

**THE VULNERABILITIES AND RESILIENCE OF HOME HEALTH CARE AIDE  
WORKERS WITH CHRONIC PHYSICAL PAIN: A DESCRIPTIVE  
QUALITATIVE STUDY IN ALBERTA**

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A thesis submitted  
in partial fulfilment of the requirements for the degree

**MASTER OF NURSING**

Faculty of Health Sciences  
University of Lethbridge  
LETHBRIDGE, ALBERTA, CANADA

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STUDY IN ALBERTA

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Date of Defence: December 1, 2020

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## ABSTRACT

The growing demands for direct care providers in home care indicate the need for a sustainable home health care aide (HHCA) workforce in Canada. However, the nature of home care work suggests continued exposure to occupational hazards and risks that cause injury and pain among these workers. Such occupational hazards and risks may affect job retention. The purpose of this study was to examine the experiences of chronic physical pain (CPP) among HHCAs working in private residential homes in Alberta. Using a descriptive qualitative method with purposive sampling, twelve HHCA workers who reported having CPP participated in this study. Data were collected using individual, semi-structured interviews in-person or by telephone. Thematic analysis resulted in the development of the overarching themes of *intersecting vulnerabilities* and *resilience*. Findings indicate the need to address or minimize vulnerabilities and to establish a workplace culture that supports the safety and resilience of these essential workers.

## ACKNOWLEDGEMENTS

I wish to acknowledge and extend my sincere appreciation to the following individuals:

To my parents, Glenda and Michaelo Bonifacio, for believing in my potential when I could not envision it. Thank you for your love and unwavering support in all my endeavours.

To my husband, Carl, for his patience and support throughout the course of my studies. Darling, thank you for making my meals and for making me laugh when I needed it the most.

To my faculty supervisor, Dr. Monique Sedgwick, for her dedication and guidance throughout my graduate journey. Dr. Sedgwick, it has been an absolute pleasure working with you. Your support and words of encouragement have been invaluable and I am forever grateful for your time, guidance, and expertise.

To my supervisory committee, Dr. Shannon Spenceley and Dr. Sienna Caspar, for their insights and constructive comments throughout the research process that were very beneficial in my writing. I have learned so much over the past year. Thank you for creating a challenging but welcoming atmosphere.

To my sisters, Charmaine, Charelle, Czyna, and Charithe, and my fur babies, Niro and Charly, thank you for your company and the continuous joy you all bring to my life.

A special thank you to the home health care aide workers who generously shared their experiences with me. This research project would not have been possible without your participation. I am forever indebted to each of you wonderful and strong women, and I hope that your voices are heard through this work.

- Czarina -

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## LIST OF ABBREVIATIONS AND DEFINITIONS

### Abbreviations

CP	Chronic Pain
CPP	Chronic Physical Pain
HHCA	Home Health Care Aide
MSK	Musculoskeletal

### Definitions

Chronic Physical Pain	An unpleasant sensory and emotional experience derived from disease, bodily injury, or dysfunction that persists longer than three to six months (Biedma-Velázquez et al., 2018; Bonica, 1953; World Health Organization, 2019).
Home Care	Health services that includes health promotion, rehabilitation, end-of-life care, and support for people of all ages in private residential homes, group homes, or other community settings (Canadian Home Care Association et al., 2016).
Home Health Care Aide	Unregulated paraprofessionals who provide basic health services, support, and assistance with activities of daily living and instrumental activities of daily living for individuals with varying levels of need (Saari et al., 2018).
Musculoskeletal Pain	Pain caused by damages to muscles, tendons, nerves, ligaments, cartilage, joints, and intervertebral discs (Canadian Centre for Occupational Health and Safety, 2018).
Resilience	The ability to recover, maintain health, and/or positively adapt to significant challenges or adversity (Herrman et al., 2011; Stewart & Yuen, 2011).
Vulnerability	Increased susceptibility to harm, injury, and poor health outcomes (Flaskerud & Winslow, 1998; Zarowsky et al., 2013).

## CHAPTER 1: INTRODUCTION

In the Canadian and international contexts, the literature on pain among home health care aide (HHCA) workers is limited to quantitative studies that explore musculoskeletal (MSK) pain (Chang et al., 2020; Riccò et al., 2017; Shnayder et al., 2018). To my knowledge, no research has examined the experiences of chronic physical pain (CPP) from the perspective of this group of healthcare workers. CPP is pain that originates from disease, bodily injury, or dysfunction that lasts longer than three to six months (Biedma-Velázquez et al., 2018; Merskey & Bogduk, 1994). Of note, the terms chronic pain (CP) and CPP are used interchangeably in the literature (Mille & Bernal, 2014; Riva et al., 2014; Shahar et al., 2018). This is challenging because it is unclear how authors define CPP, its scope, and the populations in which the condition exists. Hence, using a descriptive qualitative approach to examine the HHCA workers' experiences of CPP attempts to address this knowledge gap. The findings of this study contribute to the existing literature by emphasizing the profound impact of CPP on all aspects of the HHCA worker's life. The findings further elucidate how their experiences of living with CPP are influenced by organizational, occupational, environmental, and systemic factors, which suggests the need to increase policymaker and employer awareness. The results of this study demonstrate the need for relevant work support and resources for HHCA workers with this condition and, thus, have implications for the development and/or revision of organizational policies and occupational health and safety procedures for these workers.

I begin this chapter by presenting the background information on the research topic and the rationale as well as purpose of the study. I also discuss the significance of

this study, my ethical considerations and approach to the research, and my findings.

Lastly, I provide an overview of the contents of this manuscript-based thesis.

## **1.1 STATEMENT OF THE PROBLEM**

### **Background and Context**

The Home Care National Action Plan in Canada envisions the home as “the best place for an individual to recover from an illness or injury, manage long-term conditions, and live out their final days” (Canadian Home Care Association et al., 2016, p. 3). In 2012, approximately 2.6 million people required home care services in Canada (Turcotte, 2014). Recipients with the greatest need for home health care services generally include older adults and people living with medical conditions, physical challenges, or disability (Poss et al., 2017; Zeytinoglu et al., 2017). As Canada’s aging population continues to grow, the demand for home care services is expected to reach unprecedented heights. Other factors such as increasing complexity of chronic diseases, rising health care costs, and shorter hospital stays also contribute to the projected demand for health services in the home and community settings (Canadian Nurses Association, 2013; Mofina & Guthrie, 2014). With these new directions in health care services, it is important to focus attention on direct care providers such as HHCA workers.

### **HHCA Workers in Home Care**

HHCA workers are an unregulated group of paraprofessionals in Canada who provide about 80% of direct care and support in the home of individuals receiving care (Berta et al., 2013; Zeytinoglu et al., 2017). Given the prevalence of HHCA workers in the provision of home care services, it is necessary to support the recruitment and retention of these workers in Canada. However, the ability to sustain this segment of the nursing workforce is threatened by challenging work conditions. The nature of the HHCA workers’

occupation and work in multiple and varied home workplace environments that are not designed for the delivery of health care services increases the susceptibility of encountering occupational hazards and risks (Agbonifo et al., 2017; Quinn et al., 2016; Zhang et al., 2019). According to recent reports, injuries among HHCA workers are higher in comparison to other occupations, including the regulated nursing professions (Hewko et al., 2015; McCaughey et al., 2014; WorkSafeBC, 2018). Given the high incidence of work-related injuries, HHCA workers are at an increased risk for CPP (Shnayder et al., 2018) and other adverse health outcomes.

### **Pain and CPP**

Pain is a personal and emotionally distressing experience that is accompanied by an unpleasant sensation associated with actual or potential tissue damage (International Association for the Study of Pain, 2017). Criteria for distinguishing pain that is chronic in nature include pain that persists beyond the expected time frame for healing (Bonica, 1953) and generally lasts longer than three to six months (Merskey & Bogduk, 1994; World Health Organization, 2019). CPP can occur with or without an identifiable cause (Holl & Carmack, 2015), can be continuous or recurrent in duration and intensity (Mille & Bernal, 2014), and can co-exist and occur at different intervals and locations in the body. Furthermore, pain can be classified as physical, psychological, or emotional in origin. Physical pain originates from disease, bodily injury, or dysfunction (Biedma-Velázquez et al., 2018). Some examples of physical pain include headache disorders; pain originating in the back, neck, abdomen, or pelvis; pain caused by chronic diseases such as arthritis and fibromyalgia; medically unexplained pain; and surgical pain (Biedma-Velázquez et al., 2018; Rizvi et al., 2017). Based on the literature review pertaining to

CPP, I define CPP as an unpleasant sensory and emotional experience derived from disease, bodily injury, or dysfunction that persists longer than six months.

The influence of biological (i.e., sex, genetic), psychological (i.e., behaviour, cognition, emotion), and social (i.e., culture, socioeconomic) factors contributes to the complex nature of pain (Gatchel et al., 2007). As such, pain is a complex experience in which some individuals may not cope or adapt, resulting in increased pain intensity, depression, fear of pain, and emotional distress which have a profound impact on a person's psychological well-being and overall quality of life (Burke et al., 2015; Tan et al., 2011). Given the multifaceted nature of pain, the findings of this study offer some insight on how to better address the needs of HHCA workers with this condition.

### **Rationale and Purpose**

The growing demands for direct care providers in home care indicate the need for a sustainable HHCA workforce. However, evidence suggests that HHCA workers are likely to leave their job (Faul et al., 2010; Keefe et al., 2011). Indeed, high injury rates have been correlated not only to lower job satisfaction and high turnover intentions among HHCA workers (Butler, 2018; Lee & Jang, 2016; Stone et al., 2017) but also to potential job loss as a result of CPP (Zontek et al., 2009). The current survey of the literature suggests that various conditions fall under the classification of physical pain. In particular, CPP among HHCA workers is mainly focused on MSK pain (Chang et al., 2020; Davis & Kotowski, 2015; Hittle et al., 2016; Lundberg & Gerdle, 2017; Riccò et al., 2017; Shnayder et al., 2018). Furthermore, these studies are predominantly quantitative in nature suggesting a need for further exploration of the subjective experiences of CPP among this occupational group. Set against this backdrop, it is important to explore HHCA workers' personal experiences of CPP, which extend beyond

MSK pain to include all physical pain, to understand the challenges in the home workplace that influence their health, work well-being, and ability to remain in the profession. Therefore, the aim of this study was to explore the experiences of CPP among HHCA workers providing home care services in private residential homes in Alberta, Canada.

## **1.2 SIGNIFICANCE OF THE STUDY**

HHCA workers provide health care services and support that are integral to the sustainability and delivery of home care services. It is essential that the healthcare system retain HHCA workers to meet the future demands of home health care needs of Canadians who require this health service (Mofina & Guthrie, 2014). HHCA workers encounter distinct safety-related challenges in unpredictable home workplace environments, thus, research participation has never been more critical and vital to addressing ongoing occupational health and safety concerns. A study about CPP is significant because of the limited literature about this phenomenon among HHCA workers in the Canadian and international context. This study also addresses relevant gaps in the current literature and contributes to a greater understanding of how HHCA workers experience and manage CPP in the home workplace environment. Further, this study gives voice to Canadian HHCA workers not only impacted by CPP but who are also already marginalized by gender, age, and migration status. Awareness and understanding of the HHCAs' subjective experience may help to inform policymakers, employers, and other healthcare workers on how best to support and accommodate these workers with CPP. Such knowledge may also result in prompt action towards health promotion and healthier work environments, which may be key to retaining the existing HHCA workforce who contribute to the well-being of Canadian communities.



### **1.3 ETHICAL CONSIDERATIONS**

I obtained approval to conduct this study from the University of Alberta's Health Research Ethics Board (ID: Pro00093271). To safeguard the rights of the participants, I followed all ethical requirements of research practice developed by the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (Canadian Institutes of Health Research et al., 2014).

### **1.4 APPROACH TO RESEARCH**

Qualitative research is rooted in the tenets of naturalistic inquiry where individuals assign their own interpretations and meanings to a phenomenon (Bradshaw et al., 2017; Lincoln & Guba, 1985). This means that reality is constructed based on subjective awareness and experiences of a phenomenon. Consistent with a naturalistic inquiry, I argue that CPP is subjective and results in experiences inclusive of perceptions, responses, and beliefs relating to pain that is unique for each individual (Melzack & Katz, 2013). Although CPP is a personal experience, there were connections within multiple perspectives and experiences of CPP among participants in this study. The analysis of multiple descriptions of CPP experiences allowed a more nuanced understanding of the HHCAs' pain experience.

Given my acceptance that pain is subjective, but has commonalities among sufferers, and my positionality as a researcher, I recognize that my personal experiences with this medical condition can influence the research process and my understanding of a HHCA's experiences with CPP. To remain open to the complexity of the experience of CPP, I remained transparent with my personal views and experiences of CPP through reflexive journaling (Palaganas et al., 2017). Engaging in self-reflection on my own biases and assumptions of CPP allowed me to maintain credibility and to capture the

participants' accurate accounts of subjective interpretations of CPP experiences throughout the research process.

The paucity of research that explores the CPP experience of HHCA workers informed my decision to utilize an exploratory descriptive qualitative design. Since pain is a subjective experience, this research design is appropriate and well suited to capture the first-person narrative of CPP experiences. I used a purposive sampling strategy to recruit 12 HHCA workers with CPP. I recruited participants through (i) presentations about the study at employer sites; (ii) a recruitment poster placed on social media, websites of relevant associations, and employer bulletin boards, and (iii) a letter of invitation distributed by administrative staff to HHCAs working in private residences.

To gather responses that reflect understanding of the HHCA workers' experiences with CPP, I conducted in-depth individual, semi-structured telephone interviews (n=12) and in-person interviews (n=2) at two public library locations in Edmonton, Alberta from September 2019 to March 2020. I used an interview guide to focus and facilitate dialogue on the HHCA workers' experiences of CPP. Interviews lasted between 30 to 90 minutes and were digitally recorded with the exception of one participant who declined audio recording. I transcribed the completed interviews verbatim using NVivo Transcription and verified the transcriptions with the audio recording for accuracy. Lastly, I analyzed the data using Braun and Clarke's (2013) thematic analysis framework and used NVivo 12 for data management.

## **1.5 FINDINGS**

In this study, HHCA workers experienced numerous challenges as a result of CPP while working in the home workplace environment. Although their work was unrecognized and undervalued by the health care system, their resilience prevailed,

allowing them to engage in meaningful work despite their pain. Thematic analysis resulted in the development of an overarching theme of *intersecting vulnerabilities* and *resilience*. Findings of this study indicate the need to address and/or minimize vulnerabilities experienced by HHCA workers. The results of the study further demonstrate the need for implementing strategies aimed at improving conditions for safe employment and enhancing resilience as well as the quality of life of these essential workers who provide home health services needed by many Canadians.

## **1.6 OVERVIEW OF THE THESIS**

This manuscript-based thesis report consists of the following chapters: a comprehensive literature review in Chapter 2; a manuscript-based examination of the research methodology in Chapter 3; a manuscript-based exploration of intersecting vulnerabilities in HHCA workers with CPP in Chapter 4; a manuscript-based exploration of HHCA workers' resilience in the context of CPP in Chapter 5; and, a concluding chapter with accompanying recommendations for future research in Chapter 6.

### **Chapter 2: Review of the Literature**

The growing problem of CP has resulted in many publications and a wealth of knowledge on the topic. This chapter provides an overview of the existing literature pertaining to CP, CPP, and the health care aide (HCA) workforce. A broad range of references including journal articles, government reports, academic textbooks, and relevant material in the grey literature was included in the review. My review of the literature produced the following themes: (i) the landscape of research on CP, (ii) HCA workers in home care and CP, (iii) challenges of working with CP, and (iv) challenges of living with CP. Analysis of the literature supports the need for investigating the HHCAs' experiences of CPP in the private, home-based workplace setting.

### **Chapter 3: The Challenges of Conducting Research with Vulnerable Populations**

Based on the principle of justice and the fair and equitable conduct of research, individuals or groups in vulnerable circumstances “should not be automatically excluded from participating in research” (Canadian Institutes of Health Research et al., 2014, p. 54). Fairness and equity in research include the recognition of vulnerability, which is caused by limited decision-making capacity or poor access to social goods including rights, opportunities, and power (Canadian Institutes of Health Research et al., 2014). In this chapter, I focus on the challenges I encountered with recruitment while conducting qualitative research with HHCA workers who have CPP, highlighting the underlying politics that served to undermine the principle of justice in the conduct of this research project.

### **Chapter 4: Intersecting Vulnerabilities in HHCA Workers with Chronic Physical Pain**

While all humans experience some degree of vulnerability, there are certain groups of people who are more likely than others to be at risk and experience poor health. In comparison to other health workers, HHCAs are particularly vulnerable as poor working conditions in the home workplace environment significantly increase their susceptibility to workplace injuries, pain, and other adverse health outcomes (Shnayder et al., 2018; Suarez et al., 2017). This chapter provides contextual understanding of multiple and persistent vulnerabilities experienced by HHCA workers with CPP who continue to work in home care. These intersecting vulnerabilities are physical, psychological, social, and economic in nature and have considerable consequences to the health conditions of these workers.

## **Chapter 5: Resilience of HHCA Workers with Chronic Physical Pain**

Ongoing physical pain and continued exposure to stressors in fast-paced home healthcare environments can increase the burden placed on HHCA workers with CPP and threaten their ability to cope and successfully adapt to challenges encountered in the workplace. This can negatively impact work productivity and potentially the sustainability of the HHCA workforce. In this chapter, I present the factors that enabled HHCA workers to remain resilient and stay at work, despite living with CPP. Participants in this study demonstrated resilience and positive adaptation to CPP through (i) positive coping behaviours, (ii) pain management strategies that foster health and wellness, and (iii) having a sense of purpose and agency.

## **Chapter 6: Discussion and Recommendations**

In the final chapter of this thesis, I review the major findings presented in Chapter 4 and 5 and discuss the implications of the research findings, limitations of the study, recommendations for future research, and the dissemination strategies of this research project. Overall, the results of this study suggest that much is needed to be done to improve the health and well-being of these essential workers. The qualitative findings of this study support a workplace culture that values the work provided by HHCA workers in the healthcare system. It is also imperative that policymakers and employers support not only resilience development and maintenance over the life course but also the reduction of vulnerabilities experienced by these workers in the home workplace environment.

### **1.7 SUMMARY**

Home care is an integral component of the healthcare system in Canada. HHCA workers are, thus, fundamental to the delivery of health services in the home care setting.

The key points highlighted in this chapter support the need to engage in a focused exploration of CPP among HHCAs working in this type of health care setting. In the next chapter, I will examine and summarize the related literature on the research topic, namely CP, CPP, and the HCA workforce. The background information on these topics provide a better understanding of the existing knowledge and potential gaps in the literature.

## **CHAPTER 2: REVIEW OF THE LITERATURE**

Estimates from population health studies report about one in five Canadians live with chronic pain (CP) (Gilmour, 2015; Reitsma et al., 2011; Schopflocher et al., 2011). Despite the prevalence of this potentially debilitating condition, it remains a poorly understood phenomenon. This chapter provides an overview of the literature pertaining to CP, chronic physical pain (CPP), and the health care aide (HCA) workforce. The terms CP and CPP are synonymous within the literature, and authors do not frequently make a distinction between these terms (Guan et al., 2019; Riva et al., 2014; Shahar et al., 2018). Unless researchers specifically refer to CPP, I use the term CP throughout this review.

I completed a comprehensive search using the online databases Cumulative Index to Nursing and Allied Health Literature, ProQuest, Medline, Academic Search Complete, and Google Scholar for peer-reviewed, scholarly articles—published in English— between 2004 and 2020. I searched the literature spanning 16 years because the reference to the HCA workforce is limited in the CP literature, and I did not want to overlook relevant studies. The key search terms I used for the search process included pain, chronic pain, chronic physical pain, persistent pain, health care aide, nursing assistant, home support worker, personal support worker, home care workers, home health aides, personal care aides, home care, home health care, and community care. I used Boolean operators (i.e., AND, OR) to expand the search process and included government reports, academic textbooks, and relevant material in the grey literature in my review. The growing problem of CP has resulted in several publications and a wealth of knowledge on the topic. My review of the literature is organized into four themes: (i) the landscape of research on CP, (ii) HCA workers in home care and CP, (iii) challenges of working with CP, and (iv)

challenges of living with CP. My analysis of the literature supports the need for investigating the experiences of CP among HCAs working in the home workplace setting.

## **2.1 THE LANDSCAPE OF RESEARCH ON CP**

The highly individualistic and subjective experience of CP that is often inexplicable or unclear in underlying pathology indicates that this phenomenon is complex and poorly understood (Turk & Okifuji, 2010). Perhaps, not surprisingly, unrelenting pain that cannot be medically explained or does not conform to anatomical or neurophysiological knowledge is commonly attributed to psychological dysfunction (Bunzli et al., 2013; Melzack & Katz, 2013). However, according to the authors who developed the neuromatrix theory of pain, CP is the result of a dynamic process generated by complex neural circuitries in the brain (Melzack, 2005; Melzack & Katz, 2013). Following injury, neurons in the brain's pain system can change, and the intense noxious stimulation that contributes to pain states sensitizes the neurons in the central nervous system. Central sensitization is characterized by hyperactivity of brain cells, which generates a multidimensional experience or hypersensitivity to pain (Latremoliere & Woolf, 2009; Woolf, 2011). Multiple factors, including genetic contributions and stress, predispose the development of CP in certain individuals (Crofford, 2015; Melzack & Katz, 2013). In fact, stress is a significant risk factor for pain and discomfort. A physical injury, infection, or any biological or psychological threat to the body activates the stress system, which in turn triggers disruptions in the brain's neural activity and homeostatic regulation. The cumulative effects of stress hormones on the muscles, bones, and tissues can result in myopathy, weakness, fatigue, decalcification of bones, and the degeneration of hippocampal neurons that can lead to some forms of CP (Melzack, 2005). However,



more research is needed to reveal further underlying mechanisms of CP conditions since extensive areas of the brain are involved in pain experiences.

The subthemes in the following section highlight various CP conditions, particularly musculoskeletal (MSK) pain and the role of age and sex in CP in an aging and overwhelmingly female HCA workforce.

### **CP Across Conditions**

Researchers frequently distinguish CP as either malignant or nonmalignant in nature. Malignant pain is associated with terminal conditions such as cancer (Turk & Okifuji, 2010). Nonmalignant CP refers to pain conditions that are non-life limiting. Numerous conditions are classified under nonmalignant CP including: (i) MSK pain (e.g., back pain, arthritis); (ii) posttraumatic pain (e.g., motor vehicle accidents); (iii) postsurgical pain (e.g., failed back surgery, breast surgery); (iv) central pain (e.g., multiple sclerosis); (v) peripheral nerve pain (e.g., complex regional pain syndrome); (vi) facial pain (e.g., temporomandibular joint disorder, trigeminal neuralgia); (vii) headaches (e.g., tension and cluster headaches, migraine); (viii) neuropathic pain (e.g., postherpetic neuralgia, diabetic neuropathy); (ix) vascular pain (e.g., peripheral vascular disease); (x) visceral pain (e.g., endometriosis, pancreatitis); and (xi) widespread pain (e.g., fibromyalgia) (Simpson, 2008; Spanswick, 2008). This is not an exhaustive list, but it is beyond the scope of this chapter to provide a comprehensive list or review of all or each CP condition. Rather, for the purposes of this literature review, I focus on MSK pain as it is a commonly experienced and investigated CP condition among HCA workers.

### ***MSK Pain***

Occupational injuries are a significant problem for healthcare workers. In comparison to other hazardous industries, like construction and manufacturing, nursing

and personal care occupations generate the highest rates of injury and illness (Macdonald & McLean, 2018; McCaughey et al., 2014; Occupational Safety and Health Administration, 2013). The majority of injuries incurred by these occupational groups are MSK in origin. Several Canadian researchers reported that HCA workers are at most risk for sustaining work-related MSK injuries (Alamgir et al., 2007; Hewko et al., 2015; Johnson et al., 2016; Ngan et al., 2010). Work-related MSK injuries refer to damage to muscles, tendons, nerves, ligaments, cartilage, and intervertebral discs that is aggravated by workplace factors (Canadian Centre for Occupational Health and Safety, 2019). Symptoms of MSK damage are located in different parts of the body and include pain, swelling, numbness, burning or tingling sensations, and loss of joint mobility. Damage to body structure and function can restrict an injured worker's ability to carry out tasks and specific work activities. Due to physical limitations and pain, workers with MSK injuries are "less productive, less attentive, more prone to consistent mistakes, and more susceptible to injury" (Association of Perioperative Nurses, 2007, p. 5). Moreover, factors such as continued engagement in strenuous work while in pain and without adequate rest influence the prognosis for recovery from long-term MSK pain (Andersen et al., 2012).

Literature about CP among HCA workers focuses mostly on MSK disorders. The majority of MSK-pain-related research among HCA personnel in the last five years has been quantitative in nature (Chang et al., 2020; Davis & Kotowski, 2015; Hittle et al., 2016; Lundberg & Gerdle, 2017; Riccò et al., 2017; Shnayder et al., 2018). Findings from these studies suggest that work-related MSK injuries and pain are prevalent among HCA workers who provide home-based health services. Injuries among these workers have been attributed to the physical demands of home care work and multiple exposures to hazards and safety risks in changing work environments (Chang et al., 2020; Macdonald

& McLean, 2018). The variability and unpredictability of home workplace environments and poor working conditions increase HCA workers' susceptibility to workplace injuries. Continued exposure to physical stressors predisposes this group of workers to the development of CP. Shnayder et al. (2018) further noted significant correlations between lower life satisfaction and emotional exhaustion for those with acute and chronic MSK pain. Despite the prevalence of injuries and pain, the voices of HCA workers suffering from CP symptoms and disorders have not been heard. Given the focus of the literature on MSK pain and the quantitative nature of the studies conducted, this qualitative study adds a significant perspective to the evidence base, namely the subjective experiences of different types of CP experienced by HCAs working in home care.

### **The Role of Age and Sex in CP Among HCA Workers**

Despite the fact that pain responses vary in each individual, some scholars argue that there are contributing factors that are of clinical importance to understanding CP. It is widely reported that CP predominantly affects women and individuals over the age of 60, with increasing prevalence as one ages (Fillingim et al., 2009; Reitsma et al., 2011). Researchers also reported an increased risk for injury and CP in female healthcare workers over the age of 45 (Agbonifo et al., 2017; Drebit et al., 2010; Kim et al., 2012; Schoenfisch et al., 2017; Suarez et al., 2017). This is significant because research indicates the majority of HCA workers in Canada are women aged 40 or older (Hewko et al., 2015; Johnson et al., 2016; Panagiotoglou et al., 2017; Slaughter et al., 2018).

#### ***Sex and CP***

Health studies on the Canadian population have demonstrated higher prevalence of CP among women as compared to men (Reitsma et al., 2011; Schopflocher et al., 2011). Other literature suggests women report more frequent headaches; migraines; and

symptoms of irritable bowel syndrome, interstitial cystitis, osteoarthritis, rheumatoid arthritis, temporomandibular joint disorder, chronic pelvic pain, and fibromyalgia (Bartley & Fillingim, 2013; International Association for the Study of Pain, 2018) as well as higher pain sensitivity relative to men (Fillingim et al., 2009; Meints, 2018). The typical physical differences between men and women (i.e., size and physical capacity) and factors such as hormonal influence, pain coping, and early-life exposure to stress have been recognized as contributors to higher reports of CP in women (Bartley & Fillingim, 2013; Taiwo et al., 2009). Differences in social roles and activities outside of work may also influence recovery time from pain-related work interference or work-related injury. When engaging in a role that is labour intensive, women may compensate for their lack of physical strength by using muscles at maximum capacity (Institute for Work and Health, 2016). This could reasonably lead to overexertion and a greater risk and incidence of injuries that cause pain. Without adequate rest and recovery time, acute or untreated pain can progress to CP.

### ***Age and CP***

Aging is associated with many changes in the body. As individuals age, reductions in mobility, muscle strength, endurance, flexibility, and hearing and visual acuity along with changes in balance may be associated with negative impacts on their functional abilities (Delloiacono, 2015; Schoenfisch et al., 2017; Silverstein, 2008; Stichler, 2013). Moreover, the increased potential for weakened bones and some spinal degeneration among individuals as they age beyond 40 years increases the probability of falls, low back pain, fractures and other trauma, and re-injuries (Drebit et al., 2010; Institute for Work and Health, 2012; Occupational Safety and Health Administration, 2013). It is important, therefore, to consider age as a contributing factor to workplace injuries and the

development of CP, as age-related changes in the body can potentially affect an individual's ability to perform physically demanding tasks in the workplace. Thus, the findings from a quantitative study conducted in British Columbia that included 23,000 healthcare workers is particularly significant. The researchers discovered a statistically significant, higher risk of fall injuries among female healthcare workers over 40 years of age (Drebit et al., 2010). Higher rates of injury are also apparent among female HCA workers over the age of 50 who have less than one year of work experience or who are employed in private agencies (Schoenfisch et al., 2017). The prognosis for recovery is also concerning as a slower recovery rate is associated with increased age, which prolongs the adverse health effects of pain (Silverstein, 2008; Stichler, 2013). In quantitative studies conducted in the United States (Schoenfisch et al., 2017) and Norway (Rustøen et al., 2005), HCA workers and Norwegian citizens over the age of 40, respectively, had higher rates of injuries and reported the largest number of pain locations in the body, putting these groups at a highest risk of developing CP. These findings suggest greater susceptibility to work-related injuries and the development of CP and suffering for individuals in this age group.

Overall, age-related changes in the body, particularly among women, are likely to lead to an increase in the incidence of CP. This is particularly worrisome given that most HCA workers are women over 40 years of age, although men are also well-represented in the HCA workforce and can also experience CP. The previous findings suggest that the current HCA workforce in Canada is not physically equipped to handle the inherent requirements and demands of the job in a home health setting. Therefore, HCA workers may be burdened with workplace injuries which result in poor workplace retention (Lee & Jang, 2016).

## **2.2 HCA WORKERS IN HOME CARE AND CP**

Characteristics of the services that HCAs provide in home care, as well as the work environment and conditions in the private home setting, have been implicated in the increased incidence of work-related injuries that cause pain (Agbonifo et al., 2017; Hewko et al., 2015). In this section, I discuss the hazards in home care services including inadequate staffing and high turnover, safety issues in the private home environment, and the available interventions for home care workers in the workplace.

### **Hazards in Home Care Services**

When caring for patients, HCA workers routinely carry out a wide range of strenuous tasks that can affect their safety and well-being in the workplace. Scholars have identified high-risk work activities that increase the risks of injury for HCA workers in the home setting. These include toileting, bathing, and dressing assistance, transferring and repositioning patients from one surface to another, lifting medical equipment and furniture, and ambulation assistance (Agbonifo et al., 2017; Chang et al., 2020; Hittle et al., 2016; Markkanen et al., 2014; Suarez et al., 2017). Other researchers also noted repetitive pushing; pulling; and assuming awkward and static postures such as stooping, bending, and reaching as risk factors to work-related MSK injuries and pain among HCA personnel (Choi & Brings, 2016; Riccò et al., 2017; Shnayder et al., 2018).

Caring for home care patients with declining physical and cognitive function also contributes to the increase in risk of injuries that may cause pain among HCA workers (Choi & Brings, 2016; Macdonald & McLean, 2018). With patients who are heavier, non-weight bearing, or uncooperative, HCA workers are often required to exert strenuous physical effort in performing multiple direct care and patient handling tasks. The cumulative effects of continuous engagement in manual patient lifting activities result in

shearing and compressive forces in the spine causing flexion and rotation injuries, especially among women (Belbeck et al., 2014; Choi & Brings, 2016). Moreover, high loading and stress on the spinal structures cause fatigue, damage, and pain (Horneij et al., 2004), which explains why back pain is common among this occupational group (Riccò et al., 2017; Samaei et al., 2017). Another unique feature of HCAs' work in home care is that it frequently requires a longer time to complete tasks. In one study, researchers found that the amount of time HCA workers spend with their patients with higher needs correlated to self-reported end-of-shift fatigue and pain (Czuba et al., 2012). More specifically, Oranye et al. (2016) found Canadian healthcare workers who spent a longer amount of time on physical tasks were twice as likely to report work-related MSK pain. All of this suggests that work technique and work organization can contribute to injury and pain among HCA workers.

Continued engagement in strenuous physical tasks that require repetition and daily overexertion can delay recovery of sustained injuries and have a further impact on the worker's functioning and well-being. Moreover, when the physical demands of the job exceed the HCA worker's physical size and capabilities, there is a greater risk for re-injury and the development of multiple CP disorders. Although several studies report on the hazards that American HCA workers encounter in the home care setting, literature within the Canadian context is limited. I was able to locate one Canadian study pertaining to the hazards of patient lifting in the home care setting (Alamgir et al., 2007). In this study, quantitative data were collected from three different nursing occupations using a web-based surveillance system. The authors of the study asserted that the study population is comparable to the nursing workforce in British Columbia. However,

differences in the utilization of nurses and HCA workers in other health regions may result in different risks of injury across all healthcare sectors.

I located a descriptive, qualitative study on the occupational safety and hazards among home-based American HCAs (Markkanen et al., 2014). Major findings of this study point to the concerns of HCA workers related to verbal abuse and MSK disorders incurred from patient care tasks, as well as tasks performed outside their specified duties in the home care setting. Markkanen et al. (2014) identified preventive interventions such as the use of patient handling devices, care plan development, and training for improving both the patient's and worker's safety. The authors presented rich descriptions of job hazards and prevention possibilities from the HCA perspective but did not examine their health challenges, particularly pain experiences. Although these findings add to the general understanding of occupational hazards faced by HCA workers, the subjective viewpoints of pain experiences by Canadian HCAs remain unknown.

### ***Challenges with Staffing and Turnover***

Although there is a growing demand for home care services, a labour shortage persists in Canada (Dill et al., 2012; Keefe et al., 2011). Workplace factors such as short staffing and high turnover magnify the likelihood of health risks and the incidence of injuries that cause pain among HCA workers in the workplace (Kim et al., 2014; Trinkoff et al., 2005). In addition to workplace hazards and occupational injuries, staffing shortages also influence turnover intentions among HCA employees (Lee & Jang, 2016; McCaughey et al., 2012; McCaughey et al., 2014). Persistent job vacancies in this occupation are barriers to occupational health and safety. In addition to affecting the ability to complete tasks safely and effectively, high turnover makes it difficult to provide and maintain up-to-date training on workplace health and safety for newly hired HCA



staff (Drebit et al., 2010). Thus, HCA workers who are unfamiliar with the work environment or hazards in the home setting may be more susceptible to injury.

In addition to work-related injuries, the restructuring of the healthcare system has also affected HCA workers. For instance, in 2012, the home health sector in Edmonton, Alberta in Canada suffered cutbacks in home service operations resulting in staffing shortages and an increased workload among home healthcare workers (Johnson et al., 2017). Understaffing and work overload can be hazardous for workers in any workplace setting, as workers may attempt to do more with less within a short period time, affecting not only the quality of healthcare delivery but also patient and worker safety. As evident in an interpretive, descriptive study conducted in Canada, home-based HCA workers reported feeling rushed in providing care due to time constraints caused by understaffing (Storch et al., 2014). As a result, physical care tasks took precedence over other needs and were often completed “quickly and sometimes even harshly” (Storch et al., 2014, p. 88). Client assessments were also often missed or not communicated in a timely manner which meant that HCA workers were seldom aware of what to expect during home care visits. Indeed, the outcomes of lower staffing levels, increased time pressures, and increased workload demands in the home setting may encourage HCA workers to place their own safety on the lowest rung of the priority list (Storch et al., 2014). Such instances may also prevent HCA workers from taking rest breaks or pacing their work, which are ideal strategies for maintaining productivity among individuals with CP (Antao et al., 2013). Lastly, the lack of proper preparation and training for home support work poses serious challenges to the health and safety of HCA workers and patients alike (Storch et al., 2014).

Despite differences in data collection, reporting procedures, and injury classifications among studies, findings of increased rates of worker injury with lower staffing levels and increased workload were consistent across different countries and multiple facilities (Dhaini et al., 2016; Kim et al., 2014; Trinkoff et al., 2005). In addition to poor physical health, Dhaini et al. (2016) also discovered associations between staffing inadequacies—and increased workload—and emotional exhaustion, fatigue, and headaches among nurses and HCAs working in nursing homes.

### **Safety Issues in the Private Home Environment**

HCAs work in the homes of individuals receiving care. The uncontrolled nature of home environments, in addition to increased patient acuity and physically demanding repetitive tasks, increases the rates of injury among HCAs working in this setting (Drebit et al., 2010; Kim et al., 2010; Lang et al., 2008). According to Miranda Ferrier, President of the Ontario Personal Support Worker Association (Born et al., 2014) and Muramatsu et al. (2019), HCA workers have limited information prior to entering private homes. This means that HCA workers may not be prepared for distinct, safety-related concerns prior to entering these homes. In contrast to hospitals that have standardized rooms and work environments that facilitate the provision of care, homes are not usually ergonomically designed or physically equipped for the delivery of personal care or other health interventions (Macdonald & McLean, 2018). Consequently, HCA workers may encounter multiple risks unique to the unpredictable nature of the home physical environment.

As a result, in the last decade, there have been growing efforts by researchers to investigate safety issues encountered by HCA workers inside and outside the home care environment (Hittle et al., 2016; Suarez et al., 2017; Wills et al., 2016; Wipfli et al., 2012). For instance, in a quantitative study conducted in Canada, Alamgir et al. (2007)

found that more injuries occurred among HCAs working in the home care environment than in hospital settings. Although the results from the study suggested patient-lifting activities as the main cause for injury, other studies have identified specific characteristics of the physical home environment as contributors to injuries among HCA workers. Possible hazards inside and outside the home that can potentially cause injury include but are not limited to: (i) poor lighting, (ii) cluttered areas, (iii) inappropriate height and size of beds, (iv) slippery or uneven surfaces, (v) improperly positioned furniture or electrical cords, (vi) limited spatial layout of the home, and (vii) unsafe conditions such as broken steps and handrails (Macdonald & McLean, 2018; Markkanen et al., 2014; Panagiotoglou et al., 2017; Quinn et al., 2016; Schoenfisch et al., 2017; Storch et al., 2014). In these working conditions, HCA workers are more prone to slips, trips, or falls that cause MSK strain and injuries (Butler, 2018; Drebit et al., 2010; Markkanen et al., 2014; Quinn et al., 2016; Walton & Rogers, 2017).

Although the studies cited above are mainly quantitative in nature, researchers in British Columbia conducted a qualitative study that explored the safety and ethical concerns of HCA workers in the home health setting (Storch et al., 2014). However, pain experiences among these workers were unexamined. Based on my review of the literature, unsafe and unfamiliar work environments contribute significantly to the risk of injury and the development of CP for HCA workers who provide home-based care services.

### **Workplace Interventions in Home Healthcare**

The prevalence of injury associated with patient lifting and the hazards encountered by HCA workers have prompted researchers to study interventions that may mitigate injuries in the workplace in long-term and acute care settings. For example,

interventions such as technical aids, lift equipment, participatory ergonomics, health promotion, and physical training have been proposed as solutions to reducing the incidence of workplace injuries or MSK pain (Gold et al., 2017; Jakobsen et al., 2015; Rasmussen et al., 2016; Soler-Font et al., 2019; Suni et al., 2018). However, the results of these studies are inconclusive. For instance, despite findings of the efficacy of using lift equipment in reducing the odds of an injury among HCAs (Andersen et al., 2014; D’Arcy et al., 2012; Gold et al., 2017; Pompeii et al., 2009), Hegewald et al. (2018) concluded that intervention studies conducted prior to February of 2018 are of low to very low methodological quality. Thus, the quality of the evidence is very poor. Some studies also did not include participants with CP.

Though using lift equipment may reduce injuries among healthcare workers, HCAs face relatively limited access to proper lifting devices in the home care setting since home care clients may not have the financial resources to afford lift equipment (Macdonald & McLean, 2018; Markkanen et al., 2014). HCA workers may then complete home care visits without having access to safe patient handling equipment (Craven et al., 2012; Quinn et al., 2016). The lack of time and improper use of the equipment may also hinder the efficacy of such interventions (Storch et al., 2014). Furthermore, the physical layout of private homes (e.g., narrow doors and hallways, unsuitable flooring surfaces, and small rooms) may make lift equipment challenging to use (Czuba et al., 2012; Macdonald & McLean, 2018).

Other interventions such as ergonomics training have yielded mostly nonsignificant results. After comparing pre- and post-training questionnaire scores, completed three months prior to training and one month after training, researchers in the United States concluded that a classroom-based ergonomics training program designed to

control risk factors in the work environment did not significantly decrease pain or improve physical and mental health outcomes among HCA workers (Schneider et al., 2004). According to Beauvais and Frost (2014), the theoretical principles of ergonomics training may not be transferrable to unpredictable situations in the home care setting. In my literature review, only one study conducted in Denmark yielded positive results for an intervention implemented in the home care setting. The researchers conducted a stepped wedge cluster randomised control trial testing the efficacy of a multifaceted intervention that included physical training, cognitive behavioural therapy, and participatory ergonomics in the reduction of physical work demands and maladaptive pain behaviours among a sample of 594 home care HCAs with lower back pain (Rasmussen et al., 2016). As stand-alone interventions, neither physical training nor cognitive behaviour therapy were effective in improving MSK pain. Scholars generally agreed that individually focused interventions are unlikely to make a significant impact in reducing MSK disorders and pain (Oakman et al., 2016; Soler-Font et al., 2019).

Recently, researchers in the United States have developed a home healthcare virtual simulation training system for identifying work hazards in the home setting (Lavender et al., 2019). Although home health workers were able to identify salient hazards, the authors indicated that other less salient hazards are context-dependent and may be overlooked. Thus, at present there is no strong evidence that current interventions can improve HCAs' health and safety in the home health sector. The private home environment is unregulated making it more difficult to control the numerous stressors HCA workers' encounter. In the absence of consistently effective interventions and appropriate support in the provision of care, HCA workers must engage in demanding tasks that require them to assume awkward postures and perform repeated movements,

thus ensuring the continued occurrence of injuries and pain among this occupational group. My study provides some insight to address the issue by identifying the types of support HCA workers with CP prefer to utilize in the home workplace setting.

### **2.3 THE CHALLENGES OF WORKING WITH CP**

Many pain syndromes are without effective treatments (Health Canada, 2019; Takai et al., 2015). As such, some level of pain persists in workers with CP despite various pain management strategies. This has implications for work and productivity for individuals with CP. The subthemes in this section focus on the impact of CP on work productivity and support in the home workplace.

#### **Work Productivity and CP**

Canadian researchers in a quantitative study concluded that nurses with work-related MSK injuries were more likely to take prolonged time off work as a result of the sporadic and intermittent nature of pain and severity of symptoms (Murray et al., 2013). In addition to pain-related work interference, fatigue, difficulties with concentration, and psychological distress are also barriers to work productivity for individuals with persistent pain (Antao et al., 2013; de Jong et al., 2015). Although productive employment is of benefit to society, and engaging in work enables individuals with CP to have better financial outcomes, as well as a sense of normality and identity (Antao et al., 2013; de Jong et al., 2015), continued effort to self-manage pain conditions can become exhausting and diminish over time (Devan et al., 2018; Ploeg et al., 2017). This may lead to sick leave, unemployment, or early withdrawal in the workforce (Häuser et al., 2014).

#### **Support for HCA Workers in Home Care**

According to several sources, in addition to reducing physical demands and increasing job control, support in the workplace is a key factor in reducing pain, work

absence, and maintaining psychological well-being and work productivity (Andersen et al., 2019; Franzosa et al., 2018; Muramatsu et al., 2019; Oakman et al., 2017). However, HCAs typically work alone in the home health setting with little to no supervision, guidance, or resources and, as such, there is no opportunity to request assistance or support during emergency situations (Levertson et al., 2019; Olson et al., 2016; Saari et al., 2018; Storch et al., 2014). According to Walton and Rogers (2017), working with minimal support creates more stress and psychosocial issues for HCA workers, which further worsens ongoing pain and the ability to self-manage pain conditions. The lack of personnel or sufficient equipment to assist with patient care and handling leave HCA workers with little choice but to risk their own safety. As evident in an interpretive qualitative study conducted in Canada, the HCA participants reported an ethical commitment to risking their personal safety during transfers, for instance into bathtubs and commodes, or when clients fell because assistance from another person or a lifting device was rarely available (Storch et al., 2014). The HCA workers in the study also expressed knowledge deficits related to the safe and proper use of patient handling equipment. Although the authors interviewed HCAs working in home care, the study was limited to the province of British Columbia and the ethical and safety issues encountered by these workers rather than CP experiences. Hence, my study contributes to a greater understanding of the challenges encountered in the home health sector by HCA workers with CP.

#### **2.4 THE CHALLENGES OF LIVING WITH CP**

The experience of pain involves not only physical limitations but also psychological and social consequences that can greatly affect overall well-being and

quality of life. In the following section, I discuss the psychosocial impact of CP and its association with sleep deprivation and social support in the workplace.

### **Psychological Impact of CP**

Pain is both a sensory and emotional experience. Individuals living with CP report experiences of distress and negative thoughts, emotions, and attitudes as a consequence of persistent pain (Bunzli et al., 2013; Michaëlis et al., 2015). Scholars have identified significant associations between CP and psychological impairments including depression, anxiety, fear, low self-efficacy, low self-esteem, and emotional distress (Burke et al., 2015; Burri et al., 2018; Taloyan & Löfvander, 2014). In some instances, the lack of a medical explanation for the experience of CP and the invisible nature of the condition can lead to frustration, anger, and despair, leaving those affected by it to experience a downward spiral of suffering and disability (Brown, 2008; Bunzli et al., 2013). Impairments to psychological health as a result of CP, in turn, significantly influence pain severity and disability (Lumley et al., 2011; Wiech & Tracey, 2009). Negative emotions can also alter the interpretation and perception of pain (Linton & Shaw, 2011), which can have negative outcomes on social relationships and work productivity. This is evident in quantitative studies conducted with Australian nurses (Vecchio et al., 2011) and American HCA personnel who worked in hospital settings (Reme et al., 2012). Participants in both studies reported higher psychological distress due to MSK pain. These researchers found that the interference of pain with work caused elevated levels of psychological distress and greater odds of sustaining an injury in the workplace. Set against this backdrop, I suggest that it is possible that similar outcomes exist for HCA personnel with CP, regardless of the work setting.



## *Sleep and CP*

It is well documented that sleep deprivation is associated with increased pain intensity (Finan et al., 2013; Katsifaraki et al., 2018; Lautenbacher et al., 2006; Vega et al., 2019). More specifically, the outcomes of poor sleep quality, including fatigue, sleepiness, and insomnia in various CP conditions such as abdominal pain, headache, and MSK pain, generally have adverse effects on sensitivity to pain stimuli, mood, attention, cognition, and motor control (Abbasi et al., 2018; Geiger-Brown & Lipscomb, 2010; Katsifaraki et al., 2018; Vega et al., 2019). As evident in quantitative studies conducted in the United States (Chhangani et al., 2009) and Norway (Mork et al., 2014), healthy participants, and particularly women, experienced hyperalgesia to painful stimuli and an increased risk for CP as a result of disturbed sleep. Given that sleep deficiency adversely affects pain experience, as well as cognitive and motor performance, it is important to explore factors that can affect the quality and quantity of normal sleep among HCAs since they work a variety of hours and are likely to work shiftwork (Government of Alberta, 2018; Panagiotoglou et al., 2017). To that end, researchers have reported specific concerns regarding shiftwork and working extended hours (> 8 hours) among healthcare workers. According to Khatutsky et al. (2012), working extended hours increased the odds of injury in the workplace by about 80%. Researchers have also identified increases in errors, injury, and pain, particularly among female nursing personnel who work shiftwork and who experience insomnia and physical and mental fatigue (Attarchi et al., 2014; Katsifaraki et al., 2018; Magnan et al., 2015; Wong et al., 2011). Their studies suggest that poor quality of sleep can lead to the development of CP among healthcare workers, including HCA personnel who work shiftwork or extended hours.

## **Social Impact of CP**

According to Turk et al. (2010), beliefs and meaning ascribed to pain experiences can strongly affect an individual's response to pain. Pain perceived as harmful, intense, or unpleasant elicits avoidance or withdrawal behaviours. Indeed, social withdrawal and avoiding leisure activities are common among patients with CP (Bunzli et al., 2013; Dueñas et al., 2016; Spanswick, 2008). Pain that is perceived as a barrier to once valued activities can result in negative social consequences including changes of roles within the family context, decreased social connections, and loss of relationships (Bunzli et al., 2013; Dueñas et al., 2016; Michaëlis et al., 2015). The unpredictable nature of pain can further worsen social limitations as challenges to work scheduling or planning for future events and activities are encountered (Closs et al., 2009).

### ***Social Support in the Workplace***

The experience of pain is influenced by one's pain beliefs, coping strategies, and perceived social support (Flanagan, 2018). For individuals with CP, support from colleagues and supervisors can contribute to a decreased risk of injuries and a better quality of working life (Andersen et al., 2019; de Jong et al., 2015; Yanar et al., 2019). Moreover, a workplace where modification of work, as well as flexibility in breaks and work hours, are available can provide individuals with CP some control of the work routine and self-management of CP conditions (Oakman et al., 2017). However, individuals with CP often encounter difficulties in deciding whether to disclose injuries or pain conditions. Due to a fear of job loss and the perceived stigmatization that comes with the invisible and often inexplicable etiology of CP, those living with CP are reluctant to request support in the workplace (de Jong et al., 2015; Oakman et al., 2017). Hence, communication with supervisors or employers may be difficult for individuals with CP.

Perhaps it is not surprising then that a key finding in quantitative studies conducted in the United States is that HCA workers commonly underreport injuries incurred in the workplace (Boden et al., 2012; Galizzi et al., 2010; Schoenfisch & Lipscomb, 2009). Due to peer pressure or fear of losing one's job, many HCA workers continue to work despite pain symptoms and injuries.

Based upon my review of the literature, the experience of CP presents a threat to the quality of life among HCA workers with CP conditions. The quantitative findings of studies in my review offer a limited perspective on pain experiences among HCAs since some studies did not specifically include HCA workers with CP in their study population. Moreover, the authors focused on the challenges of living with CP. Thus, my study will contribute a more holistic understanding of HCA workers' experiences of CP inclusive of their challenges, experiences with CP that influence their health and work in the private home setting, and their ability to remain in the profession and deliver care.

## **2.5 SUMMARY**

A healthy HCA workforce is essential in the provision of home health care in Canada. Since CP is known to increase with age and affect multiple locations in the body, the severity of its impact on the quality of life and well-being for HCA workers is important to understand. My review of the literature reveals that the experience of CP among these workers has significant implications for work productivity, patient safety, and the quality of health care delivery. Before policy makers can propose preventive strategies pertaining to workplace injuries and the reality of CP for HCAs, it is imperative to first understand the experiences of these important healthcare workers. Thus, exploring the HCA workers experiences of CP in private home settings in Alberta is necessary.

### **CHAPTER 3: THE CHALLENGES OF CONDUCTING RESEARCH WITH VULNERABLE POPULATIONS**

Based on the principle of justice and the fair and equitable conduct of research, individuals or groups in vulnerable circumstances “should not be automatically excluded from participating in research” (Canadian Institutes of Health Research et al., 2014, p. 54). Fairness and equity in research include the recognition of vulnerability, which is caused by limited decision-making capacity or inadequate access to social goods including rights, opportunities, and power (Canadian Institutes of Health Research et al., 2014). Moreover, people in vulnerable circumstances need to be afforded special attention so that they are not “unduly burdened by the harms of research or denied the benefits of the knowledge generated from it” (Canadian Institutes of Health Research et al., 2014, p. 8). Thus, research involving underserved populations is carried out with the aim of understanding specific health needs so as to reduce health inequalities and potentially improve health outcomes (Wilson & Neville, 2009). However, conducting research with vulnerable populations, such as women, ethnocultural minorities, and workers, comes with challenges (Ellard-Gray et al., 2015; Rose & Pietri, 2002).

In this study, I drew on my experience of conducting qualitative research with home health care aides (HHCAs) working in private homes in a western Canadian province. HHCAs are paraprofessionals—mostly women who earn low wages and lack opportunities for career advancement (Hewko et al., 2015). Additionally, HHCA workers experience high levels of stress related to various factors including heavy work demands (Chowhan et al., 2019), limited workplace support (Zoeckler, 2018), and poor working conditions (Suarez et al., 2017). They are also likely to be injured in the home workplace

setting (Agbonifo et al., 2017; Hamadi et al., 2016). Thus, they experience working conditions that create numerous, intersecting vulnerabilities.

In light of the devastating effects the recent coronavirus pandemic has had on the aging population and the people who provide their care, many of whom are HHCAs (Allison et al., 2020; Almeida et al., 2020; Luk, 2020), conducting research with this group of workers has never been more important. Indeed, conducting research with HHCA workers is critical as it can provide better understanding of their experiences related to their health and work in home care, as well as provide valuable insight on how best to support them in complex work environments. In this chapter, I focus on the challenges with recruitment I encountered while conducting qualitative research with HHCA workers who have chronic physical pain (CPP), highlighting the underlying politics that served to undermine the principle of justice in the conduct of this research project.

### **3.1 VULNERABLE POPULATIONS IN RESEARCH**

The concept of vulnerability, albeit lacking a universal definition in the literature, is thought to be dynamic as it is dependent on factors that influence health outcomes and context (Allotey et al., 2012; Canadian Institutes of Health Research et al., 2014). In the conduct of research, vulnerability is linked to autonomy; that is, individuals are considered vulnerable if they have diminished capacity to consent, limited freedom to act due to external controlling influences, or special needs that must be considered to avoid unnecessary risks related to the research (Canadian Institutes of Health Research et al., 2014). According to the *Tri-Council Policy Statement 2*, people in vulnerable circumstances have the right to participate in research and should be included so that their particular needs are recognized and, thus, contribute to the improvement of access to

benefits that can improve their health and well-being (Canadian Institutes of Health Research et al., 2014).

Although all humans experience some degree of vulnerability, certain groups of people are more likely to experience greater risk and poor health outcomes. Scholars have focused their attention on populations that have been identified as vulnerable including children; ethnocultural minorities; women; older adults; individuals living with mental health issues and/or disabilities; and people who are incarcerated, economically disadvantaged, and/or marginalized based on their sexual orientation or religion, among others (Bracken-Roche et al., 2017; Canadian Institutes of Health Research et al., 2014). Certain groups of workers have also been identified as vulnerable because of their exposure to work-related hazards, the lack of workplace protections to mitigate these hazards, and their limited capacity to effect change in the workplace increasing their susceptibility to risk, injury, and adverse health outcomes (Yanar et al., 2018).

Therefore, recruitment of vulnerable populations for research is often difficult because of the sensitive nature of the research topic or the social context that impedes their participation (Dempsey et al., 2016; Walker & Read, 2011). Other factors such as geographically distant locations, social status, health conditions, stigma, fear of disclosure, competing demands with other researchers for access, time and schedule constraints, and mistrust of the research process can also increase difficulty in accessing and recruiting vulnerable populations for research (Ellard-Gray et al., 2015; George et al., 2014; Moore & Miller, 1999; UyBico et al., 2007).

### **3.2 BACKGROUND AND PURPOSE**

I sought to explore the experiences of CPP among HHCAs working in private homes in Alberta, Canada. CPP is an unpleasant sensory and emotionally distressing

experience caused by disease, bodily injury, or dysfunction that generally persists longer than three to six months (Biedma-Velázquez et al., 2018; Merskey & Bogduk, 1994; World Health Organization, 2019). The continued exposure to workplace hazards in home-based settings increases HHCA workers' susceptibility to developing CPP. However, research that explores the perspectives of HHCA workers' experiences with CPP is limited. Pain-related investigations have mainly focused on quantitative studies on musculoskeletal pain (Chang et al., 2020; Hittle et al., 2016; Lundberg & Gerdle, 2017; Riccò et al., 2017; Shnayder et al., 2018).

Sydor (2013) and Alexander et al. (2018) claimed that sensitive research topics and the social context make certain individuals or groups vulnerable and hard to reach. My experience of recruiting HHCA workers reflected similar observations by Kim et al. (2010) and Markkanen et al. (2008) who asserted that these workers are hard to reach or difficult to access for research. Challenges in accessing HHCA workers for research were the result of variable work scheduling (Markkanen et al., 2008) and workers occasionally changing their telephone numbers and residence (Kim et al., 2010). Although the participants in this study worked shiftwork, the challenges to recruitment might also have been because CPP is still stigmatized and viewed by society as an invalidated health condition (Health Canada, 2019). Moreover, many home-care organizations are privately owned (Poss et al., 2017; Slaughter et al., 2018), and the services they provide are not standardized or regulated under the Canada Health Act (Mofina & Guthrie, 2014). As such, these organizations may have corporate profits to attend to, and, therefore, they try to compete on the costs to maximize profit. Given that the interests of the company may differ from that of the worker's interests, private home-care organizations can choose to

restrict access to HHCA workers under their employ, which further compounds an already difficult situation in the recruitment process.

### **3.3 METHODS**

I utilized an exploratory descriptive qualitative design to explore the understudied experiences related to CPP among HHCAs working in private homes in Alberta. According to Wilson and Neville (2009), this research design is appropriate for interviewing individuals who are vulnerable because it focuses on giving them a voice thus, providing me with a better understanding of their experiences. Indeed, the use of this research approach allowed me to develop detailed insight and understanding of multiple behaviours and perspectives of CPP experiences from the HHCA worker's viewpoint.

According to Carr et al. (2018), 6 to 20 informants are generally sufficient to capture rich qualitative data. Using this as a guide, I recruited 12 HHCAs who worked for eight different private organizations that provided home care services in various locations in Alberta. The selection of participants was based on the following criteria: (i) current employment as a HHCA in private homes; (ii) self-report of CPP that persists more than six months; and (iii) the ability to read, write, and speak English fluently. All participants identified as female between 25 and 65 years of age. Eight participants had full-time positions in home health care. Additionally, about one third of the participants worked for multiple employers in other health care settings.

I received ethical clearance for the study from the University of Alberta Health Research Ethics Board (ID: Pro00093271). I obtained written consent from each participant prior to data generation. To maintain privacy and confidentiality, I deleted all



identifying information in all written accounts and replaced them with pseudonyms selected by the participants.

### **Data Generation**

Data were generated from September 2019 to March 2020. I conducted semistructured interviews with each participant at a mutually convenient time. Of these, 12 interviews were completed by telephone, and two were held in person in a private room at a public library. Each lasted between 30 to 90 minutes. Two participants in the original sample population participated in a second interview to further explore experiences and to confirm the accuracy of the analyzed data. The interview schedule was comprised of 12, predetermined, open-ended questions that explored the HHCA worker's perceptions, beliefs, and experiences of CPP. I asked open-ended questions (e.g., What is it like to experience CPP?) and used prompts (e.g., 'Can you tell me more about...') to elicit clarity and more detail and depth of data (Sandelowski, 2000). In qualitative research, new layers of understanding about the topic can be uncovered as the interview progresses (Loiselle & Profetto-McGrath, 2010). In my interviews, the notion of limited involvement in decision-making emerged; so, I added questions to explore this experience in subsequent interviews.

### **Data Analysis**

Thematic analysis is a flexible analytical tool that can provide rich and detailed accounts of data (Braun & Clarke, 2013). This was particularly useful in this study as little was known about Canadian HHCAs' experiences with CPP. Thematic analysis followed Braun and Clarke's (2013) framework, which involved reading transcripts in a line-by-line reiterative manner until I could identify salient features and patterns of the data and subsequently categorize them. Constant comparison of codes within each

interview and across interviews enabled the expansion or collapse of categories as patterns emerged. I used a visual map to explore relationships between categories and an overview of concepts, resulting in the identification of *intersecting vulnerabilities* and *resilience*, two concepts that best represented the HHCA workers' experiences with CPP. To ensure trustworthiness of the study, I used various strategies including an audit trail, purposeful sampling, reflexive journaling, member checking with three participants, rich descriptions of data, and ongoing supervisory and committee review of research activities (Bradshaw et al., 2017; Lincoln & Guba, 1985).

### **3.4 EXAMINING THE CHALLENGES OF SAMPLING, RECRUITMENT, AND DATA GENERATION**

In this section, I examine the challenges I encountered in various stages of the research process. Specifically, I highlight possible reasons why the vast majority of gatekeepers who were approached during recruitment declined to give me access to the HHCA workers they employed. I also explore potential reasons why the HHCA workers I recruited were reluctant to participate in research and subsequently discuss the most appropriate method of data collection given their reservations with research participation.

#### **Recruitment: The Power of Gatekeeping**

To widen the scope of recruitment for this study, I shared the recruitment poster (Appendix A) on social media and asked members of my personal network to distribute the poster to prospective HHCA participants in Alberta. However, there was no progress after one month of recruitment so I learned that I would need to rely heavily on gatekeepers in the home care industry and that it would be necessary to get their buy-in. A challenge I encountered almost immediately was that many home care organizations are owned by for-profit or not-for-profit groups (Poss et al., 2017; Slaughter et al., 2018),

and there is little clarity regarding with whom to communicate to seek permission to conduct the research study. So although it is important to establish a trusting relationship with gatekeepers (Dempsey et al., 2016), not having a clear point of contact or entry into the field created a barrier to accessing potential participants. Consequently, I developed a recruitment plan aimed at establishing research partnerships with relevant professional associations that have longstanding relationships with multiple gatekeepers in home care.

The recruitment plan included reaching out to these professional associations and inquiring as to whom I could speak regarding assistance with the recruitment of participants for this study. I was often directed to individuals in leadership positions; once these individuals were identified, I requested face-to-face meetings to formally introduce myself and the objectives of the study. Along with this request, I sent a letter (Appendix B) via email that contained all necessary details of the study such as purpose, research involvement, and time frame of the research activities. Upon receipt of the letter, two of the four leaders agreed to an in-person or telephone meeting. The meeting provided me with the opportunity to establish a trusting relationship and to share detailed information about the research study, to answer questions and concerns they might have had pertaining to the study, and to explain the potential value of taking part in this research (Dempsey et al., 2016). Once this information was shared and questions or concerns were addressed, the leaders were very encouraging and agreed that a study involving HHCA workers was needed. Four professional associations agreed to assist in the recruitment phase of the study although three of the associations did not have direct access to HHCA workers. Despite having limited direct contact with HHCAs, they posted the recruitment poster on their websites and in their monthly newsletters for a period of four months. This helped disseminate the information about the study to home care employers or other

people who may know HHCA workers with CPP. One of the four associations also agreed to provide a list of contact information of decisionmakers from various private home care organizations in the province.

Although I succeeded in establishing a relationship with four professional associations, it was still difficult to reach individuals in leadership positions within targeted organizations. The process required multiple follow-ups by telephone or email. Response time varied from a few days to two months. Frequently, I was asked by administrative staff to leave a message or to forward a letter to the organization with the details of the study, including the involvement of the organization and HHCA employees in the study. Some of these letters remained unanswered.

It is important to note that the sensitive nature of the research topic and the social context created a number of challenges in the recruitment process. Indeed, during the course of recruitment, 53 of the 71 gatekeepers who were approached to assist with recruitment declined to give us access to the HHCA workers they employed and cited concerns with the potential negative impact the study findings might have on their organization. A total of 18 gatekeepers permitted access to their employees. In these instances, recruitment activities included (i) meeting presentations (n=10) about the study at different employer sites, (ii) placement of the recruitment poster on bulletin boards where HHCA workers congregate such as staff rooms, and/or (iii) distribution of the letter of invitation (Appendix C) via email by the administrative staff to HHCA employees.

Some gatekeepers also indicated that this study was relevant and much needed. Although the majority of gatekeepers denied access to their HHCA employees, the contradiction presented might have been due to organizational interests that conflicted with the workers' interests. Scholars note that gatekeepers' own agendas can keep

researchers from accessing participants (Alexander, 2010; Dempsey et al., 2016; Walker & Read, 2011). Possible reasons for denying access to participants can also be due to time pressures and inconvenience, unsuitability of the research topic, reluctance to expose the organization to public inquiry, and/or perceived threat from the implications of research such as legal liabilities and controversial findings (Gallo et al., 2012; Heath et al., 2007).

Denying HHCA workers the opportunity to participate in research that is designed to explore health needs related to CPP violates the principle of justice, concern for welfare, and the right of HHCA workers to autonomous decision making and research participation, further marginalizing this group of workers. So, although potential participant refusal to take part in the study should be respected, in this study, many HHCA workers were not provided the opportunity to exercise their right to decide whether or not to participate in the research study and to be heard. The exclusion of potential participants due to the actions of gatekeepers might be acceptable from an organization's perspective; however, there may be significant harm to those in vulnerable positions if they are excluded in research studies (Gallo et al., 2012; Gehlert & Mozersky, 2018). According to Alexander (2010), it is unethical to deprive already vulnerable populations, like HHCA workers, from the potential benefits of research. Denying HHCA workers the opportunity to share their voices can exacerbate their vulnerabilities in the home workplace setting.

### **Sampling: Stigma as a Barrier to Research Participation**

I used a purposeful sampling strategy to recruit HHCA workers in Alberta who experienced CPP. I also employed a snowball sampling technique to gain access to information-rich sources and obtain sufficient participants for the study. Scholars have noted that snowball sampling is ideal when research topics are sensitive or when target

populations are hidden or invisible (Ellard-Gray et al., 2015). Moreover, Davis et al. (2018) claimed that this sampling technique is effective since recruitment from a familiar person can enhance trust and reduce fear, anxiety, and stress associated with participation in a study.

Although private home-care organizations typically have smaller groups of employees who are likely familiar with each other, snowball sampling did not prove to be effective for our study. Out of the 12 participants, only three verbally agreed to tell their coworkers about the research project and pass along my contact details. Other participants were hesitant to provide contact information of prospective participants from their social network and subsequently did not share this information with me. There are likely many reasons why participants may be reluctant to participate in research or share information about the research. Possible reasons include stigma associated with CPP or fear of employer reprisal for participating in research.

Stigma is the occurrence of discrimination, stereotyping, labeling, separation, and status loss as a result of unequal power circumstances (Link & Phelan, 2001). Stigma may hinder prospective participants from participating in research because they fear social repercussions from disclosing sensitive information such as medical conditions (George et al., 2014; Salganik & Heckathorn, 2004). Social stigma, therefore, may be one reason why participants in this study were hesitant to share contact information of potential participants from their social network with me, or convey information about the research study to their colleagues. The assumption of stigma as a barrier to research participation is supported by the study findings where the participants reported limiting social interactions with colleagues for fear of stigma and judgement associated with their CPP conditions.

Sometimes you don't feel like telling everybody about your pain because you don't want to feel judged by coworkers. Sometimes there might be a stigma like, "You're just playing it up or just want attention" or "You just want to have a day off." (Sue)

### **Data Generation: Telephone Interviewing for Sensitive Research**

HHCA workers who were interested in participating in the study contacted me by telephone or email and were subsequently screened for eligibility. Once participants gave their informed consent (Appendix D), an interview was scheduled within a week following initial contact, depending on their availability. I sent a text or email reminder to the participants the day before their interview date. Ten of the 12 participants in this study requested to be interviewed by telephone. Reasons for opting to be interviewed by telephone varied and included living at geographically distant locations, having full-time positions, working 12-hour shifts, having to juggle competing demands of multiple employers in other health care sites, and familial obligations. Considering their busy schedules at work and at home, two participants requested that the telephone interview be conducted during their lunch break at work. Four participants rescheduled their interview because they had important errands to attend to, had unforeseen health appointments, were emotionally drained from dealing with the death of a resident, or were exhausted from the heavy demands at multiple workplaces and/or stresses in their daily lives.

To address any anxiety about participating in the interview, the participants were reminded that their employment status would not be affected by participating or withdrawing from the study. Despite firm assurances that anonymity and confidentiality would be upheld throughout the research process and in the dissemination of the findings, some participants were still fearful of losing their jobs and were hesitant to provide their real names or meet in person. Indeed, during one of the recruitment presentations, one

HHCA worker suggested that in-person interviews would limit confidentiality, suggesting that fear of possible repercussions for participating in the study was a central concern.

These participants signed the consent forms with pseudonyms and/or opted for a telephone interview instead of a face-to-face meeting.

A telephone interview was an effective option for participants in this study, and it encouraged them to participate. According to various researchers, telephone interviews are considered to be effective in generating qualitative data because telephone interviews allow respondents to disclose sensitive information more freely, thereby increasing the quality of the data (Holt, 2010; Sturges & Hanrahan, 2004; Trier-Bieniek, 2012).

Telephone interviewing is also beneficial in terms of minimizing social pressure and enabling the participants to control the privacy of the conversation in their chosen social space (Bolderston, 2012; Sturges & Hanrahan, 2004). The convenience of telephone interviewing was also particularly useful in this study since most participants had limited availability or lived in geographically distant places. Audio-recorded, in-person interviews are common data generation strategies especially when interviewing vulnerable people about sensitive topics (Elmir et al., 2011; Neville et al., 2016). For these reasons, audio-recorded, telephone interviewing was considered an ideal method for data generation for this study.

Despite the advantages of telephone interviewing, there are also limitations to this method of data generation. For instance, I was unable to observe social cues such as body language and gestures during the interview process (Holt, 2010; Novick, 2008). To compensate for this shortcoming, I paid attention to the participant's pauses, hesitations, sighs, and tone of voice during the interview discussion (Novick, 2008; Sturges & Hanrahan, 2004). Other disadvantages to telephone interviewing include poor quality of



the signal, which interrupted the natural rhythm of three telephone interviews in this study (Trier-Bieniek, 2012). Although interruptions can occur in any interview method, participants were forewarned that in the event of a disconnection I would immediately call them back to minimize the loss of data and the interruption to the conversation.

Another limitation to telephone interviewing is the inability to build rapport with participants (Trier-Bieniek, 2012). Many scholars have noted the critical importance of developing rapport and establishing a trusting relationship when conducting sensitive interviews with vulnerable populations (Morrison et al., 2012; Murray, 2003). In this study, several strategies were undertaken to enhance rapport and maintain a nonhierarchical relationship between the researcher and the participant. For instance, I engaged in an informal conversation with each participant prior to the start of the telephone interview (Dempsey et al., 2016). Topics varied and included conversations about the weather, approaching holiday events, and upcoming plans for the week. During the recruitment phase of the study, I also disclosed that I had personal experiences relating to CPP. Being open and transparent served to enhance the connection, authenticity, and the maintenance of a trusting and balanced relationship between the participant and me.

It is important to note that although I shared information relating to having personal experiences with CPP, the focus of the interviews remained on the participants and their stories related to CPP. Prior to the start of interviews, I stressed that the purpose of the study was to learn about their experiences with CPP. To create an atmosphere more reminiscent of a discussion rather than a formal interview and to help ease into the interview process (DiCicco-Bloom & Crabtree, 2006), at the start of the interview I asked the participants a broad question pertaining to a general description of their work in home

care. Subsequently, I used open-ended questions to explore the different aspects of the HHCA worker's perceptions, beliefs, and experiences of CPP (Appendix E). To maintain professional boundaries, I clarified my role as a researcher and engaged with the participants in a respectful, empathetic, and nonjudgmental manner throughout the course of the study.

According to Morrison et al. (2012), equal importance should be placed on meaningful closure of the researcher-participant relationship, especially when studying sensitive topics. Having an exit strategy upholds the moral and ethical conduct of research as it not only demonstrates the researcher's respect and concern for the participants but also upholds clear boundaries in the researcher-participant relationship. Prior to ending the interview, the participant was invited to provide feedback on the interview process and the impact it may have had on them (Murray, 2003). Consistent with what other authors have previously reported in their own work (Alexander et al., 2018; Elmir et al., 2011), the HHCA workers in this study reported cathartic effects of participating in research. For instance, Ila indicated that the interview provided her with a sense of relief in that it allowed her to share her CPP experiences, which she was unable to do elsewhere. Other participants, like GBear, gained new insights, indicating that engaging in the interview made her more aware of her attitudes and how CPP affected the quality of her own work. This strategy facilitated a meaningful and positive closure to the interview process. When sensitive issues are explored, it is important to have support structures in place for participants and the researcher in the event that the interview process gives rise to potential harm such as emotional discomfort (Alexander et al., 2018; Dempsey et al., 2016). In this study, I engaged in self-care measures and was able to

provide each participant in this study with support in the form a referral for counselling services when needed.

### ***Outcome: Overcoming Fear and Finding Voice***

Once participants felt reassured that confidentiality and anonymity would be maintained, they were more than willing to share their experiences and participated in the interview for altruistic reasons. For instance, Aimee indicated that by participating in the study she felt she was helping future generations of HHCA workers through the potential benefits of this research. Altruism is an important aspect of participation in qualitative research interviews as it enables validation of disempowering experiences and, in turn, allows the participants to feel heard, valued, and empowered (Alexander, 2010; Neville et al., 2016). Participants in this study expressed their gratitude for my interest in the research topic and for the rare opportunity to tell their story and be heard.

### **Recommendations**

Conducting research with HHCA workers was a highly valuable learning experience and provided me with unexpected insights on the challenges of carrying out sensitive research with vulnerable populations. Based on the challenges I encountered in recruitment and data generation, conducting research with HHCA workers who were hard to reach warrants innovative strategies. For example, according to Markkanen et al. (2008), participation incentives may enhance research participation among HHCA workers. Other strategies and venues for recruitment should also be considered, such as social networking sites or conferences, respectively, to advertise the research study (Dempsey et al., 2016; Sydor, 2013) so that maximum variability might be achieved.

In order to maximize recruitment success, researchers ought to also consider negotiating entry with gatekeepers by offering incentives such as sharing of the study

findings (Dempsey et al., 2016). Negotiating access requires the development of trusting relationships with gatekeepers early in the research process. This can be done by making an effort to connect with those in leadership positions, or members of associations who have long-term relationships with the target population (George et al., 2014), and collaborate with them in planning the research (Stevens et al., 2016). Knowledge of the organizational structure of target organizations may have benefits in the recruitment of participants. For instance, this may ultimately be an efficient way to save the researcher's time in figuring out who has the power to grant access to targeted populations (Moore & Miller, 1999). Based on my experience and the evidence, I suggest establishing relationships with gatekeepers while the research proposal is being written.

Stack-Cutler et al. (2017) further recommended offering multiple ways for participants to engage in the research. This is possible through computer-mediated communication strategies such as email or instant text messaging, which can be used to conduct qualitative interviews on sensitive research topics (Cook, 2012; Elmir et al., 2011; Neville et al., 2016). Although this method of communication requires considerable researcher engagement, it is user-friendly and allows individuals living in geographically distant locations to participate in the comfort of their chosen space, where they can disclose personal experiences without social pressure or being identified. Computer-mediated interventions that allow virtual data collection may also be beneficial for the researcher in that transcription of generated data is no longer necessary (Elmir et al., 2011). In a similar vein, virtual data collection was successful in the Rodham et al. (2009) study where online message boards were used to collect qualitative data from people who lived in distant places and had complex regional pain syndrome.

## **Final Thoughts**

Social justice is a term that refers to moral and ethical judgements about fairness and equity (Canadian Nurses Association, 2010). To promote equity and social justice, it is imperative that HHCA workers' autonomy and agency are supported. One way to promote agency and autonomy is to align recommendations that uphold the principle of justice. Recommendations inclusive of widening the recruitment strategies, negotiating access with gatekeepers, and offering multiple mediums of communication may enhance researchers' access to HHCA workers and, thus, provide these workers the opportunity to be included and make informed decisions to participate in research. Bracken-Roche et al. (2017) further suggested that HHCA workers should also be provided the opportunity to influence research by taking part in the planning phase of the study to enhance their capacity for participation. Overall, these strategies can facilitate the participation of HHCA workers by allowing them to exercise their personal agency and by providing them with fair and equal opportunities to participate in, and reap the benefits of, research.

## **3.5 SUMMARY**

In this chapter, I examined the inherent challenges I encountered in conducting qualitative research that is both politically charged and sensitive with a vulnerable group of workers. I reflected on issues concerning stigma, gatekeeping, and the benefits gained in utilizing telephone interviewing for this study. Recommendations to overcome challenges in recruitment and data generation with vulnerable and hard-to-reach populations like HHCA workers have also been presented. My purpose in writing this thesis is to raise awareness of the importance of including the voices of those who are vulnerable and stigmatized like HHCA workers, in the hope that they may have the equal

opportunity to exercise agency in participating in a research study that has the potential to enhance their well-being.

## **CHAPTER 4: INTERSECTING VULNERABILITIES IN HOME HEALTH CARE AIDE WORKERS WITH CHRONIC PHYSICAL PAIN**

The emphasis on aging in place and caring for people in the comfort of their homes and communities draws attention to frontline health workers like home health care aides (HHCAs). HHCAs are an unregulated group of paraprofessionals who provide supportive and personal care services to individuals with medical conditions and/or functional limitations in various home and community settings (Government of Alberta, 2018). There is currently no national registry of the HHCA workforce in Canada (Hewko et al., 2015). A directory has recently been launched to collect demographic data for this workforce in Alberta, but this information is currently not available to the public (Alberta Health Care Aide Directory, 2020). Thus, characteristics of individuals in this occupational group are unknown. However, research on the occurrence of musculoskeletal (MSK) injuries among these workers is well documented (Craven et al., 2012; Macdonald & McLean, 2018; Storch et al., 2014). Many of these injuries have been attributed to the nature of home care work and exposures to hazards and risks unique to the unregulated home workplace environment (Macdonald & McLean, 2018; Sims-Gould et al., 2013). The constant exposure to workplace injuries increases HHCAs' vulnerability to developing chronic physical pain (CPP) (Shnayder et al., 2018). CPP is most often referred to as pain that originates from disease, bodily injury, or dysfunction that persists longer than three to six months (Biedma-Velázquez et al., 2018; Merskey & Bogduk, 1994; World Health Organization, 2019). CPP has many implications including functional impairment, disability, loss of work productivity, and poor psychological health and well-being resulting in an overall reduced quality of life (Kawai et al., 2017). Although increasing attention is directed towards CPP, to my knowledge, no Canadian

studies have been conducted on the experiences of CPP from the perspective of HHCA workers (Gilmour, 2015; Health Canada, 2019). The safety and well-being of HHCA workers are important given the unprecedented growth of the aging Canadian population and the increasing demand for home care services (Macdonald & McLean, 2018). Thus, the aim of this study was to explore the experiences of CPP among HHCAs working in private homes in a western Canadian province.

#### **4.1 CPP AND VULNERABILITY DEFINED**

For this study, I adopted the following definition of CPP as an unpleasant sensory and emotionally distressing experience associated with disease, bodily injury, or dysfunction that generally persists beyond six months despite treatment (Biedma-Velázquez et al., 2018; Merskey & Bogduk, 1994; World Health Organization, 2019). The prevalence of CPP increases with age and can have a substantial impact on physical, psychological, social, and economic well-being (Health Canada, 2019). Reduced work productivity and workdays further cause negative consequences that extend to employers, the health care system, and society (Dueñas et al., 2016; Kawai et al., 2017).

Importantly, the burden of CPP is not distributed equally in society (Health Canada, 2019). Certain individuals, particularly those experiencing discrimination and social inequities, are more vulnerable to CPP. Marginalization can complicate the challenges of living with pain among those already in vulnerable situations (Allen et al., 2015). Indeed, unfair treatment and discriminatory experiences can result in chronic stress, consequently leading to exhaustion, heightened sensitivity to pain stimuli, and an overall worsening pain experience (Chan et al., 2013; Dugan et al., 2017; Nortvedt et al., 2015).



## **Vulnerability**

The concept of vulnerability, derived from the Latin term *vulnerabilis* which means wounding or likely to injure (Angel & Vatne, 2017), is critical to understanding the ways in which HHCA workers are at risk due to CPP. Vulnerability is a term most often associated with susceptibility to risks and the inability to manage such risks effectively (Flaskerud & Winslow, 1998; Zarowsky et al., 2013). Risks can be physical (i.e., illness, disease, injury, or pain), emotional (i.e., fear, anger, or distress), cognitive (i.e., compromised understanding and reasoning; (Boldt, 2019), social (i.e., discrimination, isolation, violation of rights, lack of opportunities and power; (Leight, 2003), or economic in nature (i.e., low wage and limited health benefits; (Himmelstein & Venkataramani, 2019). People may also experience vulnerabilities based on several factors including inequities in access to health and health care (Jones & Smith, 2014); diminished ability to exercise autonomy and safeguard one's interests (Canadian Institutes of Health Research et al., 2014); unsafe work and living conditions (Yanar et al., 2018); individual characteristics such as age, sex, race, and ethnicity (Aday, 1994); reduced life expectancy; and poor quality of life (Flaskerud & Winslow, 1998). Thus, the notion of vulnerability is dynamic as it is context specific and dependent on various factors that influence health outcomes (Allotey et al., 2012). In this study, I use the term vulnerability to refer to situations that increase susceptibility to harm, injury, and poor health outcomes.

## ***Literature Review***

All humans experience some degree of vulnerability, although certain groups of people are more likely than others to be at risk and experience poor health. Several interventional and descriptive studies have been conducted on populations that have been

identified as vulnerable including women; children; older adults; ethnocultural minorities; individuals living with mental health issues and/or disabilities; and people who are incarcerated, economically disadvantaged, and/or marginalized based on their sexual orientation or religion, among others (Bracken-Roche et al., 2017; Nyamathi et al., 2007). In the context of occupational health and safety, vulnerability is determined by the degree of exposure to workplace hazards, the lack of workplace protections to combat these hazards, and/or a workplace culture that excludes workers from participating in decision making related to injury prevention (Smith et al., 2015). Workers providing direct patient care have often been described as vulnerable because they sustain the highest rates of injuries in the workplace (McCaughey et al., 2014; Qin et al., 2014). In comparison to other health workers, HHCAs are particularly vulnerable as they experience significantly higher rates of injury in the home workplace setting (Hewko et al., 2015; Riccò et al., 2017; Suarez et al., 2017) and face high levels of stress related to various factors including heavy work demands (Chowhan et al., 2019), lack of workplace support (Zoeckler, 2018), poor working conditions (Muramatsu et al., 2019), and inadequate pay and health benefits (Shotwell et al., 2019). The level of vulnerability is further exacerbated because most HHCA workers are women with low socioeconomic status, who are born outside of Canada, and who receive few opportunities for job advancement (Hewko et al., 2015; Novek, 2013; Sims-Gould & Martin-Matthews, 2010).

The scholarly literature about the work of HHCAs has focused on physical vulnerability from occupational injuries caused by the daily performance of high physical job demands, such as transferring and repositioning clients as well as lifting furniture or medical equipment (Czuba et al., 2012; Suarez et al., 2017). The lack of resources to support these functions presents further physical health risks to these workers. Performing

strenuous tasks with limited equipment and support can increase susceptibility to workplace injuries (Arlinghaus et al., 2013) and stress (Muramatsu et al., 2019). Challenging home workplace environments pose numerous hazardous situations (i.e., exposure to slipping or tripping hazards such as clutter and icy conditions) with implications for clients' and HHCA workers' safety (Wills et al., 2016).

According to Geiger-Brown et al. (2007), safety protections in private homes are not comparable to those implemented in other health care settings. Because HHCAs often work alone, they may be exposed to other factors that increase their vulnerability to harm (Storch et al., 2014). In addition to risks to physical safety, HHCA workers are subject to various forms of violence and abuse in the home setting (Green & Ayalon, 2018; Karlsson et al., 2019; Nakaishi et al., 2013; Sims-Gould et al., 2013). Exposure to workplace violence and harassment can lead to psychological distress, headaches, depression, and burnout among these workers (Lever et al., 2019; Mento et al., 2020; Saavedra Macías et al., 2019). Thus, the nature of home care work and its unpredictability, as well as hostile work environments, increase HHCA workers' level of vulnerability in the home workplace setting. Set against this backdrop, HHCA workers are at an increased risk of developing CPP and other adverse health outcomes. Despite the importance of HHCAs in the provision of home healthcare, pain-related research involving these workers is limited to quantitative studies on MSK pain (Chang et al., 2020; Lundberg & Gerdle, 2017; Riccò et al., 2017; Shnayder et al., 2018). This gap means that there is limited understanding regarding the experience of CPP among these vulnerable workers. Before solutions or workplace protections can be developed or modified to protect HHCA workers against undue harm and violence, it is first important to understand the experience of CPP from the perspective of these workers.

## 4.2 METHODS AND PROCEDURES

### **Research Design**

I used an exploratory descriptive qualitative design to explore HHCA workers' experiences related to CPP. Qualitative description is a widely used methodology that aims to describe the “who, what, where, and why” of events or experiences, particularly those that are not well understood and/or from the viewpoint of those who have experienced them (Sandelowski, 2000). Since pain is a personal experience and no research specific to CPP has been conducted among HHCA workers in Canada, a qualitative descriptive design was appropriate and well suited to capture rich, descriptive, first-person narratives (Sandelowski, 2000) of CPP experiences.

### **Sample and Setting**

I used a purposive sampling strategy to recruit participants for this study. Multiple recruitment strategies involved (i) presentations, (ii) a recruitment poster placed on social media, relevant association websites, and employer bulletin boards, and (iii) a letter of invitation distributed by the administrative staff of private agencies and organizations to HHCA employees. HHCA workers who were interested in participating in the study contacted me via telephone or email and were subsequently screened for eligibility. Inclusion criteria consisted of (i) current employment as a HHCA in private homes; (ii) self-reported CPP condition lasting longer than six months; and (iii) the ability to read, write, and speak English. HHCA workers with acute pain or those on sick leave were ineligible to participate.

A total of 12 female HHCA workers, ages 25-65 years, with self-reported, multisite CPP conditions volunteered to participate in the study. Similar to the sample population of HHCA workers in other Canadian studies (Panagiotoglou et al., 2017;

Slaughter et al., 2018), participants in this study were primarily middle-aged women (>40 years old). Their work experience varied and ranged from 1 year to more than 20 years. Eight of the participants were employed full-time and about one third worked for multiple employers to earn a living wage. In Table 1 (Appendix F), I outline the characteristics of participants based on their age, country of origin, years of work experience as a HHCA, work schedule, number of current employers, background education, marital status, and dependents.

### **Ethical Considerations**

I received approval to conduct this study from the University of Alberta's Health Research Ethics Board (ID: Pro00093271) and adhered to the ethical requirements of research practice developed by the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (Canadian Institutes of Health Research et al., 2014). I obtained verbal and written consent from each participant before initiating data generation. Pseudonyms were selected by the participants and are used in this manuscript.

### **Data Generation**

Data generation occurred from September 2019 to March 2020. I conducted a total of 14 semistructured interviews. Ten individual, digitally recorded interviews were conducted by telephone; two were conducted in-person. Two participants from the original participant sample engaged in a second telephone interview to further explore experiences and to verify accuracy of generated data. Open-ended and probing questions (e.g., "What is it like to experience chronic pain?") made up the interview schedule. To uncover new layers of understanding, I modified or added questions as the interviews progressed. For example, the notion of "limited involvement in decision-making" emerged during the interviews and initial stages of analysis. To further explore these

ideas, I added the question, “Can you describe your involvement in decision-making in the home care context?” Lastly, I transcribed the interviews verbatim using NVivo Transcription, and utilized NVivo 12 for data management.

### **Data Analysis**

I analyzed the data using Braun and Clarke’s (2013) thematic analytical approach. Data analysis involved multiple stages including the reading of transcripts in a line-by-line reiterative manner until I could identify salient features and patterns of the data and subsequently categorize them. To further develop categories, I used a constant comparative method to systematically analyze and compare codes within each interview and across interviews. Categories were expanded or collapsed as patterns emerged. Using a visual map, I explored the linkages between categories to identify the theme that best represented HHCA workers’ experiences of CPP.

The trustworthiness of the study was established by using Lincoln and Guba’s (1985) criteria. The establishment of trust and confidence in the research findings was demonstrated in this study through (i) an audit trail (dependability); (ii) purposeful sampling and the thick and rich descriptions of data (transferability); (iii) a description of participant demographics, direct quotations from the interviews, ongoing supervisory and thesis committee review of research activities, and reflexive journaling (confirmability); as well as (iv) use of a semistructured interview guide utilizing open-ended questions and member checking activities (credibility). Of note, I engaged three participants in member checking to confirm the accuracy of the findings with their experiences of CPP (Bradshaw et al., 2017; Liamputtong, 2013).

### 4.3 RESULTS

The findings of this study reflect multiple, intersecting vulnerabilities that HHCA workers face as a result of CPP, hazards in the home environment, and systemic conditions. These vulnerabilities are physical, psychological, social, and economic in nature and are described below.

#### **Physical Vulnerability**

Participants in this study described significant limitations with physical functioning (i.e., reduced strength) as a result of CPP that interfered with their ability to perform activities at home and in the workplace.

I'd like to be able to assist my client in standing up a little better. I would like to be able to get down in the position to help somebody stand but I can't. My back won't tolerate that kind of lifting. (Sandy)

Although participants indicated that pain was “always there”, the quality, severity, and timing of pain changed daily. The unpredictable nature of CPP often created challenges with pain management, which compromised work ability and productivity. As GBear said, “you're moving slower when trying to accomplish the simplest of tasks, which does affect the clients in getting their care or getting things done in a timely manner.”

Participants in the study also identified hazards that increased susceptibility to safety risks in their clients' homes. That is, specific elements inside (i.e., poor physical layout of homes with clutter; non-adjustable beds, tripping hazards, etc.) and outside (i.e., icy driveways, motor vehicle accidents) the home increased the likelihood of experiencing pain and further workplace injury.

We don't have mechanical beds so we can't adjust the height. They [clients] have their own furniture. So, if stoop over their bed, your back may hurt that day. You go by their four-poster-bed and you end up with a giant bruise on your leg because you hit your leg on the bedpost. Not having great furniture to do care can affect your pain. (Tabitha)

Several aspects of home care work also worsened pain or caused recurrence of physical injuries. Participants in this study cared for aging and/or overweight clients who were frail. At times, these clients also had cognitive impairments, which exacerbated their level of frailty. The participants described care for this cohort as hard because it involved multiple physical and mental demands often in less than ideal situations (e.g., uncooperative, or combative clients). According to Sandy, “clients who have challenges with memory don't really understand why you're in there trying to take their clothes off and change them or shower them. They get mad and start kicking, swinging, and pinching.”

Job expectations that were greater than the participants' abilities further increased physical vulnerability to injury and pain. Although assigned tasks differed with each employer, seven participants in this study reported the expectation that they would provide a wide variety of supportive and care services for clients with varying levels of needs. In addition to providing assistance with activities of daily living (ADL), HHCA workers delivered services related to instrumental activities of daily living (IADL), for example, meal preparation and serving; laundry and closet organization; garbage disposal; and cleaning rooms, bathrooms, windows, fridge, floor, tables, and dishes. Participants also revealed that they would perform tasks that regulated nurses would otherwise provide in healthcare settings. This included medication assistance, emotional support, safety and emergency response, documentation, catheter assistance, checking blood glucose, and taking vital signs. A few of the participants identified other additional tasks such as assisting with recreation, moving equipment and furniture, and even changing light bulbs.



It is a lot of responsibility and a lot of care for one person. I do have a full load and I multitask to do all the public cleaning, mopping of the floors, moving the furniture, meal prep, the housekeeping, taking out the garbage, changing the light bulbs, cleaning the vent in the room, or scrubbing the floors. It's a physical job, and we do a lot of walking, bending, and lifting. (Tabitha)

Considering their varied job responsibilities, participants described situations in the workplace where their safety and health were compromised. For instance, many of the participants described multiple injuries like “twisted” hands and thumb; “broken” wrist; “destroyed” back; and pain in their shoulders, neck, jaw, and knees. Physical pain and injuries were also the result of falling on hard surfaces, lifting patients or heavy objects, and catching clients from falling. Although some participants indicated that “you’re sore no matter what” (Kelsi) from engaging in home care work, performing repetitive strenuous activities such as transferring; assuming awkward postures like bending; lifting laundry bags and garbage; pushing and pulling heavy kitchen carts and wheelchairs; and sitting, standing, or walking for extended periods of time aggravated their CPP conditions. Vulnerability to injury and pain was further exacerbated by limited access to assistive devices (i.e., ceiling lift, slider sheets); inadequate training for certain services; working with other staff who are injured; and organizational factors such as heavy workload, understaffing, long hours of work, and time constraints. Participants indicated that when workload intensified during these circumstances, they would miss scheduled breaks and often had to overlook pain management strategies.

You know working short is a nightmare. You still have to do all those tasks. So, if you're working short then God help you. There is no way you can try to manage your pain because you just don't have time. You just go, go, go. You don't stop. I don't think I even had a sip of coffee. (Aimee)

## **Psychological Vulnerability**

The nature of pain also had consequences for psychological states of well-being. Most of the participants expressed frustrations with their inability to have restful and restorative sleep due to persistent pain. Inadequate rest and recovery from pain and work demands led to overwhelming complaints of mental and physical exhaustion, which consequently affected their engagement in social and leisure activities. Being exhausted further caused some HHCA workers to “forget things” (Alaina) and “feel on edge or become snappy” (Kelsi). Participants admitted this was not a good combination, as fatigue and exhaustion had lasting effects beyond their experience of pain. According to Aimee, “when you're exhausted, you cannot provide that quality of care for yourself or the client.”

Participants also reported memory loss, problems with concentration, and difficulties in controlling their emotions because of CPP. HHCA workers disclosed experiencing a range of mood and emotions including frustration, anger, agitation, irritability, depression, guilt, shame, and increased stress and anxiety.

I would sometimes just cry because I'm so frustrated that I can't do this or I can't do that or I feel incompetent. I do get down on myself a lot about it and sometimes I'll even go through a depression. It's frustrating sometimes. (Teenie)

Most participants reported experiencing considerable ongoing stress and being “burnt out” (Anna) or “run down” (Alaina) from exposure to various forms of violence (i.e., physical, verbal, emotional) and harassment (i.e., bullying, discrimination) in the workplace. Several participants described situations when colleagues, clients, and clients’ families were rude, demanding, and/or disrespectful. The violence they experienced provoked high levels of stress, which in turn heightened the intensity of their pain and/or triggered other pain conditions.

Well, like for example, one of the clients would say a bad word, swear at you, or tell you “You are incompetent.” The way they treat you causes severe damage emotionally and mentally. Sometimes they are racist. For example, they would say, “You came to this country, and you can go back to your country.” You know after I come from a client like that,—very critical, racist, and discriminating—I have a heavy heart. The stress I encounter at work, with the client, with the family who are unsatisfied with the care, those are stressors that trigger the pain. It triggers my headaches. It’s not right to have a thing like that because you already know you are experiencing arthritis. That is more stressful. (Ellena)

Other participants like Teenie, disclosed feelings of vulnerability related to fears of losing her job as a result of CPP impairments. Due to fear of job loss, Teenie was reluctant to inform her supervisor about her pain or injuries sustained in the workplace.

I didn't want to complain and I didn't want to say I can't do this or I can't do that because it would risk me losing the client or not having enough hours that I need. It’s kind of hard for me to do but I'm not going to say anything because I don't want to lose my job. (Teenie)

Participants also expressed concerns about provincial health care budget cuts that would reduce the number of beds available in acute care and long-term care facilities, resulting in an increased level of complexity in a population that was, by necessity, cared for at home. Participants, like GBear, indicated that a lack of resources left them ill-equipped to care for this increasingly dependent population with complex medical needs. In such circumstances, HHCA workers “make do with less” which often resulted in increased stress and pain.

We've had clients as of late who have surgery and are sent back to us before they're ready because acute care is running short of beds. When they send them back to us before they're ready, that changes the dynamic or the needs at our end. Now that person requires a whole lot more care that time wise you're struggling to provide properly. When the dynamics have changed, you just do the best that you can with what you've got. The place that I work, you do what you can. (GBear)

We aren't supposed to have anybody that requires full lifts because once they get to that point they are meant to move on to a higher level of care. When you tell them that the clients are getting to be beyond our care, they're not listening and trying to move them to a different level of care. Three workers were injured at once from such a heavy load. (IIa)

## **Social Vulnerability**

Four participants limited their social interactions with colleagues for fear of stigma and judgement associated with their pain conditions. In many cases, the lack of a clear medical explanation for their persistent pain meant that some people did not believe or understand what they were going through, which seemed to increase the participants' sense of vulnerability.

You get a lot of people that look at you and go, "Well you look fine." Yeah I may look fine. That doesn't mean I feel fine. And they're like, "Well you're still doing the work." That is definitely the hardest part of it all. It's very frustrating and people really look down on you when you say something because they tend to not believe you. They don't try and understand what's going on. They're just quick to judge. (Kelsi)

Decreased social interaction with family, friends, and colleagues left most of the participants feeling isolated.

Some days I just feel like hiding or like staying in bed for the day and not do anything. It makes me feel kind of isolated because I'd like to get involved in other things. Sometimes I just focus on the pain and not about what they're [family and friends] going through. Basically, I put myself in a bubble. (Sue)

The HHCA workers in this study also expressed frustrations about being undervalued and viewed as low-skilled employees rather than essential members of the health care team. According to Aimee, lack of respect and appreciation from managers and clients—and their families—led to feelings of disempowerment.

Nobody appreciates that we are doing the job. You only hear things when they're not done but nobody sees the things that you do beyond your duty. Every time somebody looks at you, you get that, "Oh my god, what are they going to say now?" You have some families that they're never happy. You know when you enter the house and you wipe your feet on the rug? I feel I'm the rug. In every aspect I am the rug. (Aimee)

Other participants, like Alaina, relayed concerns about the absence of voice and participation in decisions that directly affect them in the workplace.

There's nothing like, "How do you think we could help with preventing more injuries?" It's just kind of like we're not asked what we think, and we should be because we're the ones that are injured or the ones that are there. So, we should be the ones that are talked to. (Alaina)

Conflict and lack of support from nursing staff and managers were also repeatedly reported. There was a belief among half of the participants that managers and employers prioritized profit over their well-being.

You know working short and because of the reduced budget, you don't even mention that you have pain. To whom are you going to mention it to? So, even if I say I have a pain, who's going to listen to you? They'll say, "Go to the doctor" or something. Everybody wants to save money. But saving money on us you know?. (Aimee)

Participants further described situations where they were made to feel at fault for being injured or in pain.

Well they make you feel like crap if you complain about being in too much pain or having a migraine and you're already at work or something has happened that you're just feeling unwell. There is a great sense of shaming. It's a major inconvenience. Those who are genuinely in pain are made to feel guilty because "Now your partner is going to work alone" or "We'll never get somebody to cover you." It is kind of like I understand that but that's not my fault. (GBear)

Overall, the participants' morale, work relations, and job satisfaction were negatively influenced by poor working conditions, lack of support, and unfair treatment by clients and colleagues.

You do the small things for somebody and the gratitude. But some days it just isn't enough. I mean you're butting heads with management and then you've got clients who are extremely demanding and rude and violent. How do you be happy with your job? (GBear)

### **Economic Vulnerability**

Participants in this study indicated that earning a low wage and receiving minimal health benefits negatively influenced their ability to access pain-related treatments, making them more vulnerable to increased levels of CPP.

We have a \$300 health benefit plan and \$300 for chiropractor or massage. If you have chronic pain, these could be gone in six months. I stopped going to the chiropractor because I ran out of benefits. Even my medications, you run out of that so you're having to pay for it all out of pocket. Well, no wonder people stop taking their medications because they can't afford them. (GBear)

Seven, of the 12 participants interviewed, reported working for multiple employers and/or working overtime to meet their financial obligations.

You have to make a living to pay your bills. We have a family to feed. That's why most people are forced to have two jobs. Some [HHCAs] are working two jobs because they are a single mom. I go to another place to work casual because I cannot survive with one job. We are dealing with people, with a human being and the pay is ridiculous. Even after 20 years of working, you have to fight for an increase of 20 cents. (Aimee)

Most of the participants indicated that financial constraints were compounded by limited opportunities for job advancement given their age, educational background, and physical limitations due to CPP.

We all have some background education that is not recognized [in Canada]. (Aimee)

Because I'm in my 60's, it's kind of late for me to find another career. I've thought about it, but I do have some limitations [due to CPP] so I can't apply for a job and say, "I can't do this, and I can't do that." (Teenie)

Engaging in housework in addition to multiple work demands left these workers with little to no time to recover.

You're just sore all the time. It's like even on your days off you just start to recuperate but there's also stuff that needs to be done [at home]. After one 12-hour shift, you're so sore again. I don't have enough time to recuperate because I only have one day off. (Ila)

Overall, the results of this study highlight the multiple, intersecting vulnerabilities faced by HHCA workers in this study. The entanglement of various vulnerabilities encountered by these workers exacerbate and heighten the complexity of pain experienced.

#### 4.4 DISCUSSION

The narratives in this study represent the views of HHCAs who work for different home care employers across a western Canadian province. In line with other studies (Dueñas et al., 2016; Kawai et al., 2017), the unpredictability of CPP and accompanying physical, psychological, and social effects had a negative impact on the HHCA's work and personal life. While the findings of this study highlight the many forms of vulnerability faced by these workers, they also highlight how the intersections of these vulnerabilities exacerbate or heighten the experience of CPP. For instance, several participants stressed how lack of sleep as a result of persistent pain contributes to exhaustion, and thus, their inability to engage in social activities, which further amplified their social vulnerability. Poor sleep quality is also associated with increased pain intensity (Vega et al., 2019) and has adverse effects on mood, daily performance, and mental capacity to manage pain (Abbasi et al., 2018). For the participants in this study, the impact of sleep deficiency on cognitive and motor performance further exacerbated their psychological vulnerability. The intersections of multiple vulnerabilities put HHCA workers' safety at greater risk, particularly when working long hours and carrying out considerable physical demands in poor working conditions.

HHCA workers are also exposed to many on-the-job hazards that put their health and safety in jeopardy. In addition to working in highly variable and unpredictable home environments that limit their control over work and surroundings, the HHCA workers in this study engaged in strenuous and demanding physical work to provide care for people with complex medical needs. This resulted in mental and physical exhaustion and increased pain, which intensified when resources (i.e., time, staffing, equipment, and management support) to cope with care demands were limited. Participants also missed

scheduled breaks to complete client care. Engaging in continuous, strenuous work without adequate rest, or time to self-manage pain symptoms, led to increased stress and worsening pain. Since unpredictable work environments, heavy workload, time pressures, and limited workplace resources are linked to violence, physical injuries, and chronic MSK pain (Kim et al., 2010; Merryweather et al., 2018; Sims-Gould et al., 2013), the intersections of vulnerabilities may exacerbate the HHCA worker's experience of each vulnerability. Thus, HHCA workers are at an increased risk to (re)injuries, pain, and further physical decline and suffering.

Structural factors further increase risk for HHCA workers who work full-time, overtime, or have multiple jobs to make ends meet because they work longer hours with pain and physical injuries. According to macroergonomics theory (Kleiner, 2006), HHCA workers with CPP are not fit to carry out the inherent requirements of their work environment since their job expectations exceed their abilities. This suggests that HHCA workers are vulnerable to further harm and negative health outcomes, which could potentially affect patient care and hinder sustainable employment, thereby exacerbating their economic vulnerability.

Findings that pertain to the lack of recognition for the care and emotional labour provided by HHCA workers are in line with prior research (Spetz et al., 2019; Stone & Bryant, 2019). Participants in this study expressed frustrations and increased stress from being undervalued and from having to meet excessive work demands in hostile work environments. According to Liu et al. (2019), chronic stress causes functional changes related to pain processing in the brain, resulting in increased intensity and duration of pain. Chronic stress can also lead to cardiovascular disease, decreased immune functioning, and mental health problems (Delgado et al., 2017). Moreover, workplace



conflict has been linked to emotional exhaustion and depersonalization among Japanese home care workers (Fujiwara et al., 2003). Thus, repeated exposures to social vulnerabilities such as stigma, unfair treatment, and conflict in the workplace can exacerbate physical vulnerabilities through heightened pain experiences and adverse health outcomes related to chronic stress. The intersections of vulnerabilities may also lead to detrimental effects on mental health and work performance, worsening the impact on psychological and economic vulnerabilities.

Due to perceived budget constraints, the HHCA workers in this study believed they had to do more with fewer resources. Perceived lack of resources (i.e., staff, equipment, time) in the provision of care to frail, older clients may put HHCA workers at risk for experiencing more frequent and severe moral distress (Pijl-Zieber et al., 2018; Spenceley et al., 2019). Moral distress occurs when the right thing to do is threatened by institutional constraints, which consequently affects a person's values and integrity (Lachman, 2016). For instance, as noted by one participant in this study, the lack of time to carry out work functions impeded her from using best practices (Estabrooks et al., 2015) resulting in the inability to attend to all of her client's basic needs (Martin-Matthews et al., 2013). This may lead to client safety concerns and unmet health needs, compromising the HHCA worker's professional integrity and values.

Last, a significant finding expressed by the participants in this study, that perhaps added to their experience of moral distress, is their perceived lack of influence in decision-making and policy development in the home care setting. As indicated by Afzal et al. (2018), decision making in health care follows vertical power hierarchies, which means HHCA workers have limited opportunities to contribute in the organizational and clinical context. This demonstrates the systemic devaluation and marginalization of this

group of workers in the health care industry. Overall, the results from this study highlight the pervasiveness of multiple, intersecting vulnerabilities and the disproportionate burden of health challenges among HHCA workers with CPP.

### **Implications**

Continued exposure to work-related hazards that lead to injury, stress, and worsening pain outcomes raise health and safety concerns for these workers. Hence, it is imperative that policymakers, employers, and supervisors consider the development or modifications of policies and interventions that respond to the unique intersections of vulnerabilities among HHCA workers with CPP. To be able to continue the delivery of supportive and caring services to the community, interventions aimed at improving workplace health and safety for HHCA workers are needed. For example, workplace wellness programs should consider stress management and reduction as well as health promotion for an older working population experiencing poor sleep, fatigue, and CPP. To ensure the safety of these workers, employers should also enlist HHCA workers in the development and implementation of policies that protect them from further injury and violence in the home workplace setting. Workers' participation along with supervisory support, adequate job training, and ongoing safety training can improve HHCA workers' occupational health and safety (Yanar et al., 2018; Yanar et al., 2019). Craven et al. (2012) and Larsen et al. (2018) suggested frequent assessments of home settings and evaluations of workplace environments enable HHCA workers to voice occupational health and safety concerns, which can reduce potential harm. Andersen et al. (2012) further suggested that the reduction of physical exertion at work improves recovery from CPP. Thus, employers may want to consider the coordination of work assignments that are appropriate to the worker's abilities.

HHCA workers would also benefit from appropriate resources necessary for the provision of safe care and supportive services. Resources—such as adequate staffing, access to proper safety devices, and the restructuring of work organization that allows enough time to complete work demands—have the potential to reduce occupational challenges encountered by HHCA workers and allow them to effectively manage their pain symptoms.

Most importantly, it is necessary to respect, acknowledge, and value the contributions in home care services HHCA workers make toward Canadians' health. HHCA workers need to be empowered through initiatives that enable not only their engagement but also their sense of belonging as important workers in the health care system. As such, words of appreciation from employers and policy reforms that consider their economic well-being (e.g., increased wages, retirement benefits, paid sick leave, etc.,) may make them feel valued and supported (Butler et al., 2012). Quantitative research that focuses on measuring how intersections of vulnerabilities influence each other may also increase visibility of these workers and encourage prompt action from employers and policymakers to mitigate workplace concerns related to CPP in the home care context.

### **Limitations**

There are some limitations to this study. Due to the variability of provincial health service delivery (Health Canada, 2009), the findings that represent the views of participants in this research may differ from the experiences of HHCA workers in other geographic health regions. Moreover, due to fear of job loss, there is a possibility that some participants did not fully disclose their experiences related to CPP. Last, although male HHCAs work in home care, their experiences of CPP were not captured in this

study. Given the sex differences in pain sensitivity (Meints, 2018), male participants may have different perspectives or experiences related to the condition.

#### **4.5 SUMMARY**

In this chapter, I offered a descriptive analysis of the HHCA workers' experiences with CPP. The findings drawn from the interviews provide contextual understanding of the persistent and intersecting vulnerabilities experienced by HHCA workers who continue to do heavy physical home care work despite living with CPP. The results of this study highlight the importance of workplace protections aimed at improving conditions for safe employment for these vulnerable group of health care workers. Improved policy interventions, empowerment, equitable practices, and continued research involving HHCA workers could support those with CPP conditions in maintaining their health and well-being at work.

## **CHAPTER 5: RESILIENCE OF HOME HEALTH CARE AIDE WORKERS WITH CHRONIC PHYSICAL PAIN**

Home care is an integral component of the Canadian healthcare system. Home health care aides (HHCAs) are unregulated paraprofessionals, known in various Canadian jurisdictions as home support workers, home attendants, or resident care workers (Hewko et al., 2015). They provide 80% of direct home support and caring services to Canadians who are ill, older, or are living with a disability (Berta et al., 2013) enabling these individuals to remain in the comfort of their homes and communities.

The growing demand for home care services in Canada indicates the need for a sustainable HHCA workforce. However, intersecting vulnerabilities including occupational hazards and risks in unpredictable home workplace environments increase HHCA workers' susceptibility to workplace stress (Zoeckler, 2018), injuries (Hamadi et al., 2016), and other adverse health outcomes such as chronic physical pain (CPP; Shnayder et al., 2018). CPP refers to pain caused by disease, injury, or dysfunction that persists beyond six months (Biedma-Velázquez et al., 2018; World Health Organization, 2019).

Ongoing physical pain and continued exposure to stressors in fast-paced home healthcare environments can increase the burden placed on HHCA workers and threaten their ability to cope and successfully adapt to challenges encountered in the workplace, which can negatively impact their ability to maintain productive work. It is, therefore, important to understand the concept of resilience, which refers to the recovery, maintenance of health, and positive adaptation to stress and adversity (Herrman et al., 2011), among HHCA workers with CPP. In this qualitative study, I explored the HHCA workers' subjective experiences of CPP in their work and life contexts and examined the

factors that enabled them to remain resilient and stay at work, despite living with this chronic health condition.

## **5.1 DEFINING CPP AND RESILIENCE**

For this study, I adopted the following definition of CPP as an unpleasant sensory and emotionally distressing experience associated with disease, bodily injury, or dysfunction that lasts longer than six months (Biedma-Velázquez et al., 2018; World Health Organization, 2019). Approximately 22% of Canadians over the age of 18 years—about 6 million people—live with this potentially debilitating condition (Gilmour, 2015). CPP increases in prevalence as one advances in age, and the burden imposed by the effects of CPP can have negative consequences that affect all aspects of life (Health Canada, 2019). Moreover, pain is a complex phenomenon and many pain syndromes are without effective treatments (Health Canada, 2019), which means that some level of pain persists in individuals living with CPP. Pain interference during work has been linked to increased psychological distress and greater odds of sustaining an injury in the workplace (Reme et al., 2012; Vecchio et al., 2011). Living with CPP can also result in feelings of anger, depression, anxiety, and emotional distress (Burke et al., 2015; Burri et al., 2018) that can amplify pain sensitivity and alter the interpretation and perception of pain, which can further worsen pain-related disability and negatively impact productive employment (Linton & Shaw, 2011; Lumley et al., 2011; Wiech & Tracey, 2009).

Additionally, inadequate assessment and treatment of pain conditions can cause difficulties with pain management (Hogan et al., 2016; Shim et al., 2019). Since living with CPP can be challenging, individuals with this health condition use coping strategies to manage pain. Pain coping, which refers to cognitive, emotional, and behavioural efforts people engage in to minimize the negative impacts of pain, is an important aspect of pain

management (Carroll et al., 2013; Tan et al., 2011). Coping strategies can be classified as adaptive or non-adaptive. Non-adaptive pain coping involves self-blame, catastrophizing, or fear-avoidance; whereas adaptive coping is thought to include strategies such as maintaining activity, problem-solving, positive self-statements, or refocusing one's attention from the pain (Büssing et al., 2010; Carroll et al., 2013; Tan et al., 2011). The type of coping strategies used can affect health and pain outcomes. For instance, scholars acknowledged the potential role of adaptive coping strategies in buffering the negative effects of pain-related distress (Alschuler et al., 2016; Hassett & Finan, 2016). Adaptive coping has been linked to less stress, lower pain intensity, and less functional impairment. Non-adaptive coping, on the other hand, has been associated with increased pain intensity, emotional distress, lower self-efficacy, and greater impairment to physical functioning (Büssing et al., 2010; Miller-Matero et al., 2017; Tan et al., 2011). Other aspects of coping, including personal resources like supportive social networks and socioeconomic factors, also have a potential impact on effective pain coping (Carroll et al., 2013; Michaëlis et al., 2015).

## **Resilience**

Goubert and Trompeter (2017) and Chen and Jackson (2018) claimed that individuals living with CPP can successfully cope and adapt to pain-related adversity. Resilience refers to one's ability to recover, maintain health, and/or positively adapt to significant challenges or adversity (Herrman et al., 2011; Stewart & Yuen, 2011). Some scholars consider resilience as a dynamic construct because contextual factors (i.e., cultural, environmental, or occupational factors) interact with, and consequently influence, coping responses and positive adaptation to difficult situations (Stewart & Yuen, 2011; Sturgeon & Taub, 2016). Adaptive coping strategies that enhance resilience

include acceptance of pain situations, maintaining positive relationships, cultivating supportive social networks, self-care, active coping, and engaging in positive cognitive reappraisals (Ramírez-Maestre et al., 2012; Stewart & Yuen, 2011). Additionally, being optimistic and having a purpose in life promotes coping and fosters growth and development (Cousins et al., 2015; Sturgeon & Zautra, 2010). Individuals with higher resilience report greater positive emotions (Ong et al., 2010); less fear-avoidance; increased self-efficacy; and lower levels of anxiety, depression, and pain intensity (Newton-John et al., 2014; Ramírez-Maestre et al., 2012). In this study, I use the term resilience to refer to one's capacity to cope and successfully adapt to the challenges associated with CPP.

## **5.2 BACKGROUND AND PURPOSE**

The demand for home-based care services is projected to increase in the coming years due to the aging Canadian population with chronic conditions (Canadian Home Care Association et al., 2016; Mofina & Guthrie, 2014). HHCA workers provide about 80% of personal support and caring services in the homes of individuals requiring home care services, most of whom are older adults living with chronic medical conditions (Berta et al., 2013; Poss et al., 2017). Thus, it is reasonable to conclude that HHCA workers are pivotal to the delivery of home care services. To meet the demands in home care, it is necessary to support the recruitment and retention of these workers. However, the sustainability of the Canadian HHCA workforce is threatened by intersecting vulnerabilities (Bonifacio, 2020). For example, low wages (Silver et al., 2020) and unpredictable home workplace environments increase HHCA workers' risk of encountering occupational hazards (Macdonald & McLean, 2018; Suarez et al., 2017), stress (Muramatsu et al., 2019; Zoekler, 2018), injuries (Hamadi et al., 2016; Wipfli et



al., 2012), as well as violence and harassment (Karlsson et al., 2019; Nakaishi et al., 2013). Being exposed to these workplace hazards increases HHCA workers' susceptibility to developing CPP (Shnayder et al., 2018). Ongoing stressors and challenges in the workplace also threaten the ability of these workers to cope and recover, which negatively impacts their health and well-being. Hence, the importance of examining resilience among HHCA workers with CPP.

To date, there is little research that explores the perspective of HHCA workers living with CPP. To address this gap, I sought to explore the HHCA workers' experiences with CPP in the context of their lives and their work in a home care setting. From the participants' perspective, I explored which factors enabled HHCA workers to continue delivering care despite living with ongoing pain. I found that HHCA workers utilized various adaptive strategies to cope with CPP. Findings of this qualitative study are significant for policymakers and employers to establish a workplace culture that supports the resilience of this group of workers.

### **5.3 METHODS AND PROCEDURES**

#### **Research Design**

I used a descriptive qualitative design to explore HHCA workers' experiences related to CPP. Qualitative description is rooted in the tenets of naturalistic inquiry, which focuses on the individual's subjective awareness and experiences of a phenomenon (Bradshaw et al., 2017). The goal of this research design is to develop an understanding of and capture literal and in-depth descriptions of the experience for which little is known (Sandelowski, 2000). Since pain is subjective, and no research specific to CPP has been conducted from the perspective of HHCA workers in Canada, this research design was appropriate and well suited to explore and capture detailed perceptions of CPP

experiences among HHCA workers who have experienced them (Sandelowski, 2000). Although CPP is a personal experience, there were connections within multiple perspectives and experiences of CPP among participants in this study. A more nuanced understanding of these experiences can be understood through analysis of multiple descriptions of CPP experiences.

### **Sample and Setting**

Using a purposeful sampling strategy, I conducted presentations about the study at 10 different employer sites throughout the province of Alberta, Canada. I also placed a recruitment poster on social media and on relevant association websites and employer bulletin boards. Additionally, administrative staff of private agencies and organizations distributed a letter of invitation to HHCA employees. HHCA workers who expressed interest in participating in the study contacted me by telephone or email and were subsequently screened for eligibility. To be eligible for the study, HHCA workers had to (i) be employed in private residential homes; (ii) have experienced CPP for more than six months; and (iii) be able to read, write, and speak English. The exclusion criteria included HHCA workers with acute pain or who were on sick leave. I chose to exclude these workers because they might have had different experiences outside of the phenomenon of working with CPP.

Twelve HHCA workers with self-reported multisite CPP participated in this study. Consistent with the sample population of HHCA workers in other Canadian studies (Panagiotoglou et al., 2017; Slaughter et al., 2018), participants in this study were all female (n=12) and predominantly over 40 years of age (n=10). Their work experience ranged from 1 year to more than 20 years. Eight of the participants were employed full-time and four out of the 12 participants worked for multiple employers in other health

care settings. In Table 1 (Appendix F), I outline the characteristics of participants based on their age, country of origin, years of work experience as a HHCA, work schedule, number of current employers, education, marital status, and dependents.

### **Ethical Considerations**

I obtained ethical approval from the University of Alberta's Health Research Ethics Board (ID: Pro00093271). All participants provided written consent prior to data generation and digital recording of the interviews. To maintain privacy and confidentiality, I stored research data in a password-protected computer and anonymized data using pseudonyms selected by the participants.

### **Data Generation**

I conducted a total of 14 in-depth, semi-structured interviews from September 2019 to March 2020. Ten individual interviews were conducted by telephone, and two were conducted in-person. Two participants also participated in a second telephone interview to further explore experiences and to verify accuracy of the generated data. To explore the HHCA workers' experiences with CPP, open-ended (i.e., "What is it like to experience chronic pain?") and probing questions (i.e., please tell me more about...) made up the interview schedule. I modified or added questions as the interviews progressed, which allowed for the exploration of new directions and nuanced understandings of the data. Lastly, I transcribed the interviews verbatim using NVivo Transcription and utilized NVivo12 for data management.

### **Data Analysis**

I analyzed the data using Braun and Clarke's (2013) thematic analysis framework. This process involved reading transcripts in a line-by-line reiterative manner until I was able to identify salient features and patterns in the data and subsequently categorize them.

I also systematically analyzed and compared codes within each interview and across interviews. As patterns emerged, categories were expanded or collapsed, and with the aid of a visual map, I was able to explore the relationships among categories which then led to the identification of an overarching theme that best represented HHCA workers' experiences of CPP.

I used Lincoln and Guba's (1985) criteria for rigour and trustworthiness. These criteria were (i) maintaining an audit trail throughout the study (dependability); (ii) using purposeful sampling and thick and rich descriptions of data (transferability); and (iii) describing participant demographics, using direct quotations from the interviews, and undergoing supervisory and thesis committee review of research activities (confirmability). I also engaged in reflexive journaling following each interview to examine personal assumptions and biases and how these influenced my understanding of the participants' experiences with CPP. Last, I conducted member checks with three participants to confirm the accuracy of the findings with their experiences of CPP (credibility; Bradshaw et al., 2017; Liamputtong, 2013).

## **5.4 RESULTS**

Analysis of the generated data revealed an overarching theme of resilience. Participants in this study demonstrated resilience through (i) positive coping behaviours, (ii) pain management strategies that fostered health and wellness, and (iii) having a sense of purpose and agency, which are described below.

### **Positive Coping Behaviours**

Participants in this study used positive coping behaviours to overcome challenges associated with CPP. These included maintaining positivity, pain acceptance and self-compassion, as well as social and spiritual support.

### ***Maintaining Positivity***

Maintaining positivity was commonly reported by participants in this study. Although HHCA workers recognized the negative effects of CPP (i.e., physical impairment) and expressed frustrations regarding the numerous stresses they encountered daily while at work, the participants also described the importance of having a positive attitude and the benefits of having this type of attitude. For example, maintaining positivity enhanced Ellena's self-efficacy and confidence in overcoming pain.

When you have a positive attitude in your day to day life, you can do it. You can overcome it [pain]. You can do the job. No one can help you overcome the pain except you. I know that I can do it. (Ellena)

Participants also used positive coping statements as a strategy to motivate themselves to deal with the pain.

Once in awhile I'll just have to give myself a talk and say, "It's okay to have pain" or I will slow down a bit with what I'm doing and just say, "Okay, just focus on what needs to be done. Take it easy and take a few breaths" or like say, "Exercising will help deal with the pain." (Sue)

Through self-motivation and perseverance, participants recognized their own strength and capacity to overcome pain stressors.

You can be stronger than you need to be because you're used to putting up with the pain to a certain degree. I mean you gain strength and a sense of accomplishment from pushing through and getting through the day. It tells me I can handle this [pain]. (Tabitha)

Maintaining positivity not only reduced the participants' focus on pain-related distress but also acted as a buffer against further negative pain outcomes. Such adaptive coping strategies also served as a resource for growth from the experience.

### ***Pain Acceptance and Self-Compassion***

HHCA workers, like Maya, acknowledged and accepted their pain conditions and chose to get on with their lives by continuing to engage in valued activities. These

activities provided an avenue to relieve elevated stress or pain. Maya said, “I’m not going to stop doing things because I have pain. That’s why at home I still do everything that I normally do. I like gardening, cleaning, and cooking.” Self-compassion and understanding towards what one could and could not do because of CPP also influenced acceptance of their pain experience.

Having pain definitely impacts your whole life not just your work life or your personal life. It changes the way you look at things and the choices you make. I do as much as I can and forgive myself for what I can't do. (Tabitha)

Gaining an understanding of their own pain experience enabled HHCA workers to expand their perspectives about pain adversity and demonstrate more empathy towards others in similar situations. Their growth led to greater compassion for colleagues and patients’ experiences of pain.

I have more empathy for others. I understand my patients a lot better and I understand the pain they could be in although other people may think they look okay. I have a lot more to give and I think you become a better care provider because you do understand that they are in pain so you’re a lot more careful with them. (Kelsi)

### ***Social and Spiritual Support***

Despite not wanting to be a burden to their families and friends, participants in this study acknowledged the support they received from them. This is evident in Alaina’s experience. She said, “I have a husband that supports me. He's been amazing and he understands what I'm going through. He’s been my rock.”

Although half of the participants in this study emphasized the importance of maintaining clear boundaries between their work and personal lives, participants like Ila, found relief in sharing their pain experiences with co-workers who also had CPP. Sharing her pain experience provided Ila with the knowledge that she was not alone in her pain journey, which provided her with a degree of comfort. Ila said, “I shared my pain

experience with one of my co-workers who went through the same thing. I find comfort in knowing that somebody is there who understands what I'm going through.”

Two participants also described how their religious beliefs and church communities helped them manage stress and pain adversity.

You know prayer is very powerful. The moment that you say, “Jesus Lord help me,” the help is there. I can tell you that is how I manage. We face obstacles and trials in our life day by day. But if you have faith and look upon Jesus who is the final authority of your pain, you find strength. I also have friends and the senior pastor who are very supportive in prayer. (Ellena)

### **Pain Management Strategies**

Participants in this study reported experiencing different types of pain (i.e., migraine, nerve pain, arthritis, and other musculoskeletal pain) located in different parts of their bodies. They actively used different combinations of strategies to help manage and cope with their pain, as outlined below.

#### ***Multimodal Approach to Pain Management***

HHCA workers employed a multimodal approach to managing their CPP conditions which included primary and specialty care services (i.e., surgical, dental, etc.), medication management, intervention therapies (i.e., steroid injections), psychological interventions (i.e., counselling and cognitive behavioural therapy), complementary and alternative therapies (i.e., physiotherapy, chiropractic services, acupuncture, and massage), and/or use of natural remedies (i.e., herbal treatments). The perceived effectiveness of different pain management interventions varied, and no single intervention was considered more effective than the others. However, eight of the 12 participants disclosed their reluctance to take pain medications due to fear of side effects. Kelsi said, “I refuse to take medication if I can help it because it pollutes my brain.”

### ***Self-Care and Health Promotion Strategies***

HHCA workers in this study also reported engaging in self-care and health promotion activities such as eating a healthy diet, maintaining hydration, and performing relaxation and mindfulness-based activities (i.e., meditation, taking hot baths). They also engaged in different kinds of stretching and physical activities (e.g., tai-chi, yoga, cycling, running, etc.), albeit not regularly, to alleviate pain symptoms.

When I get home, I take a hot bath to try and relax my muscles so I can function. I do lots of stretches before and during my workday to try and help alleviate the pain and prevent my muscles from having spasms or becoming tight. (GBear)

### ***Other Pain Management Strategies***

To maximize their work productivity, HHCA workers employed proactive strategies in anticipation of a pain-inducing episode. They (i) applied hot and cold compresses for temporary pain relief, (ii) used braces and slings to protect injured areas, (iii) performed distraction and redirection techniques to divert attention away from their pain, (iv) increased awareness of their physical limitations and the presence of workplace hazards, (v) asked for help from colleagues when necessary, and (vi) paced work activities when feasible.

I know my limits and I try to stay within them or else my shoulders ache more. I ask for help when I need it. My co-worker and I also switch tasks. She'll do all the mopping because that's what mostly aggravates my shoulder. I also say no when they [employer] phone for overtime because I'm just exhausted and I don't have the same strength I used to have. If I need to step away because I'm overwhelmed, anxious, my hands are aching, or I'm getting a really bad headache because my neck is tensing up, I'll go find a quiet spot and sit for 5 minutes and calm myself. Sometimes it just requires stopping for a moment. (Ila)

Although not consistently available, HHCA workers in this study also utilized health insurance benefits provided by their employer. For instance, they used insurance coverage to access massage therapy and chiropractic services to lessen their pain symptoms.



However, several participants indicated that the health benefits provided by their employers did not extend far enough to support regular treatment for CPP. Consequently, some participants reported having to pay for pain-related treatments out of pocket, which negatively affected their income. Sometimes, when their pain was severe, participants opted to use their sick benefits; although this was not frequent since some participants expressed fear that there would be negative workplace consequences.

We do have a \$300 health benefit plan. If you have chronic pain, these could be gone in six months. I stopped going to the chiropractor because I ran out of benefits. Even my medications, you run out of that so you're having to pay for it all out of pocket. Well, no wonder people stop taking their medications because they can't afford them. Some days though it's not as easy to work through the pain. I did call in sick one time because my neuropathy was so bad I could not even get out of bed. But most of the time I still go to work because you could get called into the office or suspended for sick calls or unexplained absences. (GBear)

### **Sense of Purpose and Agency**

Participants in this study demonstrated altruistic concern for the well-being of clients in their care. They expressed strong feelings of connection and responsibility for the community they served. Their sense of responsibility and accountability compelled them to identify areas in need of change as well as the determination to overcome challenges. This determination enabled them to be resilient in the face of stress and pain.

### ***Sense of Fulfillment in Home Care Work***

Despite their perceived devaluation and lack of recognition for their work, most of the participants still found a sense of pride and accomplishment in being able to provide essential services for the community. Their perception of home care work as more than a job strengthened their connection to their clients and enhanced their sense of purpose and identity. These connections served as motivating factors to continue working, despite living with varying degrees of pain.

It's not only about giving medication and about giving them [clients] care. There is more to it because you become connected with them and their families. You care about them. There's that emotional connection. I love my job and I love my clients. (Aimee)

It's never been about me. It's been about taking care of them [clients] even if it is tough or harder on me. I feel I have a responsibility to them to do my job. Not everybody has the ability to toilet their loved one. We're here to help. Part of my drive is hoping that I will be able to make a difference. (GBear)

I like the feeling of giving back. I push through the pain and go on with it because if we don't do the job, it doesn't get done. It is an essential job. We [HHCAs] care about our clients and everything that we do, we do for them. (Sandy)

It was also evident that HHCA workers felt a sense of community or belonging to their occupational group and experienced camaraderie among colleagues. This fostered not only supportive work relationships but also the determination to help their colleagues whenever and however they could, even if it meant risking their health.

We will pull together. When we're short, we try to help each other out. We're all in the same boat. We have the same tasks and we know how hard it is to do it on our own. So we definitely support each other when we can. Do to others as you want done for yourself. (Sandy)

Although having a connection with colleagues was important, three of the 12 HHCA workers in this study expressed their desire for more communication and support from employers in leadership positions. Participants, like Aimee, indicated that building healthy work relationships could improve staff morale and work productivity.

If I am the boss, I would talk to my staff everyday and get to know them. Maybe see how their day is going. If you have a good relationship with your staff, you're less likely to call in sick and perhaps be stress free. When you're closer to each other and understand each other, even if you have pain, you're going to come to work and make it through. (Aimee)

### ***Identifying the Need for Change***

The participants in this study identified the need for improvements to their work environment. These included work modifications to enhance client safety and continuity

of care (e.g., appropriate staffing, reduction of workload, proper job training, and availability of work equipment).

We need a better client to staff ratio. Like instead of 10 to 1, perhaps 6 to 1. The thought of getting people up faster and spend less time with them is not possible if you want all activities of daily living to be done everyday. We cannot do what we do faster. (Sandy)

HHCA workers in this study also expressed their desire for more support and understanding of their pain situation from their employers, especially considering the physical demands of the job and the deficiencies in resources in home workplace environments that aggravated their CPP conditions.

They [employer] could provide more support and offer it and let people know that these resources are available. (Kelsi)

They [employer] have to be more aware of our restrictions and limitations. It would be great if they had courses available for us to help work around the pain or just support in general that they hear us and understand our pain situation. (Teenie)

Positive coping behaviours, various pain management strategies, and having a sense of purpose and agency enabled HHCA workers in this study to cope and adapt to pain situations. Their sustained engagement in meaningful work suggests resilience and positive adaptation to CPP.

## **5.5 DISCUSSION**

Participants in this study demonstrated their ability to cope and adapt to challenges associated with CPP. Their positive coping skills enabled them to adapt to pain-related challenges at work and to continue to deliver required care. Similar to the findings of other studies, the results from this study highlight resiliency by the strength and perseverance these workers exhibited to overcome pain adversity (Gonzalez et al., 2019; Kawi et al., 2018; Nthekang & Du Plessis, 2019; Schaefer et al., 2013). Participants

in this study maintained positivity, accepted their pain situations, and chose to get on with their lives. This finding is similar to findings reported by West et al. (2012) in their qualitative study with individuals diagnosed with chronic nonmalignant pain. That said, there were also important differences in some of my findings compared to the findings of Newton-John et al. (2014) regarding behaviours their participants engaged in for seeking out professional support. The participants in this study found it beneficial to consult with various health care professionals regarding pain treatments since this type of support facilitated successful coping from pain. Participants in Newton-John et al. (2014) study did not specifically rely on this type of strategy for pain management. The authors claimed that this may be due to the fact that participants in their study were under the workers' compensation program and were obliged to attend specific treatments recommended by their insurer.

Another important finding from this study was that many HHCA workers found their job to be meaningful and rewarding, which was similar to what Elliott et al. (2016) observed in their qualitative study with home care workers providing care to people with dementia. In this study, participants' sense of fulfillment in the provision of home care services and making a positive contribution to society served as a motivating factor to continue working, despite the negative consequences of CPP. Although their contributions in home care were often overlooked and undervalued, their sense of purpose and agency fueled their engagement in quality improvement efforts for their own safety as well as the clients' safety and well-being in the workplace. According to Goubert and Trompetter (2017), engaging in autonomous and purposeful activities leads to enhanced performance, vitality, self-esteem, and promotion of growth and development that in turn, influences a person's motivation to continue engaging in work and daily activities. This

may explain why HHCA workers were able to sustain their engagement with their work and become resilient in coping with pain stressors.

The findings of this study also suggest that the participants were often self-reliant, for instance, in their use of proactive pain management strategies, in overcoming pain adversity. The ability to cope and adapt to pain challenges is beneficial for HHCA workers and the organization in terms of improving pain-related outcomes, quality of life, work productivity, and retention of these workers (Newton-John et al., 2014; Siu et al., 2009; Slatyer et al., 2018). However, putting the responsibility on the HHCA workers to develop self-reliant strategies is unethical and obscures the structural barriers that reinforce health disadvantages and the collective responsibility of employers and policymakers to address inequities, particularly among vulnerable workers like HHCA (Barratt, 2018; Gill & Orgad, 2018).

The structural barriers experienced by HHCA workers are apparent when the intersections of gender, race, and socioeconomic status are examined and may play key roles in understanding HHCA workers' ability to remain resilient. According to Flaskerud and Winslow (1998), people with lower socioeconomic status have limited access to resources needed to maintain healthy lifestyles or behaviours; this is particularly challenging among women employed in low status and low paying hourly jobs. More importantly, these challenges disproportionately impact aging (Butler, 2013) and racialized women, who make up the majority of the health care aide workforce in Canada (Holroyd & Laupacis, 2020; Novek, 2013), and who face systemic barriers that reinforce existing inequalities (Green & Ayalon, 2016, 2018; Luk, 2020; Zallman et al., 2019). This is particularly relevant to HHCA workers in this study who were primarily older women earning a low wage, had children to support, and lived in single-income households that

depended on their income. Moreover, one third of the participants were immigrants, and despite having foreign postsecondary credentials, they had limited job prospects in Canada. Given these circumstances, along with physical impairments due to CPP, limited education and training, and the lack of opportunities for career advancement, HHCA workers in this study faced limited choices in the labour market. They eventually resorted to working multiple jobs as a HHCA worker or worked overtime to sustain a modest lifestyle.

Although resilience is an encouraging finding in this study, the limited resources available for HHCA workers with CPP at the organizational level (i.e., insufficient health benefits) resulted in these participants accessing pain-related services that required out-of-pocket expenses which then put a strain on their financial resources. This placed limits on pain care services that the HHCA workers would access and negatively affected adherence to pain treatments. Such a barrier can make it difficult to secure an effective pain management regime. Without adequate workplace support, HHCA workers could be at continued risk for chronic medical conditions and adverse health outcomes.

### **Implications**

Coping with CPP is an ongoing process (Büssing et al., 2010), and prolonged efforts to effectively manage pain can become exhausting and diminish over time (Devan et al., 2018; Ploeg et al., 2017) or may be compromised if one is experiencing different stressors over the life course (McAllister & McKinnon, 2009). Individuals may also be resilient with one type of stressor but may not cope well when faced with a different stressor (Sturgeon & Zautra, 2010). Kawi et al. (2018) and Zaheer et al. (2016) suggested that there is a limit to resilience and that individuals can reach a breaking point and experience psychological distress. This has implications for HHCA workers with CPP as

they experience intersecting vulnerabilities that can affect their ability to cope and remain resilient.

HHCA workers in this study carried out heavy work demands despite their physical limitations due to CPP. Their continued engagement in home care work, typically in environments not optimized for care delivery and with limited resources in place, could increase their risk for job strain, distress, or injuries (Arlinghaus et al., 2013; Elliott et al., 2016; Storch et al., 2014). When combined with poor socioeconomic status, the intersections of vulnerabilities related to pain stressors and ongoing workplace challenges could become a burden for HHCA workers, leading to significant distress and burnout (Saavedra Macías et al., 2019). These negative emotional states could also exacerbate pain intensity (Linton & Shaw, 2011; Sturgeon et al., 2014), particularly when working prolonged hours without adequate time to heal and recover from elevated stress and pain-related work interference.

Workers who are older are more vulnerable to serious physical injuries, mental strain, and overall poor health (Jeffs et al., 2014; Silverstein, 2008). Hence, the exacerbations of risks associated with the intersections of vulnerabilities have the potential to weaken the biopsychosocial domains of health and functioning of these workers. This could then lead to a breaking point that can negatively impact their ability to cope and recover. Hence, HHCA workers may not always be resilient and may require support to withstand ongoing stress and adversity. The pain experiences of HHCA workers in this study highlight the importance of collective action from employers and policymakers to sustain resilience and improve the health and well-being of these workers.

## **Recommendations**

To maintain healthy coping behaviours, positive functioning, and sustain work productivity, it is important to provide HHCA workers with adequate support and implement workplace interventions that foster resilience. One way this can be done is to address and minimize HHCA workers' vulnerabilities and to promote a positive institutional valuing where they are respected, supported, and recognized for the integral role they play in the health care system (Nthekang & Du Plessis, 2019). To demonstrate that their contributions to health care are valued, it is crucial to provide HHCA workers with autonomy over their work, opportunities for meaningful interactions with clients and colleagues, and supportive structural benefits such as increasing their base incomes and expanding their health and work benefits (e.g., paid sick leave, retirement benefits) (Butler, 2013; Hart et al., 2014).

Workplace organizations that support and prioritize worker well-being and personal growth are also more likely to retain motivated and committed staff capable of adjusting to high work demands (Elliott et al., 2016). Therefore, another way to enhance resilience is to ensure that workplace policies respond to HHCA workers' safety and well-being as well as personal growth in the work environment. Successful development of resilience can be achieved if more than one intervention is implemented (Rogers, 2016). For example, employers could offer opportunities for mentorship; professional development; job advancement; debriefing sessions or wellness check-ins; health-related incentives—such as a free passes to gyms or yoga classes; and workshops on conflict management, stress reduction, positive coping, and personal resilience (Elliott et al., 2016; Hart et al., 2014; Pipe et al., 2012; Rogers, 2016). Personal resilience workshops could focus on mindfulness-based strategies and positive activity interventions—a



cognitive and behavioural focused strategy that targets positive affect (i.e., gratitude, optimism)—to buffer stress and maladaptive coping responses to pain (Hassett & Finan, 2016; Mistretta et al., 2018). Mindfulness-based strategies have been shown to reduce stress and emotional exhaustion; improve coping responses; enhance positive affect and self-efficacy; and improve job satisfaction, worker engagement, and resilience of health professionals (Janssen et al., 2018; Klatt et al., 2015; Slatyer et al., 2018). Knowledge gained from these resilience-building interventions could help the adaptation of HHCA workers and improve their capacity to manage challenging situations in the workplace. Developing strategies to cultivate resiliency could eventually be useful for HHCA workers during certain turning points in their life and enable them to identify their strengths and areas of needs to move towards a higher level of development and functioning.

Although supervisors are typically not equipped to manage employees with CPP conditions (Larsen et al., 2018), they can be instrumental in improving worker well-being and resilience (Barratt, 2018; Franzosa et al., 2018). Their support, openness, and genuine ability to relate to their employees can foster caring and trusting relationships (Morrow et al., 2016). This may help improve communication between supervisors and HHCA workers and empower them to share workplace concerns or factors that aggravate their pain conditions. Risks in the workplace can also be reduced if supervisors are aware of safety risks in the workplace and are proactive in protecting HHCA workers from potential hazards and stressors in the work environment (Yanar et al., 2019). Last, it could be worthwhile for supervisors to receive training in supporting employees with CPP who remain at work.

Women make up the majority of workers in home care (Butler, 2018; Hewko et al., 2015), and they face a double burden in juggling caregiving and other responsibilities at work and at home. Since time dedicated to unpaid care work negatively impacts the participation of women in the labour force (Ferrant et al., 2014), HHCA workers could benefit from access to free or affordable childcare services. This could lessen the burden of unpaid care work and potentially boost their economic productivity (International Development Research Centre, 2018). Other social support measures could include health promotion programs that address the needs of HHCA workers with CPP (i.e., accessible pain management options).

Employers and policymakers must hold collective responsibility to sustain and build a resilient HHCA workforce. Only then can HHCA workers better equip themselves to cope and manage ongoing stressors as well as create opportunities for a better life. As a result of this study, I recommend research that examines the effectiveness of implementing a combination of resilience-building strategies among HHCA workers with CPP be undertaken.

### **Limitations**

Due to the differences in gender responses to pain sensitivity (Meints, 2018), the findings of this study represent the views of female HHCA participants and may differ from the experiences of male HHCA workers. Moreover, there may be different coping responses from HHCA workers who chose not to participate in the study. It is also important to recognize that a range of disorders fall under CPP, with each condition differing in etiology, severity, and quality of pain experiences (Simpson, 2008). Since pain is subjective, there may be differences in experiences associated with different CPP conditions, which could undermine the breadth of such a complex and multi-faceted

phenomenon. Lastly, I did not consider the ethnocultural factors that could influence pain beliefs and coping strategies. Thus, differences in how HHCA workers of different ethnocultural backgrounds experience pain and cope with CPP may yield different findings. I recommend that consideration of ethnocultural backgrounds become a critical dimension for future research.

## **5.6 SUMMARY**

This chapter offered insights into HHCA workers' experiences with CPP in Canada. The qualitative findings of this study help to address a gap in the current literature by providing an understanding of factors that facilitate HHCA workers' positive adaptation to pain and forms of resilience. The findings are beneficial for policymakers and employers in the development and implementation of a multifaceted approach to enhancing resilience and improving the quality of life of these essential healthcare workers. Importantly, it is imperative that employers not only support their resiliency but also address the intersecting vulnerabilities that produce inequities among HHCA workers in the Canadian workforce. These strategies will significantly strengthen the capacities of HHCA workers with CPP and will support them as they continue to provide much-needed home care services to Canadians.

## CHAPTER 6: DISCUSSION AND RECOMMENDATIONS

There is evidence in the literature that home health care aide (HHCA) workers are at high risk of suffering occupational injuries and musculoskeletal pain (Hamadi et al., 2016; Shnayder et al., 2018; Wipfli et al., 2012). Poor working conditions suggest repeated exposure to safety risks in unpredictable home workplace environments increases HHCA workers' susceptibility to chronic physical pain (CPP) (Shnayder et al., 2018). However, there is limited research that examines the perspectives of HHCA workers living with this health condition.

In this qualitative study, I utilized a descriptive exploratory approach to examine the CPP experiences of 12 HHCA workers with multisite pain conditions. Using this research design, I was able to capture rich descriptions of each participant's experience in relation to CPP that were not available in the Canadian literature. The participants' narratives provided a nuanced understanding of persistent, intersecting vulnerabilities that negatively influenced their health and well-being. Despite these vulnerabilities, the HHCA workers in this study demonstrated resilience and continued to deliver home care services to their clients. In this chapter, I discuss the main findings, implications, study limitations, recommendations for future research, education, and practice, and outline the dissemination strategies for this research study.

### 6.1 MAIN FINDINGS

Data generated from the study revealed two overarching themes that reflected the HHCA workers' experience of CPP. The first theme was *intersecting vulnerabilities*. This theme is supported by four categories: (i) *physical vulnerabilities*, (ii) *psychological vulnerabilities*, (iii) *social vulnerabilities*, and (iv) *economic vulnerabilities*. This theme illuminated not only the biopsychosocial challenges HHCA workers experienced but also

the intersections of vulnerabilities that heightened their experience of CPP while they continued to deliver home care services in poor home-based working conditions. Multiple descriptions of the pain experience revealed that the consequences of living with this medical condition extended and influenced every aspect of their lives including their experience of working as a HHCA that further increased the complexity of the pain experience.

Indeed, the physical vulnerabilities identified by HHCA workers were not only related to limitations in physical functioning as a result of CPP but were affected by organizational, occupational, and environmental aspects of home care service delivery (e.g., poor physical layout of homes, tripping hazards, time constraints, heavy workloads, staffing shortages, and limited workplace support). These aspects were often out of their control and increased their risk to physical injuries, pain, and other adverse psychological health outcomes such as stress and anxiety. Participants in this study further described heightened risks to safety due to job expectations that exceeded their physical capabilities. Other vulnerabilities included the lack of sleep caused by CPP which resulted in mental and bodily fatigue, particularly when participants continued to engage in strenuous work without adequate time to recover and heal.

Negative mood and emotions associated with CPP were intensified by their limited involvement in decision-making in home health care processes and their perceived lack of value and recognition from the Alberta health care system. Their experience of stigma related to CPP, conflict, discrimination, bullying, and violence encountered in the workplace also had detrimental effects on their psychosocial well-being and overall pain experience.

The category of economic vulnerabilities is consistent with previous research in the literature which indicated HHCA workers earn a low wage and receive limited health benefits from their employer (Muramatsu et al., 2019; Silver et al., 2020; Spetz et al., 2019). The lack of economic resources significantly affected their ability to access timely pain-related treatments, hence, exacerbating the burden of CPP on these workers. Their economic vulnerability was further compounded by limited opportunities for career mobility because of their age, educational background, and physical impairments due to CPP.

Despite facing challenges from CPP and persistent vulnerabilities noted above, the participants in this study found ways to cope and adapt to pain-related challenges. For this reason, the second identified theme is *resilience* which is supported by the following categories: (i) *positive coping behaviours*, (ii) *pain management strategies that foster health and wellness*, and (iii) *having a sense of purpose and agency*. In general, the participants in this study maintained a positive attitude, accepted their pain situations, showed self-compassion, and drew strength from religious faith and supportive social networks.

The HHCA workers in this study employed multimodal pain management strategies, albeit limited as access to pain care services depended on the health insurance benefits provided by their employer. They also described the maintenance of health and productive functioning with self-care strategies and health promoting behaviours. For example, to maximize their ability to perform at work, participants in this study applied proactive pain management strategies (e.g., heat and cold therapy, distraction techniques, and pacing) to lessen the impact of their work on their pain experience.

As with other reports in the literature (Panagiotoglou et al., 2017; Sims-Gould & Martin-Matthews, 2010), participants in this study found fulfillment in the provision of home care services. This served as a motivating factor to continue working despite ongoing pain. Performing meaningful labour of care fueled their sense of purpose and, subsequently, their engagement in quality improvement efforts for their safety and the clients' safety. By engaging in sustained work, despite living with CPP, participants in this study displayed their resiliency and ability to adapt as well as to overcome the challenges associated with this medical condition.

## **6.2 IMPLICATIONS OF THE STUDY**

HHCA workers display of resiliency to pain-related stressors is not static. Rather, their ability to demonstrate resilience may change with time (Devan et al., 2018; Ploeg et al., 2017) and depend on contextual circumstances such as stressful life changing events or coping strategies used at the time of the stressor (McAllister & McKinnon, 2009; Stewart & Yuen, 2011). For instance, stigma related to CPP caused strain on social relationships and required HHCA workers to use different coping mechanisms. These mechanisms may or may not be effective in sustaining pain recovery and well-being. Scholars like Kawi et al. (2018) and Zaheer et al. (2016) suggested that there is a limit to resilience or a breaking point that can lead to psychological distress. Therefore, the continued exposure to the intersections of vulnerabilities experienced by HHCA workers with CPP may amplify the burden of risks associated with these vulnerabilities. This could negatively impact pain coping and, thus, their ability to be resilient.

The intersections of gender, race, and socioeconomic status also highlight structural barriers that exacerbate existing inequalities experienced by HHCA workers who are overwhelmingly female, aging, and experience physical limitations due to CPP.

The participants in this study earned a low wage and lived in households where their family depended on their income. Some HHCA workers were also immigrants, and despite having foreign post-secondary credentials, had limited job prospects in Canada. In fact, the HHCA workers in this study had few opportunities for career advancement because of their limited education and training as a HHCA. As a result of their limited options for employment, these women faced the burden of working multiple jobs as a HHCA. Not only do HHCA workers in this study lack the financial resources to regularly access pain care services, which impact effective pain management, they also lack opportunities to better their socioeconomic situations.

### **Thesis Contributions**

Results from this qualitative study fill a gap in the literature by providing useful insights on key areas for improvement such as organizational practices in home care and occupational health and safety policies and procedures in the home workplace environment. The findings suggest that HHCA workers may benefit from improvements in working conditions through worksite assessments to determine deficiencies in resources (i.e., staff, time, proper safety devices and equipment) as well as the presence of hazards that increase their susceptibility to workplace injuries or pain (Craven et al., 2012; Larsen et al., 2018). A plan to restructure work organization as well as implement effective strategies to minimize vulnerabilities encountered in the home workplace could lessen pain-related work interference and protect HHCA workers from further injuries and pain. For example, organizations could implement a participatory ergonomics program to involve HHCA workers in reducing work-related risk factors (Rasmussen et al., 2017; Serra et al., 2019). Home healthcare virtual simulation programs can also train them to detect and respond to safety hazards (i.e., ergonomic, environmental, biological,



and chemical hazards) in clients' homes (Lavender et al., 2019; Wills et al., 2016).

Indeed, these programs could provide insight on risk factors and less obvious hazards that HHCA workers overlook in the home workplace environment.

Participants in this study also expressed their interest in being involved in decision-making processes that directly affect them in the workplace. Decision making in health care typically follows vertical power hierarchies, which means HHCA workers have limited opportunities to contribute in the organizational and clinical context (Afzal et al., 2018). Wills et al. (2016) further claimed that there is scarce information available about HHCA workers' perceptions of risk, decision making, and the development of solutions pertaining to workplace hazards. Thus, it would be worthwhile for employers to seek the perspectives and input of HHCA workers and incorporate these in home health hazard management approaches.

HHCA workers are also likely to benefit from future workplace initiatives that target health promotion and resilience-building strategies. The physical and emotional labour that goes into caring for clients who are ill, or have functional impairments, and simultaneously attending to the demands of client's families puts considerable stress and burden on HHCA workers and can lead to burnout (Saavedra Macías et al., 2019). Increased psychological distress can further arise from their relative invisibility in the organizational and social context, compromising their resilience, sustained adaptation to CPP, and possibly the retention of these workers.

Thus, in addition to workplace wellness programs that target stress management and reduction and health promotion strategies for getting improved sleep and managing CPP, providing a sense of autonomy, empowerment, and workplace belonging through words of appreciation from employers, higher pay, retirement benefits, paid sick days,

opportunities for involvement in workplace decision-making, and recognizing their contributions to health care may make HHCA workers feel valued and appreciated for the work they do (Butler et al., 2012). Healthy Moves for Aging Well is an example of a workplace wellness program that can train HHCA workers to deliver physical activity exercises for home care clients. According to Muramatsu et al. (2017), this program not only improves the client's physical functioning but also creates a positive work environment for HHCA workers as it can improve client relationships and empower them to promote healthy lifestyle choices for themselves and others in their community. Other scholars recommended flexible work arrangements and access to appropriate workplace accommodations (Oakman et al., 2017) for HHCA workers as required.

Since resilience can be learned and developed over time (McAllister & McKinnon, 2009; Robertson & Cooper, 2013), it may also be of benefit to HHCA workers if employers and policymakers target a multifaceted approach to enhancing their resilience. This can include resilience-building strategies such as mindfulness-based interventions, positive activity interventions (Hassett & Finan, 2016; Mistretta et al., 2018), supervisor support (Yanar et al., 2019), mentorship, professional development opportunities, debriefing sessions, or workshops targeting personal resilience and positive coping (Elliott et al., 2016; Hart et al., 2014; Pipe et al., 2012). These resilience-building strategies could be implemented by employers along with other health promotion or wellness programs in the workplace. These should also be easily accessible to HHCA workers (i.e., in-person or online options).

Attention and support directed towards HHCA workers' safety and well-being may enable these workers to remain motivated to stay at work and deliver care, which could have a positive impact on the quality of home health service delivery. The

collective action of employers and policymakers in creating and sustaining safe, supportive, and inclusive workplace environments for the improvement and maintenance of HHCA workers health and well-being is crucial. Increasing stakeholders' awareness of their pain experience and providing workplace support and resources for strengthening the resiliency of these workers may lead to positive health outcomes, enhanced work productivity, and sustainability of the workforce.

### **6.3 LIMITATIONS OF THE STUDY**

The study is limited to the experiences of female HHCA workers with multisite CPP conditions who work in private residential homes in Alberta, Canada. The findings of this study may not represent male participants or HHCA workers working in other health care settings, affecting the transferability of the findings. Although regulated professionals like registered nurses (RNs) and licensed practical nurses (LPNs) also work in the private home setting, their experiences of CPP have not been captured. Moreover, due to fear of job loss, there is a possibility that some participants did not fully disclose their experiences related to CPP. Lastly, I did not consider ethnocultural factors that could influence pain beliefs and coping strategies among HHCA workers with CPP.

### **6.4 RECOMMENDATIONS**

#### **Research**

Based on the limitations noted above, it would be worthwhile to conduct another qualitative study that explores how HHCA workers of different ethnocultural backgrounds experience pain and cope with CPP. Researchers should also explore the CPP experiences of male participants as well as other Canadian healthcare professionals like RNs and LPNs working in the home workplace setting. More qualitative research is needed to explore resilience and positive adaptation to pain among healthcare workers,

especially since the prevalence of multisite pain is higher among women (Taloyan & Löfvander, 2014) who comprise the majority of workers in the Canadian health care sector (Bourgeault, 2018; Porter & Bourgeault, 2017). Examining the effectiveness of implementing resilience-building strategies in workers like HHCAs could also be a promising area for future research.

### **Practice**

Challenging work conditions in home care and the experience of pain result in intersections of vulnerabilities that negatively impact the safety and ability of HHCA workers with CPP to deliver high quality of care. The consequences of inaction could have a considerable impact to the sustainability of the current workforce already suffering from injuries and pain. This requires urgent attention and commitment from employers and policymakers to provide better working conditions and protection for HHCA workers. Successful change implementation requires a multifaceted approach. Among them, a call to prioritize the safety and well-being of HHCA workers in the workplace. One way this can be done is to ensure appropriate workplace health and safety procedures and health and wellness programs are developed and implemented.

In addition to creating a physically safe work environment, another important recommendation for employers is to provide adequate staffing and time for HHCAs to complete work demands. Reducing workload, access to proper equipment, expansion of work and health benefits, and increasing hourly wage could also prove advantageous for HHCA workers. Lastly, an inclusive workplace environment that respects and supports their autonomy and resilience in the workplace is needed. Employers could offer HHCA workers' opportunities for involvement in workplace decision-making, mentorship, and resilience-building workshops. I recommend a training program for supervisors to learn

how to support workers with CPP and to empower them to be active members in the home care sector.

It is worth noting that choosing one recommendation over others disregards the many intersecting inequalities and health disadvantages experienced by HHCA workers with CPP. This delegitimizes their pain experiences and further perpetuates their invisibility in the home workplace environment. To that end, implementing the proposed recommendations as a whole would go a long way in creating a more inclusive and equitable home workplace environment for HHCAs, validating their pain experiences as well as their significance as essential workers to our society. With adequate workplace support and equal opportunity for personal growth, HHCAs have a better chance of improving their resilience and continued engagement in fulfilling work.

### **Education**

The findings of this study could be used to initiate discussions about resilience and the potential value of applying this concept in orientation training programs to help HHCA workers cultivate resilient behaviours. Employers should consider resilience education and training as it has potential to improve HHCA workers' ability to handle stress, pain, and adverse working conditions. Providing refresher courses about building resilience may also be beneficial for HHCA workers and employers in the long run.

## **6.5 DISSEMINATION OF RESEARCH**

It is my intention to increase the awareness of CPP among HHCA workers and to initiate discussions about how to effectively support them in their choice of profession for many years. In addition to this thesis, I plan to disseminate the findings of this study by: (i) presenting the study findings at various home care agencies in Alberta; (ii) providing a summary of the research results to participants and participating organizations in this

study; (iii) submitting Chapter 3, 4, and 5 to different scholarly journals for publication; and lastly, (iv) submitting an abstract for possible presentation at conferences relevant to the study topic. Through these forms of dissemination, I could stimulate further discussion and action to promote the well-being of HHCA workers in Canada.

## **6.6 CONCLUSION**

In this qualitative study, I examined the HHCA workers experiences with CPP, specifically focusing on the impact of this medical condition in their life and work contexts. For this research project, I provided an introductory chapter (Chapter 1), a comprehensive literature review of CP, CPP, and the health care aide workforce (Chapter 2), and discussed the challenges I encountered with the recruitment of HHCA workers with CPP in Alberta (Chapter 3). Along with the intersecting vulnerabilities experienced by these group of workers (Chapter 4), I also examined adaptive coping strategies that enabled them to be resilient and continue to stay at work despite living with CPP (Chapter 5), and consequently provided a concluding chapter that connected all the study findings (Chapter 6). Overall, the results of this study suggest that much is needed to be done to improve the health and well-being of these essential workers. The qualitative findings of this study support a workplace culture that values the work provided by HHCA workers in the healthcare system. It is also imperative that policymakers and employers focus on occupational health and safety with the intent of reducing the vulnerabilities experienced by these workers in the home workplace environment as well as the implementation of initiatives that support resilience development and maintenance over the life course. At best, this type of initiative could mitigate the retention problems of HHCA workers in Canada and, in turn, allow Canadian home care recipients to continue receiving much-

needed supportive and caring services that promote their autonomy and preserve their health and well-being.

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APPENDIX A: RECRUITMENT POSTER

**ATTENTION:**  
**HEALTH CARE AIDES**

Do you work in **HOME CARE?**  
(e.g., private residences or retirement homes)

Are you experiencing **CHRONIC PHYSICAL PAIN?**  
(e.g., back pain, arthritis, neck pain, headache, endometriosis, fibromyalgia, nerve pain, pelvic pain...)

Would you be willing to talk about your experiences?  
I am looking for participants to take part in a research study that explores experiences related to chronic physical pain. The study requires an in-person or telephone interview that will last 45 to 60 minutes. Participation in the study is voluntary and confidential. You will receive a \$5.00 Tim Hortons gift card as a token of my appreciation for your time and participation in the study.

*Sharing your experiences has the potential to inform policymakers, employers, and other health care providers on how to best support and accommodate those experiencing chronic physical pain in the work setting. If you are interested in participating, please don't hesitate to contact me.*

This study has been reviewed and approved by the Health Research Ethics Board at the University of Alberta (Pro00093271).

Czarina Bonifacio BN, RN Phone: (403)-615-7242 czarina.bonifacio@uleth.ca	Czarina Bonifacio BN, RN Phone: (403)-615-7242 czarina.bonifacio@uleth.ca	Czarina Bonifacio BN, RN Phone: (403)-615-7242 czarina.bonifacio@uleth.ca	Czarina Bonifacio BN, RN Phone: (403)-615-7242 czarina.bonifacio@uleth.ca	Czarina Bonifacio BN, RN Phone: (403)-615-7242 czarina.bonifacio@uleth.ca	Czarina Bonifacio BN, RN Phone: (403)-615-7242 czarina.bonifacio@uleth.ca	Czarina Bonifacio BN, RN Phone: (403)-615-7242 czarina.bonifacio@uleth.ca	Czarina Bonifacio BN, RN Phone: (403)-615-7242 czarina.bonifacio@uleth.ca	Czarina Bonifacio BN, RN Phone: (403)-615-7242 czarina.bonifacio@uleth.ca
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## APPENDIX B: REQUEST FOR LETTER OF SUPPORT FROM HOME CARE ORGANIZATIONS AND RELEVANT ASSOCIATIONS

University of  
Lethbridge



Faculty of Health Sciences

4401 University Drive  
Lethbridge, Alberta, Canada  
T1K 3M4

Phone 403.329.2699  
Fax 403.329.2668

<http://www.uleth.ca/hlsc>

Date:

Hello,

My name is Czarina Bonifacio and I am a graduate student in the Faculty of Health Sciences, Master of Nursing program at the University of Lethbridge, Alberta. As part of the master's degree requirements, I am conducting a research project under the supervision of Dr. Monique Sedgwick. My study will explore the experiences of chronic physical pain among Health Care Aides in the workplace. I believe they have unique perspectives and experiences of chronic physical pain that would be helpful for employers and employees to understand. To that end, it is my hope to connect with Health Care Aides who work in private residential homes and retirement residences and invite them to participate in this research project.

At this stage of the research process, I seek your assistance as the director or manager of \_\_\_\_\_ (*organization or association*) in Edmonton, Alberta in providing **a letter of support for ethics approval purposes to allow me to recruit participants from your facility for this study**. This would involve having an administrative assistant send out an email of the Letter of Invitation on my behalf to the Health Care Aides in your employ. I would also like to request permission to: (i) advertise the recruitment poster on your Facebook website or allow me to place the poster in your facility's staff room, and/or (ii) attend one staff meeting to present my study. Health Care Aides who are interested in participating will be invited to contact me to discuss further details of the study.

I intend to conduct individual in-person or telephone interviews with people who volunteer to participate in the study. I anticipate the interviews will last approximately 45 to 60 minutes. Interviews will be conducted off scheduled work hours and at a place that is convenient for the participant and me.

Participation is dependent on the Health Care Aide's voluntary decision to take part in the study. Participants will be informed of their rights prior to conducting the study including confidentiality, informed consent, and the freedom to withdraw from the study without any repercussion. The participant's identity will be protected and replaced with

pseudonyms. No identifying information will appear in the thesis or final report from this study. A pseudonym will also be given to your organization.

All generated information will be kept in a secured cabinet for safe keeping and will be destroyed after five years. Finally, only myself and my supervisor, Dr. Monique Sedgwick (sworn to confidentiality), will have access to these materials.

At the end of the study, a final report will be written, and results may be shared with other researchers, Health Care Aides, and health care organizations. Knowledge derived from the study may be used to support Health Care Aides in the home workplace environment.

Thank you in advance for your time. I have attached a standardized draft of the Letter of Support for your convenience, which can be amended according to your terms for this research partnership. I look forward to your assistance in this research project.

Sincerely,

Czarina Bonifacio RN, BN Graduate Student Faculty of Health Sciences University of Lethbridge Phone: (403)-615-7242 Email: czarina.bonifacio@uleth.ca	Monique Sedgwick RN, PhD Associate Professor Faculty of Health Sciences University of Lethbridge Phone: (403)-332-5254 Email: monique.sedgwick@uleth.ca
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## APPENDIX C: LETTER OF INVITATION FOR HOME HEALTH CARE AIDE

### WORKERS

University of  
Lethbridge



Faculty of Health Sciences

4401 University Drive  
Lethbridge, Alberta, Canada  
T1K 3M4

Phone 403.329.2699  
Fax 403.329.2668

<http://www.uleth.ca/hlsc>

Date:

Hello,

My name is Czarina Bonifacio and I am a graduate student in the Faculty of Health Sciences department at the University of Lethbridge. I am conducting a study that will focus on the experiences of chronic physical pain among Health Care Aides working in home care. I would like to understand how Health Care Aides experience and deal with their chronic physical pain. Chronic physical pain refers to persistent pain lasting six or more months. Chronic pain may be a result of a disease or injury such as back pain, arthritis, fibromyalgia, endometriosis, headache, and neck pain, among others.

I would like to invite Health Care Aides such as yourself to participate in the study. Your experiences and insights are valuable to the research study. Eligible participants will be privately interviewed in-person or through a telephone interview. I anticipate interviews will last about 45 to 60 minutes. The place and time for the in-person interview will be decided between us. The time for the telephone interview will be negotiated as well. There is a possibility for a second interview conducted over the telephone that will last about 15 to 20 minutes. This second interview is to make sure I have accurately captured your experience. Interviews will not be scheduled during regular work hours.

Your participation in the study is voluntary. All information I receive, including names and place of employment, will remain confidential. I will not share any personal information in reports or my final paper or with your employer. All the information collected during the study will be kept in a locked drawer and password-protected computer. Only I and my supervisor, Dr. Monique Sedgwick (sworn to confidentiality) will have access to the data. Although I do anticipate risks such as emotional discomfort for taking part in the study, you can stop the interview at any time for any reason. You can also choose to not answer any question I ask.

As a token of my appreciation for your time and participation in the study, at the start of the interview you will receive a \$5.00 Tim Hortons gift card.

If you would like to participate, please contact me directly at (403)-615-7242 or [czarina.bonifacio@uleth.ca](mailto:czarina.bonifacio@uleth.ca). I will then provide you with further information about the study. If you wish to speak to my supervisor, please contact Dr. Monique Sedgwick at (403)-332-5254. For questions regarding your rights as a participant in this research study, you may contact the University of Alberta Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators. This research has received ethics approval from the Health Research Ethics Board at the University of Alberta.

Sincerely,

Czarina Bonifacio BN, RN  
Graduate Student  
Faculty of Health Sciences  
University of Lethbridge  
Phone: (403)-615-7242  
Email: [czarina.bonifacio@uleth.ca](mailto:czarina.bonifacio@uleth.ca)

## APPENDIX D: PARTICIPANT CONSENT FORM



4401 University Drive  
Lethbridge, Alberta, Canada  
T1K 3M4

Phone 403.329.2699  
Fax 403.329.2668

<http://www.uleth.ca/hlsc>

### **Title of the Study:**

A Descriptive Qualitative Study of Chronic Physical Pain Among Home Care Health Care Aides in Alberta

### **Principal Investigator:**

Czarina Bonifacio BN, RN  
Phone: (403)-615-7242  
Email: [czarina.bonifacio@uleth.ca](mailto:czarina.bonifacio@uleth.ca)

### **Research Supervisor:**

Monique Sedgwick PhD, RN  
Phone: (403)-332-5254  
Email: [monique.sedgwick@uleth.ca](mailto:monique.sedgwick@uleth.ca)

### **Why am I being asked to take part in this research study?**

You are being asked to take part in this research study because I believe that you have knowledge and valuable insights related to the experience of chronic physical pain (CPP) in the home workplace setting. Before you make a decision, I will go over this consent form with you. You are encouraged to ask questions if you feel anything needs to be clearer. You will be given a copy of this form for your records.

### **What is the reason for doing the study?**

You are invited to participate in my research study. The purpose of my study is to explore and understand the Health Care Aides (HCAs) experiences related to CPP in the private home and/or retirement residential environment. I intend to explore the following:

1. How HCAs with CPP experience and manage their pain?
2. How the private residential work environment influences the experiences of CPP?
3. What types of support in the workplace HCAs utilize to manage their CPP?

**What will I be asked to do?**

Your participation in this study will involve a face-to-face or telephone interview that will take about 45 to 60 minutes. There is a possibility for a second interview completed over the telephone that will last about 15 to 20 minutes. This interview is to check that I have accurately captured your experiences. The interview will be audio-recorded with your permission. I may also write notes during the interview. A mutually convenient interview time, date, and location (a private room at the public library is suggested) will be negotiated.

**What are the risks and discomforts?**

I do not anticipate any dangers with participating in the study although talking about your pain experience may make you feel uncomfortable. If this happens, you have the right to stop the interview. If you feel that you need more help, I will provide you with a list of appropriate referrals for services that might be helpful to you. It is not possible to know all of the risks that may happen in a study, but I have taken all reasonable safeguards to minimize any known risks to a study participant.

**What are the benefits to me?**

Although there are no direct benefits to you for participating in the study, the results of the study can help increase knowledge that may be used to support HCAs working in the private home environment. However, you may not get any benefit from being in this research study.

**Do I have to take part in the study?**

Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time, and it will in no way affect your employment at your place of work. There are no consequences if you do not answer a question or if you decide to stop the interview. You may ask questions at any time of the study. You can also take a break, stop the audio recording, or withdraw from the study for any reason. If you withdraw, the interview recording will be stopped. You will have one week after the interview to contact me to request that your transcript and demographic information be destroyed.

**Will I be paid to be in the research?**

You will receive a \$5.00 Tim Hortons gift card as a token of my appreciation for your time and participation in the study. You will receive the gift card regardless if you complete the interview. For in person interviews, participants will receive the gift card at the start of the interview whereas for telephone interviews, the gift card will be mailed to the recipients.

## **Will my information be kept private?**

During the study I will be collecting data about you. Steps will be taken to ensure your privacy and confidentiality is protected. Your name will not be included in any reports or the final paper. A different name of your choice will be used instead. As well, your employer's name or names of co-workers will be changed or deleted from the transcript. If you share names of people, events or places that may be identified by others, these will also be changed. At no point will your personal information be used outside of this study. Sometimes, by law, I may have to release your information with your name so I cannot guarantee absolute privacy. However, I will make every legal effort to make sure that your information is kept private.

Interviews will be transcribed using a secure transcription software. Additionally, all the information I collect in this study will be kept strictly confidential in a locked drawer and password-protected computer that only I will have access to. As well, only I and my supervisor, Dr. Monique Sedgwick (sworn to confidentiality) will have access to your transcript and demographic data. All collected information will be safeguarded in an external hard drive kept in a locked drawer and safely destroyed by shredding and permanently deleting documents after five years.

At the end of the interview, you will be asked to provide suggestions for eligible participants who may be interested in participating in the study. You have no obligation to provide a referral of contacts and there are no consequences for not providing this information. However, in the event that you do provide me with names and contact information, I need to inform the potential participants how I came to have access to their contact information. I would also truly appreciate it if you would tell other HCAs about the study. Interested participants can contact me directly.

You will have the chance to review the initial explanation of the study results before it is written in the report. You will be given one week to provide corrections to the initial findings. The results of the study including direct quotes from the interview will be used in the written report and may be shared with other researchers, HCAs, and health care organizations. No identifying information will be associated with any of the quotes.

## **What if I have questions?**

If you have any questions about the research or want to receive a copy of the written report, please contact me directly at (403)-615-7242 or email at [czarina.bonifacio@uleth.ca](mailto:czarina.bonifacio@uleth.ca). You may also contact my supervisor, Dr. Monique Sedgwick at (403)-332-5254 or email at [monique.sedgwick@uleth.ca](mailto:monique.sedgwick@uleth.ca).

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators. The study has been reviewed and approved by the Health Research Ethics Board at the University of Alberta (Pro00093271).

## CONSENT

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**Title of Study:** A Descriptive Qualitative Study of Chronic Physical Pain Among Home Health Care Aides in Alberta

**Principal Investigator(s):** Czarina Bonifacio BN, RN    **Phone Number(s):** (403)-615-7242  
**Study Coordinator:** Monique Sedgwick PhD, RN    **Phone Number(s):** (403)-332-5254

	Yes	No
Do you understand that you have been asked to be in a research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you read and received a copy of the attached Information Sheet?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand the benefits and risks involved in taking part in this research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had an opportunity to ask questions and discuss this study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your present and future employment?	<input type="checkbox"/>	<input type="checkbox"/>
Has the issue of confidentiality been explained to you?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand who will have access to your study information?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to the audio recording of the interview(s)?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to revealing your identity to participants you have referred?	<input type="checkbox"/>	<input type="checkbox"/>
Who explained this study to you? _____		
I agree to take part in this study:	<input type="checkbox"/>	<input type="checkbox"/>
Signature of Research Participant: _____		
Printed Name: _____ Date: _____		
I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.		
Signature of Investigator _____ Date _____		

You will receive a copy of this consent form for your records and reference.

Adapted from:

Research Ethics Office, University of Alberta. (2020). *Guidelines for informed consent & template – Health studies*. Retrieved from <https://www.ualberta.ca/research/support/ethics-office/forms-cabinet/forms-human>

## **APPENDIX E: INTERVIEW PROTOCOL**

1. Can you describe what HCAs do in the provision of care in homes?  
Probe: What are your daily responsibilities?
2. What is it like to experience chronic physical pain?  
Probe: How would you describe your pain?
3. How does chronic physical pain affect your life? (Positively and negatively)  
Probe: Physically? Emotionally? Professionally? Please elaborate.
4. How does chronic physical pain influence your daily activities?  
Probe: How does it affect your work? How does it affect your participation in leisure activities?
5. How does chronic physical pain affect your relationships with your family?  
Probe: Friends? Colleagues?
6. What aspects of working in a home environment affect your pain? Probe:  
What factors increase your pain at work? What factors decrease your pain at work?
7. How do you manage your chronic physical pain at work?  
Probe: What types of strategies are helpful in coping with your pain?
8. What types of support does your work offer to help you manage your pain?
9. What organizational support can be provided to help with your pain?
10. What types of supports are missing in the workplace to help you cope with your pain?
11. What positive opportunities have you experienced while living with chronic physical pain?
12. Is there further information that you would like to add or share?



## APPENDIX F: PARTICIPANT CHARACTERISTICS

Table 1

*Participant Characteristics*

Characteristics	<i>N</i>	%
Sex		
Female	12	100
Age		
20-30	1	8.3
31-40	1	8.3
41-50	4	33.3
51-60	5	41.7
>61	1	8.3
Country of Origin		
Canada	8	66.7
Foreign	4	33.3
HHCA Work Experience (years)		
1-5	2	16.7
6-10	3	25
11-15	3	25
16-20	1	8.3
> 20	3	25
Work Schedule		
Full-Time	8	66.7
Part-Time	4	33.3
Number of Current Employers		
One	8	66.7
Two	4	33.3
Education		
High School	1	8.3
Certificate	5	41.7
Diploma	2	16.7
Degree	4	33.3
Marital Status and Dependents		
Single, No Children	2	16.7
Single, Have Children	2	16.7
Married, No Children	1	8.3
Married, Have Children	4	33.3
Not Disclosed, Have Children	3	25