (Smith et al., 2007).

IV. Personal Factors

The personal factors which impacted on participants were age, gender, financial constraints, co-morbidities and coping.

Ageing. Ageing seemed to play a role in how low disability focus group participants perceived their disability. Some participants questioned whether their experiences with disability were simply resulting from the normal ageing process rather than having LBP:

“I think my emotional state is just understanding that this is a 51 year old body that has gone through a lot of sports and athletics and knocks and bruises and stuff like that.” Val [LDFG1]

Meanwhile, high disability focus group participants did not seem to perceive that their age was a factor in their level of disability as it was not mentioned in our conversation. This observation is not supported by the literature, which suggests that increasing age is associated with the increase in musculoskeletal symptoms (Manchikanti, 2000). Similar findings were reported by Hoy, Brooks, Blyth and Buchbinder (2010) who found that the prevalence of LBP increases with age until approximately age 60.

Gender. Gender was not openly discussed in the focus groups. However, inferences about gender could be made based upon what participants shared in the focus groups. The data suggests that male participants in all three groups, were more physically active, whether it was in the gym or taking part in other outdoor activities. One low disability focus group male participant commented on verbalizing pain to male friends:

“Especially with the ‘macho-ness’ of some guys...we don’t talk about how sore we are ... but realistically a lot of us probably have a lot of pains.” Leo [LDFG2]

This quote is typical of the social norms for men, who tend to be less forthcoming about their expression of pain. This finding supports previous research which reported that women were significantly more likely to report temporary or persistent pains than men (Unruh, 1996; Manchikanti, 2000).

Financial Constraints. Finances seemed to be less of a concern amongst participants in the low disability focus groups but financial constraint was a recurrent theme in the high disability focus group. Participants expressed that the cost of participating in certain activities or using resources such as the gym was sometimes a barrier to social interaction (Ashby et al., 2012). Understandably so, as loss of jobs and difficulty finding new employment required participants to be frugal. Satisfying basic needs such as food and shelter were participants’ primary priorities. It was clear that many of their decisions were based on what they were able to afford at any given time.

“Eating is expensive...You buy what is healthy and what is on sale and you try to eat healthy...they say with the inflammation you have to watch what you eat...you have to watch dairy and gluten and all that stuff but again they are expensive stuff.” Francine [HDFG3]

Even with trying to implement health conscious diets, high disability focus group participants have had to worry about the cost of some recommended foods making it challenging to achieve this objective.

Co-morbidities. Additional co-morbidities likely caused some of the disability of the participants in the low and high disability focus groups alike. These included arthritis,

previous neck injuries, residual injuries from motor vehicular collisions and an acquired brain injury. However, participants in the low disability focus groups were less affected by their previous and ongoing ailments. Chronic comorbidities were more common amongst high disability focus group participants.

Coping. Self-management was the primary coping mechanism for participants in both low and high disability groups. It allowed them temporary relief from their LBP and gave them the opportunity to function more adeptly in everyday situations. They used various temporary modalities to alleviate their pain such as hot/cold packs, topical pain relieving creams and painkillers. A few participants also mentioned that they found deep breathing exercises and meditation to be effective. Participants in the low and the high disability focus groups believed that a healthy diet could improve their functioning and many participants tried to eat healthily. High disability focus group participants however, found that they were often unable to afford healthier (organic) foods.

Other enablers to functioning included developing creative self-management techniques and interacting with other LBP patients. One participant in the high disability focus group arrived at a creative solution to improve her travel on public transit. She carried a backpack stuffed with soft items (scarves, clothes etc.) which functioned as a cushion to ease the pressure on her back. Another participant said that receiving advice from other LBP patients was one way she was able to function as she learned about new coping strategies and available resources.

“Hearing what other people are doing, I think community support is a big thing, because everybody knows one piece of the puzzle but nobody knows the whole puzzle.” Corrina [LDFG1]

Acknowledging that self-management strategies cannot heal and that they seldom produce long-term relief is important for LBP patients to consider. However, their use of these self-management strategies could be indicative of what patients must do to function until their next chiropractic treatment. Also, the frequent use of self-management strategies could point towards patients preferring the often immediate pain relief they feel using temporary relievers that may cause them to utilize chiropractic treatment as a secondary form of pain relief and management, rather than in a primary capacity. Thus, it may be beneficial for chiropractors to advise their patients that these self-help strategies are not curative and in many cases, they offer minimal benefits to managing LBP.

2.4 Discussion

Previous research has shown that little focus has been placed on the social aspect of the biopsychosocial model (Carr and Moffatt, 2005). The results of my thesis suggest that the social and psychological challenges associated with LBP are equally as salient as biomedical challenges.

My study suggests the ICF framework captures the range of experiences identified by low and high disability groups within the ICF domains. In general, persons in the low disability groups had higher functionality but having LBP caused them to modify some of the activities they carried out and they were cognizant about what events they could participate in. In most cases, familial relationships and friendships were only minimally affected, if at all. However, they expressed emotional responses and depressive symptoms associated with living with LBP. Persons in the high disability group experienced similar emotional responses but their depressive symptoms appeared to be more extreme. Their physical capabilities were far more diminished and

relationships with family and friends were significantly strained. Participants in the high disability group showed more of a proclivity to social isolation as a result.

Also, the findings highlight the applicability of the ICF model by demonstrating the interaction between the various elements of the framework, how they feed off each other, and ultimately how they impact different aspects of the lives of LBP sufferers. The multi-directional arrows in the framework are consistent with participants' experiences and support feedback loop between the domains in the framework. My findings also support that disability associated with LBP does not occur singularly but rather has multiple, often simultaneous effects (Arnow et al., 2011). For example, participants expressed that physical pain caused a lack of ability to complete activities or participate in leisure events which often influenced the attitudes of people they interacted with. This example exemplifies the direct interaction between body function, activities, participation, and environmental factors of the framework. Another example of the interaction between the domains in the framework can be seen in participants' belief that damp weather conditions exacerbated their LBP. As a result, they felt less able to complete tasks or participate in leisure activities. From a causal perspective, there is little evidence to support that weather intensifies pain sensations (MacFarlane, McBeth, Jones, Nicholl & MacFarlane, 2010; Patel et al., 2016). However, from a biopsychosocial stance and specifically the premise of the ICF framework, the personal belief that this environmental factor could impact patients' lives is significant.

A significant portion of the findings were categorized within the domains of environmental factors and personal factors. Public transportation, as well as the facilitators and barriers of patient functioning were the major environmental factors of

focus in our dialogues. The consensus amongst low disability and high disability groups within the downtown core was that many of their experiences using public transportation were unpleasant. The uncomfortable seating and less than smooth rides had physical consequences for LBP patients. However, previous literature has focused primarily on the LBP in transit operators rather than passengers, suggesting that drivers' seats needed to be ergonomically evaluated and adjusted accordingly (Okunribido, Shimbles, Magnusson & Pope, 2007).

The ICF framework effectively captured the array of expressions identified in the environmental factors domain, which intently addresses the attitudes of others.

Participants in the high disability group felt that living with LBP severely affected people's attitudes towards them and that they were no longer able to maintain social relationships or carry out gainful employment. These experiences support findings by Walker et al. (2006) who developed the theme of loss in their article. Our participants demonstrated physical loss, social loss and economic loss that can occur as a result of high levels of disability associated with LBP.

This study supports the notion that LBP often produces social and psychological consequences in sufferers' daily lives that are not typically assessed, documented or addressed in their clinical care. This highlights the need to use a biopsychosocial model to determine disability and functioning in patients with LBP. The findings of this study can be used to raise awareness about some of the fundamental enablers and inhibitors of functioning while living with LBP. The ICF framework addresses the often overlooked, social factors of the biopsychosocial model but also goes beyond the literal 'biopsychosocial' meaning by exploring the impact of environmental and personal

factors. The findings of the study support the need to measure and address social factors, often underrepresented in previous work. Furthermore, the findings demonstrate the interactions between the dimensions of the ICF framework and highlight the complex nature of social and psychological factors and the challenges with assessing them.

Strengths and Limitations

Numerous criteria were used to validate this work and assure quality in the execution of this project. Recruitment took place in multiple chiropractic clinics in the Greater Toronto Area. This helped in presenting accounts of persons with varying demographic profiles and shows the spectrum of disability within the Greater Toronto Area. The WHODAS-12 questionnaire was used to dichotomize focus groups into high and low disability. The self-administration of the questionnaire was a method of encouraging participants to candidly share their experiences. The answers to the questionnaire also reflected that the experiences of LBP patients vary with their level of disability.

By exploring the experiences of persons living with LBP, I was able to communicate directly with participants and clarified what was being communicated. I acknowledged my thoughts and pre-conceived notions *a priori* and refrained from sharing them in an effort to diminish their influence on participants' responses. Rather, I aimed to view LBP through the figurative 'lens' with which LBP sufferers saw their own experiences. Participants in this study seemed comfortable in a group of persons with whom they had much in common and they seemed to interact smoothly. This speaks to the benefits of homogeneity within groups when conducting focus groups. There emerged

a genuine interest in exchanging ideas and resources which helped to achieve authenticity within the data (James, 2008).

Detailed records of my research environment and clear methodological justifications have been provided to increase transferability within similar contexts. The subjective nature of the qualitative methodology encouraged participants to share freely and the results are likely to have wide applicability. Additionally, the probable connections between the data collected in the study and data previously collected in other studies that also utilized the ICF model, is likely to be a major strength of this study.

The data was reported with clarity so that the participants' accounts were not obscured or misrepresented in the interpretation of them. Re-stating what was understood from participants' accounts served as verification that their experiences had not been misunderstood and added credibility to the data (Jensen, 2008; Morrow, 2005).

I observed that persons who were unemployed seemed to be more available to actually participate in focus group data collection sessions, which may be a limitation of this study as we were unable to represent fully the similarities and/ or differences between employed and unemployed participants. Moreover, only one high disability focus group was conducted. The results showed that LBP patients with high disability experienced greater restriction in mobility (transportation) than those with low disability. This could be an indication that even attending focus groups were more difficult for persons with high levels of disability. There is an opportunity for further research to be conducted looking at the similarities and differences in high and low disability groups. While there is still room for further research, it is important to acknowledge the likelihood of having saturated some of the categories within the data.

Likewise, those who were busier (employed) might have had less time to participate in a focus group. Further efforts might be made to target and investigate this population. Thus, my sample may be different from the typical profile of LBP patients who seeks chiropractic care; these patients tend to be younger urbanites of higher-than-average social status (Côté et al., 2001). Admittedly, stratifying LBP into only two groups, instead of three or four, while an important first step, could be seen as a harsh delineation that may not account for more discrete distinctions amongst LBP sufferers.

Clinical Significance

As one component of the larger collaborative study, the insights gained from my research will provide rich qualitative data to the international collaboration between UOIT and the ICF Research Branch—a cooperation partner within the WHO Collaborating Centre for the Family of International Classifications in Germany (at DIMDI). Presenting data collected in Canada about how LBP patients experience disability will complement data collected in Norway and Botswana. Obtaining data from different regions will make it possible to compare the similarities and differences across cultures and nations. Also, the data collected in Norway and Botswana was collected using similar focus group schedules thereby strengthening the ability for regional and cultural comparisons to be made. The aim within this larger project is to identify the aspects of functioning which were most important to our participants. In this study, I was able to determine some on the environmental and personal factors of the ICF framework which seem to influence LBP patients' disability and functioning. With the insightful qualitative data obtained from various countries, the main objective of the collaborative project will be achieved by using this new knowledge in the development of an ICF-based assessment schedule

for manual medicine for standardized measurement and reporting of functioning across countries. Creating an assessment tool based on this framework is sure to contribute to improved patient centered models of care. Clinicians are likely to be more in-tuned with how patients' needs and expectations can be met by being able to assess and document disability in LBP patients.

2.5 Conclusion

The experiences of persons living with LBP are far reaching. The stratification of levels of disability in LBP patients provided a window into the differing experiences described by patients. While participants in the low disability focus group continued to maintain their everyday activities and lifestyle without significant changes, more severely disabled persons often could not, and were perceived as malingerers. This sometimes led to a sense of social isolation because of the invisible and debilitating nature of their condition.

The ICF model was helpful in organizing and analyzing data obtained through the focus groups. We now have a clearer view of the beliefs and perceptions of LBP patients and can suggest what changes would improve their functionality. This study can inform family and friends about ways in which they may better facilitate LBP care.

Environmental and personal factors within the ICF framework accounted for a large portion of the data which suggests that using a biopsychosocial approach is important for the treatment and management of LBP. It will be important for clinicians to consider all aspects of the model that can impact disability when assessing, documenting and recommending treatment for LBP.

Chapter Three: Discussion and Conclusion

3.1 Main Findings

The primary objective of my thesis was to describe how persons experience disability and construct their lives when faced with LBP. The accounts of LBP patients, obtained from our focus groups shows that their experiences of disability and function span across physical, psychological, social and environmental realms. Although there were areas of similarity, there were also several differences between persons in low disability and high disability groups. Additionally, grouping participants into the severity of their disability demonstrated that varying disability is consequential to the experiences that LBP patients are likely to have.

Woven throughout the tapestry of our dialogues was the concept of the invisible illness. The impact of the invisibility of LBP was reflected in the ways in which patients were treated by others, their interactions in various settings and also the ways in which they viewed themselves. Participants in the high disability focus group seemed to be more self-consciousness about their LBP, especially while in the presence of others which reiterated previous findings (Smith et al., 2007; Corbett et al., 2007; Snelgrove et al. 2013).

Emotional symptoms such as feelings of depression, a loss of self-worth and social isolation were common experiences amongst focus group participants. Because LBP does not always present with visible disabling symptoms that external parties can recognize, when persons shared that they had LBP, they often felt that persons were dismissive of their condition, and feelings of marginalization and stigmatization became apparent (Goffman, 1963; Holloway et al., 2007). Participants' accounts often illustrated withdrawal from social settings or the decision to refrain from sharing their experiences

of living with LBP with non-LBP sufferers (Larsen et al., 2013). Also of significance, was the presence of an ambivalent relationship between participants and environmental factors, which the ICF describes as physical settings, social settings and the attitude of persons within those settings. In the case of this project, environmental factors included public resources (transit, building design, community resources), the response of others and healthcare services. My results demonstrate the interrelatedness of the findings and how, as a whole, their effects on everyday life are all-encompassing.

The results of this study support much of the existing literature with regard to the need to consider social factors in the development of effective treatment strategies for LBP. Substantial findings within the environmental factors domain indicate that factors outside of the biomedical model greatly affect the level of function or disability experienced by LBP patients.

3.2 Strengths and Limitations

This study was carried out with careful consideration of ensuring that the data adds new knowledge and richness to the body of work that already exists. A review of the literature suggests that few qualitative studies have focused on the biopsychosocial model. Numerous authors made reference to the biopsychosocial model, but acknowledged that the model has yet to be addressed in entirety (Carr et al., 2005; Campbell et al., 2012). My focus on the biopsychosocial model and specifically on environmental and personal factors provides unique and useful insight. The use of an in-depth qualitative methodology and study design allowed for the patients' perspectives to be appreciated for their authenticity. Moreover, the use of a focus group schedule specifically created based on the domains of the ICF framework – a multidimensional

biopsychosocial model - aided in obtaining information. Supporting probative questions were asked as needed to unearth any other ideas that arose and clarify any uncertainties. Participants were recruited from a number of different clinics in a variety of locations which allowed multiple socioeconomic profiles to be presented. Had recruitment occurred in only one location, it is likely that it would not have been possible to comparatively show the spectrum of disability within the Greater Toronto Area.

While the sample size was relatively small, it was reflective of those who were able to attend scheduled focus group sessions. It is important to acknowledge that due to the qualitative nature of this study, and the subjectivity of participants sharing their own thoughts and perspectives, results may have wider applicability within the general population. However, with a larger sample and conducting a few more focus groups, it is possible that differences with regards to gender, and perhaps age, might be more clearly elucidated.

The WHODAS-12 questionnaire is a valid and reliable tool to measure disability (Von Korff et al., 2008) and was used to stratify participants into high and low disability focus groups. Since the questionnaire was self-administered and based on participants' perspectives, this was an additional element of allowing participants to share their beliefs freely. The use of WHODAS-12 questionnaire also suggested that participants with varying severity of disability have different experiences, which helps to substantiate the generalized belief that people with disability are not homogeneous due to the temporality of their pain.

The goal of this research was to obtain and present the perspectives of an array of persons from diverse backgrounds and with varying levels of disability. The recruitment

strategy allowed for an assortment of participants to be obtained. Those who were unemployed seemed to be more available to volunteer and actually participated in the focus group data collection sessions. Those who were employed had a harder time making the time commitment with their busy schedules. This suggests that the variation in the sample was lower than desired. However, it is likely that the sample is skewed towards the low disability groups more than the high disability group because two times more low disability focus groups were conducted.

In the low disability groups, data saturation was approached and shows the validity of having multiple focus groups and presenting numerous outlooks. With only one high disability group conducted, I am unable to say if data saturation was achieved in this case. This does not invalidate the results but rather creates an opportunity for further research to be conducted about what strategies may be implemented to increase participation, especially in participants who work. Furthermore, since this data will be used in conjunction with data obtained in other countries for the larger collaborative study, the combined data may help to determine if saturation was actually reached.

It should also be noted that all individuals with high disability came from the downtown Toronto. This biased sample may be indicative that persons outside of the downtown core seek care more quickly for their LBP or may have more financial resources available to put towards more aggressive and/or frequent treatment strategies. Further research into this speculation is needed.

It is important to recognize that the focus groups took place in a location which was outside of participants' everyday environment. This, in itself may have taken away

some of the richness in the data that could have been achieved if participants were observed and interacting in familiar settings.

Another limitation of this study was that the focus groups were quite small and only one high disability focus group was conducted. Therefore, readers should remain cautious in generalizing from the results. However, this data in addition to complementary data obtained for the larger study is likely to improve generalizability.

The interactions identified in each focus groups offer points of departure for further investigation. Notwithstanding these limitations, the study population did not seem otherwise atypical, at least not with respect to LBP sufferers seeking chiropractic care.

3.3 Significance of the study

LBP is a health condition of major concern worldwide and its effects are far reaching. The literature has indicated that some parts of the biopsychosocial model have been neglected when treating LBP patients. Therefore, this study is significant in its aim to present all aspects of the biopsychosocial model and their varying impacts on disability and functioning amongst those living with LBP. By using the ICF model as the framework for obtaining the lived experiences of LBP patients, the data clarified the parts of the domains which were most salient and especially with respect to social aspects which were neglected in previous work. Also, minimal research has been conducted to compare levels of disability associated with LBP and its impact on everyday life. The use of this data to inform the UOIT-ICF collaborative project should confidently yield a viable assessment schedule that will improve the assessment and treatment process for clinicians and patients alike.

3.4 Implications for future research

Future research might employ more targeted recruitment strategies to gain the perspective of more high-disability and employed participants. As an implication for further research on this topic, it may also be beneficial to consider if socioeconomic status affects the likelihood of participation in LBP patients. As this was an initial study, all results may not reverberate with other LBP sufferers but the areas of similarity between low and high disability groups are an indication that some of these findings will be transferable in a similar setting and using a similar target sample. Thus further research into this topic is necessary. Also, the distinction between persons with low and high disability yielded some useful data about similarities and differences in these groups. However, the division, in some cases, was quite crude and so the level of differences could not be ascertained. This offers an opportunity in which future studies could try to determine the significance of discerning more discrete differences. Likewise, the notions of gender roles and gender differences were seen briefly in the review of the literature as well as in focus groups. These concepts may warrant more in-depth exploration.

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Appendices

Appendix A: Invitation letter and Informed Consent Package



LETTER OF INVITATION

Researcher(s): Sharli-Ann Esson, MHS Sc Candidate (Primary Investigator), Pierre Côté, PhD (Co- Investigator) Ellen Aartun, PhD (Co-Investigator), Silvano Mior, PhD (Co-Investigator) and Robert Weaver, PhD (Research Supervisor)

Departmental and institutional affiliation(s): Faculty of Health Sciences, UOIT

Contact emails: sharli-ann.esson@uoit.ca ; pierre.cote@uoit.ca ; ellen.aartun@uoit.ca ; smior@cmcc.ca ; robert.weaver@uoit.ca

Dear Sir/Madam,

The purpose of this letter is to invite you to participate in our research study. Our study seeks to understand how persons living with lower back pain (LBP) experience disability and function in their daily lives. As per our recent introductory conversation at the clinic, you have expressed an interest in our study and you are being asked to participate because you are living with LBP, are currently seeking chiropractic care for the condition and you are between 20-65 years of age. The enclosed Informed Consent Form provides all the details about our study, which we discussed when we spoke. Please take some time to review this document thoroughly and consider all details before deciding whether you would like to take part in the study.

You are not obligated to participate in this study. If you do not wish to participate, you are free to withdraw from the study at any time and may do so without impact to yourself or your level of care. You are not required to give a reason for your withdrawal.

If you would like to participate in this study, once you have carefully considered the details provided, please sign the attached Informed Consent Form and return the completed copy to me by October 30, 2016. If you would like to discuss any of the information provided or have questions about anything, do not hesitate to contact myself or Dr. Côté.

Thanks so much for taking the time to review this information.

Kind Regards

Sharli-Ann Esson (Investigator) sharliann.esson@uoit.ca



INFORMED CONSENT FORM

Title of Research Study: How do persons with Lower Back Pain (LBP) experience disability in their everyday lives? A qualitative analysis.

You are invited to participate in the research study named above. This study has been approved by the Research Ethics Boards of University of Ontario Institute of Technology (REB # 15-145) on August 28, 2016 and the Canadian Memorial Chiropractic College (REB # 162014) on September 16, 2016. Please read this form carefully and feel free to direct any questions you may have concerning the research study to Sharli-Ann Esson or Dr. Pierre Côté via email. Any questions regarding your right as a participant, may be addressed to the Ethics and Compliance Officer - researchethics@uoit.ca or (905) 721-8668 x 3693.

Researcher(s): Sharli-Ann Esson, MHSc Candidate (Primary Investigator), Pierre Côté, PhD (Co-Investigator) Ellen Aartun, PhD (Co-Investigator), Silvano Mior, PhD (Co-Investigator) and Robert Weaver, PhD (Research Supervisor)

Departmental and institutional affiliation(s): Faculty of Health Sciences, UOIT

Contact emails: pierre.cote@uoit.ca; sharli-ann.esson@uoit.ca; ellen.aartun@uoit.ca ; smior@cmcc.ca ; robert.weaver@uoit.ca

External Funder/Sponsor: The Norwegian research foundation “Et liv I bevegelse” (ELIB). 2015-2017

Purpose and Procedure:

The purpose of the study is to understand how persons living with LBP experience disability and functional limitations in their daily lives. This research utilizes focus groups to obtain the personal accounts and viewpoints of participants, where you can speak freely with the researcher and other participants about your experiences. Participation in this study will require me to complete a self-administered questionnaire which will obtain information about my general activities and the degree of disability I experience with LBP while carrying out regular tasks. I will also participate in a focus group. I understand that I am agreeing to participate as a volunteer member in both parts of this study. The focus groups will be audio-recorded and transcribed verbatim thereafter. The principal investigator may also take notes by hand during the process. It is anticipated that the focus groups may take approximately 60-90 minutes to complete and will be conducted in a private conference room at CMCC, 6100 Leslie St., North York, ON, M2H 3L1. Each participant will be assigned a pseudonym that will be used without identifiers throughout the focus groups and subsequent write-up of data and results. Participants will be asked not to use their real names during the focus groups. An Excel spreadsheet will be created that will contain the email address, pseudonym and real name of each participant. This information will be stored on the secure and encrypted

online UOIT storage platform accessible only by members of the research team and guarantees confidentiality. Following the completion of the focus groups, the feedback will be transcribed by a professional transcriber; who has also signed a confidentiality agreement to guarantee your privacy and anonymity. All data obtained from these focus groups will be used solely for analysis to answer the research question i.e. how do persons living with lower back pain experience disability in their everyday lives?

Potential Benefits:

This study is likely to have wide reaching impacts on a variety of persons including the participants themselves, their family members as well as clinicians and healthcare policymakers. First, it will provide a deeper understanding of how LBP patients perceive the impact of LBP on their lives. Second, it will improve our understanding of what LBP patients need to function effectively. The study will also provide rich qualitative data to the international collaboration between the University of Ontario Institute of Technology and the International Classification of Functioning, Disability and Health (ICF) Research Branch. Presenting a Canadian perspective on the impact of disability on patients with LBP will compliment qualitative data also being collected in Norway and Botswana. Obtaining data from different regions will make it possible to compare the similarities and differences across cultures and nations. This information will be used for the development of an assessment schedule for improved manual medicine. Informative insights about patients' experiences with, and expectations of, the treatment of LBP and how clinicians may better facilitate patient care will be obtained from this research. Finally, this study will elucidate ways in which family members, seeking to understand their loved ones condition, can provide enhanced care and support.

Potential Risk or Discomforts:

You may feel uncomfortable or embarrassed sharing your experiences with low back pain and disability and functional limitations, with others in a group setting. However, the groups are small to provide a more comfortable atmosphere for discussion. Also, please be advised, that although this occurrence is unlikely, it may be possible that you may encounter another patient you are familiar with, since more than one person from the same clinic may volunteer to participate in this study. Also, the use of clinicians to aid in the recruitment process (although minimally) may cause you to feel somewhat coerced. Please be assured that this study is completely voluntary and will in no way affect the services you receive from the clinic. More importantly, all data collected during the focus groups is confidential and cannot be accessed by any clinicians.

Storage of Data:

Recorded focus groups will be transcribed on Google Docs within the Google Apps for Education on the UOITnet server and will be accessible only by the principal investigator and research team listed above. Any hand written notes taken by the principal investigator will be shredded, once transcriptions are complete. Participants can be assured that their real names or other identifiers will be kept in confidence as they will be referred to by pseudonyms during the focus groups and in all transcripts and published works. Raw data transcripts will be kept for 7 years by the principal investigator on the UOITnet server. This data may be useful for further research. All data will be stored without identifiers to safeguard the privacy of our participants.

Confidentiality:

Your experiences in accessing health and social care services will be collected for the purposes of informing the research questions and will only be shared with members of the research team listed on this form. Your privacy shall be respected. No information about your identity will be shared without your permission, unless required by law. Confidentiality will be provided to the fullest extent possible by law, professional practice, and ethical codes of conduct.

Right to Withdraw:

Your participation is voluntary, and you can answer only those questions that you are comfortable with. The information that is shared will be held in strict confidence and discussed only with the research team. You may withdraw from this study at any time. If you withdraw, your data will be removed and destroyed and not included in the research. You do not need to offer any reason for why you wish to withdraw your consent. Please note that honorariums are provided at the end of the focus group sessions but will not be contingent upon your decision to withdraw.

Compensation:

Each and every participant will receive a \$10 gift card as an honorarium for participating in this study. Parking validation will also be provided to those who utilize the paid parking facilities.

Debriefing and Dissemination of Results:

A hard copy of the published thesis research will be given to the Canadian Memorial Chiropractic College (CMCC), Sherbourne Health Centre and the South Riverdale Community Health Centre. Information on how to access an electronic version of the thesis from the National Library Archives of Canada will also be communicated, should any clinicians or participants be interested.

Participant Concerns and Reporting:

I have been provided the opportunity to ask questions and if I should have any additional questions or concerns, I can contact Sharli-Ann Esson or Dr. Pierre Côté via email at any time; all conversations will be kept confidential.

This study has been approved by the UOIT Research Ethics Board (REB# 15-145) on August, 2016 and the CMCC Research Ethics Board (REB# 162014) on September 16, 2016. If you have any questions concerning the research study or experience any discomfort related to the study, please contact Sharli-Ann Esson at sharli-ann.esson@uoit.ca or Dr. Pierre at pierre.cote@uoit.ca.

Any questions regarding your rights as a participant, complaints or adverse events may be addressed to the Research Ethics Board through the Ethics and Compliance Officer- researchethics@uoit.ca or 905-721-8668 ext. 3693.

The results of this study should be completed by May 2017. If you desire to receive information regarding the results of this study, please contact the researchers by email at pierre.cote@uoit.ca or sharli-ann.esson@uoit.ca.

Consent to Participate:

If you consent to participate in this study, please read and affirm the following:

- I consent to voluntarily take part in the study with the understanding I may withdraw at any time. I have had an opportunity to ask questions and my questions have been answered. I am aware of all the risks and benefits associated with my participation and have read the entire consent form. I am free to ask questions about the study in the future.

- I agree to allow the data collected in the study to be used for future secondary research.

- I will receive a copy of my signed Informed Consent form upon signing.

Name (print): _____

Signature: _____

Date: _____

Appendix B: World Health Organization Disability Assessment Schedule (WHODAS-12)



WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

12-item version, self-administered

This questionnaire asks about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.

Think back over the past 30 days and answer these questions, thinking about how much difficulty you had doing the following activities. For each question, please circle only one response.

| In the past 30 days, how much difficulty did you have in: | | | | | | |
|---|---|------|------|----------|--------|----------------------|
| S1 | <u>Standing for long periods</u> such as <u>30</u> minutes? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S2 | Taking care of your <u>household</u> responsibilities? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S3 | <u>Learning a new task</u> , for example, learning how to get to a new place? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S4 | How much of a problem did you have <u>joining in community activities</u> (for example, festivities, religious or other activities) in the same way as anyone else can? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S5 | How much have <u>you</u> been <u>emotionally</u> affected by your health problems? | None | Mild | Moderate | Severe | Extreme or cannot do |

Please continue to next page...



WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

12
Self

| In the past 30 days, how much difficulty did you have in: | | | | | | |
|---|--|------|------|----------|--------|----------------------|
| S6 | <u>Concentrating</u> on doing something for <u>ten minutes</u> ? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S7 | <u>Walking a long distance</u> such as a <u>kilometre</u> [or equivalent]? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S8 | <u>Washing your whole body</u> ? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S9 | Getting <u>dressed</u> ? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S10 | <u>Dealing with people you do not know</u> ? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S11 | <u>Maintaining a friendship</u> ? | None | Mild | Moderate | Severe | Extreme or cannot do |
| S12 | Your day-to-day <u>work</u> ? | None | Mild | Moderate | Severe | Extreme or cannot do |

| | | |
|----|--|------------------------------|
| H1 | Overall, in the past 30 days, <u>how many days</u> were these difficulties present? | Record number of days |
| H2 | In the past 30 days, for how many days were you <u>totally unable</u> to carry out your usual activities or work because of any health condition? | Record number of days |
| H3 | In the past 30 days, not counting the days that you were totally unable, for how many days did you <u>cut back</u> or <u>reduce</u> your usual activities or work because of any health condition? | Record number of days |

Please indicate what days and times are most convenient for you to attend the focus group (select all that apply):

- | | |
|------------------------------------|---------------------------------------|
| <input type="checkbox"/> Monday | <input type="checkbox"/> 9am-10:30am |
| <input type="checkbox"/> Tuesday | <input type="checkbox"/> 10:30am-12pm |
| <input type="checkbox"/> Wednesday | <input type="checkbox"/> 12pm-1:30pm |
| <input type="checkbox"/> Thursday | <input type="checkbox"/> 1:30pm-3pm |
| <input type="checkbox"/> Friday | <input type="checkbox"/> 3pm-4:30pm |
| <input type="checkbox"/> Saturday | <input type="checkbox"/> 4:30pm-6pm |
| | <input type="checkbox"/> 6pm-7:30pm |

This completes the questionnaire. Thank you.

Appendix C: Focus Group Interview Guide

Focus Group Guide

1. Introduction: 5 – 10 minutes

- a) Collect Informed Consent prior to audio-recording. Ask if participants have any questions about the reason for, or content of, the informed consent. Subjects will need to sign the informed consent form prior to commencement of focus groups.
- b) Set the stage and explain the purpose for the meeting. The purpose of the focus group is to obtain participants' perspective and experiences on matters related to lower back pain and experiences of disability.
- c) Outline rules and procedures for the focus groups.

Introductory Script:

“Hello Everyone and Welcome. Thank you all so much for being here and taking the time to join our discussion about experiences with LBP. My name is [insert name] and I am a [insert position] on this research team. You have been asked here today to share some of your personal insight into living with LBP and how that affects your ability to function. You have been invited because you all live with LBP and undoubtedly have many stories to share about living with the condition; in particular family support, work environment, healthcare resources, age etc. that may influence their ability to function. This information will ultimately be used to help improve the way in which LBP is managed. There are no wrong or right answers. We expect that you will have different perspectives and feel free to share those perspectives, regardless of if it differs from what others have said.

Remember, as you have acknowledged on your informed consent form, this focus group will be recorded so that we don't miss any of your comments. In front of each of you, there is a name card. Those name cards will help me to remember your names and will also help you, should you need to comment or follow up on a point made by someone previously. Also, to maintain confidentiality and privacy, we ask that you do not disclose where it is that you were recruited from or the name of the clinician that provides your treatment.

We are interested in hearing from each of you so feel free to chime in at any point. We want to ensure that everyone's voice is heard. We ask that each of you identify yourself by first name only prior to speaking. Also, please wait to be called upon to speak so only one person speaks at a time. Alright let's begin...I will start with an easy question...[ice breaker question]"

2. Focus Group Questions and Probes: 90 minutes

Simplified definition of LBP: muscle ache, stiffness or tension confined between the bottom of the rib cage and the upper thigh, with or without sciatica.

Ice Breaker:

- a. How is it to live with LBP? (Tell us a little bit about your LBP)

Main Questions:

Body structure- the anatomical components of the body (WHO, 2001)

1. **In what part of your body is the pain localized?**

Probe: What do you mean? (asked as needed)

- i. Do you find that the pain/discomfort is localized in only one area? What other areas do you feel are involved? (Where else do you feel pain?)

2. **In what part of your body do you feel the pain is coming from? (Joints, muscles, bones)**

Probe:

- i. Do you feel pain in more than one area at the same time? Or does it jump from one area to the next?

Body Function - the physiological systems and mechanisms within the body (WHO, 2001)

1. **What sorts of physical problems have you noticed about yourself while living with LBP?**

Probe: What do you mean? (asked as needed)

- i. How would you describe your muscle strength or endurance? Are you able to stand up or sit down, bend forward, or make normal body movements with ease?
- ii. What parts of your body just don't work as well as they used to?

2. What sorts of emotional or mental responses have you noticed about yourself while living with LBP? **When you think about your mind, is there anything unusual e.g. problems with emotions or mood, sleep and energy/drive?**

Probes:

- i. How would you describe your ability to concentrate? Are you easily distracted?
- ii. Describe your energy level on a typical day? High? Low?
- iii. Do you find it hard to fall asleep or stay asleep? If yes, why?

Activity and Participation- the execution and completion of tasks. Participation refers to involvement in day-to-day situations (WHO, 2001)

1. **If you think about your daily life, what difficulties do you encounter living with LBP?**

Probe: What do you mean? (asked as needed)

- i. Do you think your day-to-day activities have been impacted? For instance, do you encounter difficulty carrying on with usual work or household activities? Self-care? In what ways?

2. **Tell me about some of the social activities you are involved in.**

Probes:

- i. What are the limitations, if any, you feel in doing these activities?
- ii. What activities would you like to participate in, but cannot participate in because you are inhibited?
- iii. Has your interactions with others (e.g. friends, family, colleagues) been affected? Do you socialize more often or less?

Personal Factors- the background features of an individual, not easily changed (WHO, 2001).

1. **Think about yourself, your life situation, gender, who you are – how does it affect the way you function?** How does it affect your experiences with lower back pain?

Probe: What do you mean? (asked as needed)

Environmental factors- the physical environment, social settings and the attitudes of persons in this context (WHO, 2001)

Let's discuss the factors we have around us, like work, family, community, environment- whatever you can think about. First, we want to understand more about what you have around you that you believe **improves** your functioning, what facilitates you and make you feel better?

1. Thinking about your environment, e.g. home, working conditions and social settings, **what do you think are some things that enable you to function better?**

Probe: What do you mean? (asked as needed)

- i. Describe any habits you have developed or any devices you utilize in various settings that you find beneficial.

2. How well do you think society understands you? **Would you say people are supportive in helping you manage from day-to-day?** How?

Probe:

- i. In what ways do people assist you? What are the attitudes of people around you?

3. **What services and/ or resources in the community have you used and found helpful?**

Probe:

- i. In what ways, if at all, have your health care system facilitated your functioning? From whom so you seek care?

Now that we have talked about the things that you think improve your functioning, we also want to know about the things around you that you feel **hinders** your functioning.

1. Reflecting or thinking about your surroundings, e.g. home, working conditions and social settings, **is there anything that limits your ability to adequately function?** What limits you and how?

Probe:

- i. Would you say that people makes it more difficult for you to function from day-to-day? How so? What are the things they do to inhibit you?

2. **Describe any services or resources which you find difficult to use or implement into your everyday life?**

Probe:

- i. Do you have any difficulties accessing or using resources or services? For example accessibility issues (transit, building design-elevator/escalator)? Equipment at work such as uncomfortable chairs, tools, machinery etc.?

3. **Describe any devices or equipment that you have used in these settings that you find prevents you from function or act as a hindrance in any way.**

3. Conclusion: 5 – 10 Minutes

Verbal acknowledgement and thank you”

“We have come to the end of our focus group. Once again we’d like to thank you for joining us today and sharing so openly and honestly about your experiences. Here is a brief summary of the main points we heard today.....[insert here].....Is there anything we have missed? Ok we’d like to wish you’re a safe journey home. I will direct you to the table on the left where [insert name] will provide you with our ‘thank you’ gift to you.”

Appendix D: REB Approval from UOIT

Date: September 02, 2016
To: Pierre Cote
From: Shirley Van Nuland, REB Chair
Title: (15-145) How do persons with Lower Back Pain (LBP) experience disability in their daily lives? A qualitative analysis
Decision: APPROVED
Current Expiry: August 01, 2017

Notwithstanding this approval, you are required to obtain/submit, to UOIT's Research Ethics Board, any relevant approvals/permissions required, prior to commencement of this project.

The University of Ontario, Institute of Technology Research Ethics Board (REB) has reviewed and approved the research proposal cited above. This application has been reviewed to ensure compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2 (2014)) and the UOIT Research Ethics Policy and Procedures. You are required to adhere to the protocol as last reviewed and approved by the REB.

Continuing Review Requirements (forms can be found on the [UOIT website](#)):

- **Renewal Request Form:** All approved projects are subject to an annual renewal process. Projects must be renewed or closed by the expiry date indicated above ("Current Expiry"). Projects not renewed within 30 days of the expiry date will be automatically suspended by the REB; projects not renewed within 60 days of the expiry date will be automatically closed by the REB. Once your file has been formally closed, a new submission will be required to open a new file.
- **Change Request Form:** Any changes or modifications (e.g. adding a Co-PI or a change in methodology) must be approved by the REB through the completion of a change request form before implemented.
- **Adverse or Unexpected Events Form:** Events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view of the Principal Investigator) the safety of the participants and the continuation of the protocol (i.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).
- **Research Project Completion Form:** This form must be completed when the research study is concluded.

Always quote your REB file number (15-145/14050) on future correspondence. We wish you success with your study.

REB Chair
Dr. Shirley Van Nuland
shirley.vannuland@uoit.ca

Ethics and Compliance Officer
researchethics@uoit.ca

NOTE: If you are a student researcher, your supervisor has been copied on this message.

Appendix E: REB Approval from CMCC

Certificate of REB Approval



Project Number 162014 REB Approval 1609X05
Principal Investigator Esson, Sharli-Ann
Faculty Supervisor Faculty Project

The project entitled How do persons with Lower Back Pain (LBP) experience disability in their daily lives? A qualitative analysis.

has received CMCC REB Approval as of: 16-Sep-16

This approval expires in one year. The status of the project must be reported in advance of: 16-Sep-17

The investigator, or in the case where this pertains to a Student Investigative Project, the faculty supervisor, is responsible for ensuring that the work is conducted in accordance with the CMCC's Research Policy and the Research Procedure manual.

The investigator/faculty supervisor is responsible for notifying the ORA when this study is completed.

September-16-16

Mark Fillery, BA
Research Administrator, Office of Research Administration