EXPERIENCES OF HEALTH AND AGING:
YOUNGER ADULTS WITH DISABILITIES
IN LONG-TERM CARE FACILITIES

by

Brittany Barber

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ABSTRACT

Canada's 2011 census revealed that Nova Scotia comprises the largest proportion of people over the age of 65 and the highest proportion of people living with a disability (Statistics Canada, 2012; Statistics Canada, 2013). The challenge of meeting the health care and housing needs of these marginalized populations continues to grow, evidenced through long waitlists for long-term care (LTC) and residential group homes across Nova Scotia (Curry, 2015; Nova Scotia Community Services, 2013). In response to a province-wide deficit of appropriate health care housing, younger adults with various disabilities are placed within LTC institutions designed to provide services to a population of older and often sicker residents (Barken, 2013). As such, the objectives of this study were to explore how the perceptions and experiences of health and aging for younger adults in LTC are influenced through complex relationships between individual, interpersonal, and environmental level relationships.

LIST OF ABBREVIATIONS USED

LTC   Long-term care

M.S.   Multiple Sclerosis

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CHAPTER 1: INTRODUCTION

"It's not appropriate for someone who is 23 to be living with the sick and dying."
A 23-year-old woman living in a long-term care nursing home (Taylor, 2014)

Canada's 2011 census revealed that Nova Scotia comprises the highest proportion of people living with a disability, while also lacking adequate health care and housing resources to meet the needs of this marginalized population (Statistics Canada, 2013; Nova Scotia Community Services, 2013). Evidenced through long waitlists for residential group homes across Nova Scotia, there continues to be a province-wide deficit of appropriate housing to provide health care services for a population of younger adults with disabilities (Curry, 2015; Nova Scotia Community Services, 2013). In response to these waitlists across Nova Scotia, approximately 600 individuals under the age of 65 with various disabilities are placed within long-term care (LTC) institutions that are primarily designed to provide services to an older population (Statistics Canada, 2011b). Although individual diagnoses of disability for these 600 individuals (8% of total long-term care residents under the age of 65) are not available within public reports (Statistics Canada, 2011b), research from LTC facilities indicates the most common experiences of disabilities for younger adults in LTC include; traumatic brain injury, multiple sclerosis, intellectual and developmental disability, and Huntington's disease (Swartz, Miake, & Farag, 2012). As younger adults with disabilities move into LTC institutions at a younger age and can expect to live for longer periods of time, it is increasingly important to explore how individual processes of health and aging are influenced by larger structures within the LTC setting.

The experience of LTC institutionalization for younger adults with disabilities is a concern internationally, as communities beyond Nova Scotia face similar challenges with providing adequate residential housing (Persson & Ostwald, 2009; Winkler, Farnworth, & Sloan,

2006). While the immediate physical health care needs of younger adults with a disability are a primary concern within LTC institutions, it is largely unknown how the complete mental and social well-being of younger adults are met through the living environment (Barken, 2013; Persson & Ostwald, 2009; World Health Organization, 1986). Surprisingly, little research has explored the lived experiences of younger adults with disabilities in LTC settings with a focus on how living among older, often sicker, residents influences their own health and aging (Perkins & Friedman, 2012). Exploring the individual, interpersonal, and institutional experiences of health and aging for younger adults in LTC facilities will provide preliminary evidence towards understanding a structural approach to age-appropriate LTC, while also understanding the multi-level experiences of this marginalized population (Bronfenbrenner, 1977). The importance of which will direct future research beyond individual-level experiences of health and aging, contributing a more complete understanding of topics within health promotion.

Individual Experiences of Younger Adults with Disabilities in LTC

When exploring the lived experiences of younger adults with disabilities in LTC, it is important to recognize the characteristics of this population that lead to placement in LTC institutions. Populations of younger adults are substantially different from older residents in LTC, as they are characterized by experiencing a range of physical and/ or intellectual and developmental disabilities (Barken, 2013; Persson & Ostwald, 2009). Beyond considering the unique circumstances under which younger individuals are placed into LTC, meeting the greater health care needs of this heterogeneous population within one LTC facility presents a challenge (Winkler et al., 2006). Although younger adults with disabilities often experience poorer health conditions when compared to people without disabilities, they can expect to live longer and experience different levels of health as life expectancy increases (Ouellette-Kuntz, Martin, &

McKenzie, 2015). While people with disabilities continue to live longer it is recognized they experience different processes of health, thus influencing overall processes of health and aging through the life course (Burke et al., 2014; Kim, El Hoyek, & Chau, 2011). Surprisingly, little is known about the individual level experiences of health and aging as younger adults with disabilities live longer (Burke et al., 2014; Strnadova, Cumming, & Knox, 2015).

Given that process of health and aging are shifting for people with disabilities, a dearth of literature focuses on the biomedical conditions of individual diagnoses (Haveman et al., 2010; Krahn, Hammond, & Turner, 2006). For example, preliminary research on younger adults in LTC follows this biomedical lens by gathering data of individual diagnoses of disabilities and focuses less on experiences of younger adults (Cameron, Pirozzo, & Tooth, 2001; Colantonio, Howse, & Patel, 2010). While it is important to gather an understanding of the medical conditions younger adults experience, the lived reality of younger adults in LTC are not defined by one's diagnosis (Spassiani & Friedman, 2014). As such, further research is required to explore younger adults' individual experiences of aging while living amongst an older population in LTC.

Interpersonal Experiences of Younger Adults with Disabilities in LTC

In addition to the individual-level lived experiences of aging, it is increasingly recognized that processes of aging later in life are affected by one's relationships with older adults earlier in life (Levy, 2008; Levy & Myers, 2004). Evidence indicates that children are influenced by interpersonal relationships that promote positive or negative perceptions of aging, relative to cultural space and time, leading them to internalize and carry with them expectations about their own processes of aging (Levy, 2008). Factors that influence negative or positive perceptions of health and aging are explored for older adults with disabilities in a group home setting, whereby

results indicate that interpersonal relationships between parents, roommates, and staff influence experiences (Spassiani, Harris, & Hammel, 2016; Strnadova et al., 2015). Thus, the social interactions between younger adults with disabilities and older residents in LTC facilities may affect younger adults' perceptions of health and aging over time. Research has yet to explore factors that influence perceptions and experiences of aging for younger adults with disabilities in LTC. The experiences younger adults with disabilities have living amongst older residents may prove to shape the individual experiences of aging that younger adults describe.

Institutional Experiences of Younger Adults with Disabilities in LTC

Experiences of living within LTC institutions are typically represented within research for residents over the age of 65 (Xu, Kane, & Shamliyan, 2013), yet little is known about the experiences of residents under the age of 65 (Persson & Ostwald, 2009). Environments within LTC institutions are designed to provide specialized health care and housing accommodations for older populations towards the end of their lives (Perkins & Friedman, 2012), versus facilitating active involvement of younger adults in everyday activities (Winkler et al., 2006). While LTC facilities are often designed and operated according to institutional policies, there are no indications of institutional policies regarding age-appropriate policies that guide the specialized health care and housing accommodations for younger adults under the age of 65.

Without clear guidelines for LTC institutions to provide specialized health care services and housing accommodations for younger adults, individual and interpersonal experiences of aging may differ according to the social, physical, and cultural environment that exists within the institution. While gathering the experiences of aging for younger adults in LTC, it is important to include how the larger institutional environment influences lower levels of interpersonal relationships and individual experiences of younger adults. Thus, a reciprocal relationship

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between multi-level structures that operate from the top down and bottom up influence younger adults' perceptions of health and aging. Research has begun to explore how LTC institutional environments are conducive to exclusion and isolation however, little information indicates how the LTC institution addresses or neglects processes of health and aging for younger adults.

Key Terms

In summary of this brief overview, it is important to operationalize key terms that are relevant within this study and will be used frequently throughout this report. Beginning with the frequent use of the term age stereotypes and age perceptions, this study references both these terms as beliefs about older people as a generalized group (Levy, 2003; Meisner & Levy, 2016). The term perception is frequently used to describe as a way of understanding or interpreting what individuals think or feel towards an idea or conception. Experiences are also frequently used to describe how individuals share direct contact, gain participation, or become involved within a situation.

Within the context of this study, long-term care is referenced as the health care setting in which the study took place, as well as an institution offering health care services and housing accommodations. The LTC facility selected for this study offers health care services for individuals requiring 24-hour nursing care, individuals requiring some assistance with activities of daily living, and finally care for individuals with minimal supervision and assistance towards activities of daily living (Nova Scotia Department of Health and Wellness, 2015).

Participants were required to be the age of majority, which is 19 in Nova Scotia, and under the age of 65, the age at which individuals are characterized as an older adult and typically enter LTC facilities (Nova Scotia Community Services, 2008). A sample of participants within

this study are often referred to as younger adults and fall between the ages of 36 to 60. The term

older residents are used to describe the population of older adults above the age of 65 in LTC.

Disability and impairment are also key terms characterizing the experiences of health and

aging for younger adults. Rooted within a social model of understanding, the academic discourse

of disability describes experiences of impairment within larger socially constructed systems that

create social exclusion and environmental barriers (Barnes & Mercer, 1997). Impairment is a

term used to characterize younger adults' experiences of functional limitations, often referencing

their medical diagnoses of disability. Although the discourse of disability is referenced

throughout this study, contextualizing the narrative for younger adults, impairment is also used

to describe participant experiences of functional limitations (i.e., use of a wheelchair, loss of

hearing and/or vision). This theoretical differentiation becomes clear when describing academic

discourse of disability versus describing physical experiences of daily limitations for younger

adults.

Importance and Relevance to Health Promotion

This area of research is important and meaningful to explore given its focus to promote

and protect long-term health and aging among one of Nova Scotia's most rapidly increasing

populations (Statistics Canada, 2012b). Focusing on perceptions and experiences of health and

aging through a multi-level approach, by giving voice to younger adults with disabilities, builds

evidence towards exploring the complex experiences of health and aging for younger adults in

LTC. This multi-level understanding explores how perceptions and experiences of health and

aging are influenced through individual, interpersonal, and institutional structures.

Through a multi-level analysis this research project follows the framework of the social-

ecological theory, foundational to health promotion and health psychology (Bronfenbrenner,

1977; Engel, 1981). Applications of health promotion theory and approaches to research emerged as the "new public health" for understanding complex systems of health disparities across communities (Stokols, Allen, & Bellingham, 1996). Health promotion fields often apply the social-ecological model within research to explore and describe interconnected characteristics of individuals, interpersonal relationships, and environments that influence health outcomes (Golden & Earp, 2012). As originally proposed by Bronfenbrenner (1977), the social-ecological model is characterized as a network of relationships portrayed through each level of the individual, interpersonal, institutional, societal, and political systems. Understanding how each level of the social-ecological model influence and in turn shapes individual health outcomes also connects to principles outlined within the Ottawa Charter for Health Promotion (1986). The Ottawa Charter conceptualizes a definition of health promotion as:

> The process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. (World Health Organization, 1986, p. 1)

Operationalizing this definition within the context of this study is important, as evidence indicates younger adults with disabilities in LTC are not in control of improving experiences of their health and aging. Although re-orienting existing health services to meet the complete physical, mental, and social well-being of younger adults is a long-term goal, we must first understand how LTC institutions influence processes of health and aging. Following health promotion action outlined in the Ottawa Charter (1986), this study will contribute to healthy public policy, supportive environments, and reorient health services to improve the sustainable

development of LTC institutions designed to meet the complete health and aging needs of younger adult populations.

Purpose of the Study

In summary, the overall purpose of this research study is to understand the perceptions and experiences of health and aging among younger adults with disabilities living in LTC. Exploring the individual, interpersonal, and institutional factors are critical to understanding the experiences of health and aging for younger adults in LTC. Research has begun to explore the biomedical characteristics that comprise the population of younger adults with disabilities in LTC (Colantonio et al., 2010). Surprisingly, little is known about the design and operation of LTC institutional environments that influence the individual experiences of younger adults, with a focus on health and aging. Beyond the biomedical profiles of younger adults' disabilities, and focus on quality of life within LTC facilities, research is needed to explore the unique experiences of health and aging for this marginalized population.

Understanding that health and aging are a complex health phenomenon that is experienced through multi-levels leads to the exploration of the individual, interpersonal, and institutional perceptions and experiences of younger adults in LTC. Beginning with the individual experiences of younger adults in LTC, this study will explore what the perceptions and experiences of health and aging are for younger adults with disabilities. Beyond individual level factors of health and aging, this study will then explore how these perceptions and experiences of health and aging are positively or negatively influenced by social interactions with older residents in LTC. Finally, this study will explore how the larger LTC institution and operation of health services promotes or prevents positive perceptions and experiences of health and aging for younger adults with disabilities. By taking a new multi-level approach to an

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important area of health promotion research, this study contributes to the existing field of

research while addressing a gap in knowledge.

CHAPTER 2: LITERATURE REVIEW

This chapter will review the most current and applicable research studies that build evidence and contribute to the significance of this research project. Beginning with an overview of a rapidly aging population, a changing profile of aging will be discussed as it affects populations of older adults as well as people with disabilities. Secondly, as greater levels of health care services are required to meet the needs of an aging population and people with disabilities, environments of care will be explored as they exist to deliver specific health care and housing needs. Following environments of care, the unique circumstance of providing health care services and housing to younger adults with disabilities in LTC institutions will be explored. Lastly, this review will outline what we know about the experiences of living in LTC for younger adults with disabilities. This chapter presents a discussion of the current literature and gaps in knowledge surrounding the perceptions and experiences of health and aging for younger adults in LTC, and will demonstrate that further research is required using a health promotion framework.

Aging Population Demographics

Canada has experienced an unprecedented demographic shift of an aging population. This demographic shift is expected to progress over the next 25 years as the number of people entering old age continues to increase (Statistics Canada, 2015a). Although Canada's population overall will continue to age, certain provinces are expected to experience even greater changes. It is reported that Canada's Atlantic provinces, including New Brunswick and Nova Scotia, are most greatly affected by the greatest proportion of older adults over the age of 65 when compared to proportion of children between the ages of 0 to 14 (Statistics Canada, 2015a). Specifically, Nova Scotia comprises the highest ratio of individuals aged 65 and older compared

to children aged 0 to 14 (Statistics Canada, 2015a). This presents a unique health care concern for communities in the Atlantic provinces to provide appropriate housing and health care resources for a growing population of older adults (Swartz et al., 2011).

Providing appropriate housing and health care resources for an increasingly aging population continues to remain a challenge as older adults are more likely to experience multiple forms of disability in later life (Statistics Canada, 2015b). As measured by Statistics Canada within the Canadian Survey on Disability framework (2015b), disability is defined as individual experiences of, "a difficulty or impairment due to a long-term condition or health problem but also experience [of] a limitation in daily activities" (p. 89-654-X). Results from the most recent Canadian survey in disability in 2012 indicated that the prevalence of disability increases steadily with age, and remains the highest among adults over the age of 65 (Statistics Canada, 2015b). As Canadians can expect to live longer, those who are/will be over the age of 65 can expect to experience some form of disability related to pain, mobility, flexibility, and hearing (Statistics Canada, 2015b). Acquiring a form of disability in later life indicates individuals can also expect to experience different processes of aging (Heller & Sorensen, 2013; Janicki et al., 2002). Research indicates that in later life people with disabilities are more likely to live sedentary lives, experience a high prevalence of undiagnosed conditions, lack access to health care services, and are at higher risk of injury from falling (Hilgenkamp et al., 2012; Morin et al., 2012; Ouellette-Kuntz et al., 2015). Experiences of greater health care needs for older adults with a disability indicate processes of health and aging are likely to be influenced. As the proportion of older adults likely to experience a form of disability continues to increase, it remains important to explore how individual processes of health and aging are influenced by experiences of disability (Strnadova et al., 2015).

Preliminary evidence has shown experiences of health and aging extend beyond biomedical conditions for older adults with disabilities, and can be characterized through individual, interpersonal, and environmental factors (Burke et al., 2014; Spassiani et al., 2016; Strnadova et al., 2015). For example, research has explored experiences of health and aging for older adults with disabilities through first-hand knowledge of individuals that experience Down syndrome, a physical disability, and intellectual and developmental disability (I/DD) (Bittles et al., 2006; Burke et al., 2014; Strnadova et al., 2015; Yorkston, Bourgeois, & Baylor, 2010). Specifically, a small but growing field of research has begun to explore the experiences of aging for older adults with I/DD within a group home setting. The results of two most recent studies indicate that when older adults perceive and experience health and aging positively, they also gave high ratings of personal health (Burke et al., 2014; Strnadova et al., 2015). The significance of these findings indicate that perceptions and experiences for older adults with I/DD are often influenced by positive and/or negative individual, interpersonal, and environmental factors. While the experiences of aging for older adults with I/DD are not generalizable to all people with disabilities, this area of research is the first to explore how older adults with disabilities experience and perceive aging (Spassiani et al., 2016). As a greater proportion of our population is expected to experience different processes of health and aging, due to increased prevalence of disability, it is surprising that few studies explore experiences of aging throughout the life course.

Focusing on perceptions and experiences of aging, it is known individual processes of health and aging are not independent but rather influenced by larger social and environmental experiences (Levy, 2003). Individual attitudes and beliefs towards aging become influenced and/or are dependent upon larger cultural and social structures that portray how 'normal'

experiences of aging should be experienced and perceived (Burke et al., 2014; Levy, 2009; Meisner & Levy, 2016). Although there is no evidence to indicate that a specific experience of aging is 'normal' (Weir, Meisner, & Baker, 2010), negative age-perceptions rely on the assumption that aging is the process of inevitable disease and decline (Levy, 2003). Negative age-perceptions continue to dominate our cultural understanding of aging through largely a biomedical lens (Meisner & Levy, 2016). It is increasingly recognized, through successful aging theories, that age and health are not dependent processes tied to a positive linear relationship (Janicki et al., 2002; Lehmann et al., 2013). Successful aging theories oppose negative age stereotypes that assume increased age causes a negative decline in health or well-being for people with or without a disability (Havinghurst, 2008). Additionally, successful aging theories challenge a breadth of research focusing on individual negative experiences and perceptions of aging through largely quantitative biomedical research (Havinghurst, 2008). The importance of exploring experiences of aging lies in gathering how one thinks and feels about the/their own processes of aging, which are influenced by the larger social and environmental experiences of aging (Levy, 2009). The significance of processes of health and aging highlight through perceptions and experiences that subsequent health outcomes are more complex than biomedical diagnoses. As the population of older adults will continue to increase and can expect to experience some form of disability, it is pertinent that research continues to explore how unique processes of health and aging are influenced.

Environments of Care

While aging should not be synonymous with inevitable disease and decline, it remains true that as one experiences processes of aging they can often expect to require higher levels of care when compared to the rest of the population (Barkan, 2011). To deliver appropriate health

care and housing needs to a diverse population of older adults, long-term care (LTC) institutions have been created. LTC facilities are institutions that provide rehabilitative and/or ongoing care from health professionals to individuals that require assistance with activities of daily living (Swartz et al., 2012). Although LTC facilities serve an important purpose to provide adequate housing and health care needs to a population of aging residents, they are often stigmatized within the general population (Dobbs et al., 2008). Older adults in LTC represent a heterogeneous group that vary in all aspects of life; however, due to a structured organization of everyday events and activities, the environments of LTC tend to be associated with isolation, dependency, restriction, and decline (Dobbs et al., 2008; Guse & Masesar, 1999). Exploring both positive and negative conditions of living within LTC institutions, a dearth of knowledge exists gathering the experiences of life and aging for older adults over the age of 65 in LTC (Dobbs et al., 2008; Winkler et al., 2006).

Environments within LTC facilities are targeted not only as settings within research studies but are also recognized as key areas of political contention. As resources are allocated for major LTC facilities under a publically-funded budget (Statistics Canada, 2011a), mandating adequate resources and planning for the future of a rapidly aging population remains a challenge for local communities (Smith, Rayer, & Smith, 2008; Swartz et al., 2012). Evidenced through long waitlists to receive appropriate housing and health care services, many older individuals continue to wait for appropriate health services in LTC (Curry, 2015). The challenges that exist for older adults to receive appropriate housing are also similar for people with various disabilities that require supportive community-based housing (Canadian Life and Health Insurance Association Inc., 2012; Winkler et al., 2006). Providing adequate environments of care within

institutions or community-based housing continues to present additional concerns for marginalized populations of older adults and people with disabilities.

While improving the overall health of people with disabilities continues to be a challenge, quality of life and life expectancy has steadily increased over the past 40 years (Bowers, Webber, & Bigby, 2014; Ouellette-Kuntz et al., 2015). This longitudinal trend of increased quality of life is linked to the deinstitutionalization of people with various disabilities, as they move out of long-term, institutionalized care and into community-based housing (Kim et al., 2011). Living in community-based housing is shown to provide numerous benefits and improvements to living standards for people with disabilities including; strengthened social networks (Forrester-Jones et al., 2006), increased social inclusion, greater community participation (Heller et al., 2014), and targeted health promotion and disease prevention activities (Ouellette-Kuntz, 2005). Beyond improvements to quality of life and health outcomes for people with disabilities in community-based housing, individual experiences of aging are expected to change within different environments of care.

One environment of care within community-based housing has been found to promote self-determination, autonomy, and life choices of individual with disabilities (Wehmeyer & Bolding, 2001). A strong characteristic of community-based housing environments includes opportunity for individualized health care support provided to smaller numbers of residents living in one location (Clement & Bigby, 2009). Overall, environments of care within community-based housing have been found to improve quality of life, health outcomes, and opportunity for meaningful engagement within the communities' people reside (Clement & Bigby, 2009). It is significant that community-based housing, when compared to institutionalized

facilities, provides measurable improvements in multiple domains of health and quality of life for people with disabilities.

Although discussion over institutional versus community-based environments of care continues, few studies explore the influence of environments of care when considering factors that influence perceptions and experiences of health and aging among individuals with disabilities. Within this small body of literature, the most recent findings from studies by Burke et al. (2014), and Strnadova et al. (2015), begin to describe the perceptions and experiences of aging for older adults with I/DD in community-based housing. Preliminary evidence indicates that when older adults with I/DD perceive aging positively, they also give high ratings of personal health (Burke et al., 2014). This suggests that positive associations of aging can be linked with one's perception of individual health and wellbeing within the environment of community-based housing. A second study to demonstrate similar results found within Burke et al., (2014), also provide beginning evidence that few differences exist between gendered experiences of aging between women and men with I/DD over the age of 50 (Strnadova et al., 2015). Lastly, evidence from Spassiani et al., (2016), indicates that experiences of aging are best characterized through individual, interpersonal, and environmental factors within community-based housing for older adults with I/DD. Building upon pre-existing knowledge, Spassiani et al. (2016) gathered in-depth information from various stakeholders (i.e. older adults with I/DD, staff, management), about the larger structures that influence processes of aging within community-based housing. While research in the field of aging perceptions and experiences continues to expand in the health context, further research is required to focus on environments within LTC facilities as the number of younger adults with disabilities becoming institutionalized is expected to increase.

To meet the health care and housing needs of people with disabilities, LTC facilities are providing care for individuals that require immediate assistance when accommodations in community-based housing are not available (Cameron et al., 2001; Colantonio et al., 2010). Based on 2011 Statistics Canada census, there are approximately 18,500 individuals under the age of 65 living within long-term care facilities across Canada, of which approximately 600 live within Nova Scotia. Considering the proportion of younger adults within LTC across Canada and specifically within Nova Scotia, it is surprising that research has not yet explored experiences of aging for younger adults that enter LTC earlier in life and live for longer periods of time. While it is understood that experiences of aging are complex, it remains largely unexplored how experiences of aging for people with disabilities are influenced by individual, interpersonal, and institutional factors within LTC facilities.

Younger Adults in LTC

Within the population of LTC residents that experience disability, relatively 'younger adults' - those under the age of 65 years - are increasingly being placed to live amongst older, and often sicker residents (Perkins & Friedman, 2012). As younger adults enter LTC institutions at an earlier point in life than most and continue to live for longer periods of time, they are likely to experience aging differently than older adults who enter LTC later in life. Not only can younger adults with various disabilities expect to live longer with a higher quality of life, they can expect to experience different processes of aging influenced by environments of care, such as LTC (Ouellette-Kuntz et al., 2015; Spassiani et al., 2016). Living in an institution that is traditionally reserved to provide end-of-life care presents many challenges for younger adults with various disabilities, some of which are being recognized by the development of youth centered wings within some LTC institutions (Nova Scotia Canada, 2010; Shannex, 2016).

Youth centered wings are briefly described as providing specialized care, services, programs, and activities that are specific to the needs of younger adults (Shannex, 2016). Little to no information exists describing the lived realities of younger adults in youth centered wings within LTC facilities in HRM. Although research has begun to explore the challenges associated with living in LTC for younger adults, little evidence exists focusing on perceptions and experiences of aging and disability in this setting. Although disability does not define younger adults' lived experiences of aging in LTC (Spassiani & Friedman, 2014), it is important to understand how disability influences individual perceptions and experiences, bringing this unique group together within LTC facilities.

As reported within Statistics Canada (2012a), younger adults between the ages of 19 to 55 experience the highest prevalence of pain, flexibility, and mobility-related disabilities and 92% of diagnoses including multiple disabilities. A more detailed account of specific diagnoses of disabilities is reported for populations of younger adults that live in LTC within Australia, Canada, Glasgow, and United States indicate that the most prevalent diagnoses of disability for younger adults living in LTC include traumatic brain injury (TBI), multiple sclerosis (MS), I/DD, and Huntington's disease (Colantonio et al., 2010; Winkler et al., 2006). Although the following diagnoses of disabilities for younger adults in LTC is categorized within international research, individual level lived experiences of disability are heterogeneous and are often influenced by larger structures across individual, interpersonal, and institutional factors. Surprisingly, there are few studies that explore the quality of life and living conditions for younger adults residing in LTC facilities.

Beginning with experiences of TBI as the leading cause of disability among younger adults, individuals are often diagnosed after enduring a blunt and penetrating force to the brain

(Kraus, Rock, & Hemyari, 1990). Upon enduring this injury, individuals are likely to experience physical and cognitive impairment for the rest of their lives, thus leading to younger adults seeking 24-hour care within LTC facilities (Winkler et al., 2006). Secondly, experiences of MS cause both physical and psychological disability (Edmonds et al., 2007). Even after undergoing disease-modifying therapies, it is expected that someone diagnosed with MS will develop significant disabilities throughout their life course (Edmonds et al., 2007). It is most common that people with MS are unable to walk, experience limited upper limb function, depression, and intellectual impairments (Borreani et al., 2014). Thirdly, people with I/DD experience poorer health than the general population (Krahn et al., 2006). More severe diagnosis of I/DD can lead to substantial limitations in activities of daily living resulting from delays or impairments that affect motor, cognitive, and speech abilities (De Ligt et al., 2012). These more severe I/DD require increased medical and supportive care from family and health professionals. Lastly, Huntington's disease is a common experience among younger adults in LTC. Experiences of Huntington's disease include involuntary movements, cognitive impairment, and progressive behavioral changes over the life course (Myers, 2004).

Beyond the individual diagnoses, the prevalence of younger adults living in LTC with disability is a concern within communities across Nova Scotia (Barken, 2013). As stated before, a significant challenge in meeting the housing and health care needs of younger adults with disabilities is the lack of available community-based housing supports and resources (Nova Scotia Health, 2013). Similar to the experiences of younger adults with disabilities internationally, younger Nova Scotians are being placed within LTC facilities to receive adequate housing and health care. The issue of providing adequate community-based housing for younger adults with disabilities has not gone unnoticed. For example, the Standing Committee

on Public Accounts Nova Scotia Annual Report (2011) recognized this issue as a key area of concern that organizational leaders and government officials must provide solutions. While effective and sustainable solutions take time to develop, the health and well-being of one of Nova Scotia's most rapidly increasing populations are being influenced as they age within LTC facilities. Although LTC facilities exist as a temporary solution to meet the physical health care and housing needs of younger adults with disabilities, little evidence exists to indicate whether the complete health and health care needs of younger adults are being met within LTC facilities (Nova Scotia Health, 2013; Standing Committee on Public Accounts, 2011).

Experiences Among Younger Adults in LTC

To gather the experiences of younger adults in LTC, research has begun to explore how the health and well-being of younger adults with disabilities are influenced by the LTC institution and environment. Leading research within Australia, the United States, and Canada provide evidence for the experiences of, and perceptions among, younger adults in LTC, in addition to exploring policy-level changes targeting quality of life for this population. To illustrate, beginning with Winkler et al., (2006), a profile of younger adults with disabilities provides specific details of diagnoses from a variety of LTC facilities across Australia. In addition to providing an overview of disability diagnoses for younger adults outlined previously in this chapter, it was also discovered in this study that younger adults in LTC experience social isolation and exclusion, lack of opportunities and participation in recreational activities, and a loss of autonomy (Winkler et al., 2006). This foundational study provides evidence to advocate for alternative or supplementary models of care within LTC institutions across Australia, in addition to recommending how these models of care could be evaluated (Winkler et al., 2006). Although this study presents significant results on the measures of social inclusion and

participation, data were gathered from directors of nursing through survey questionnaires. This indicates social inclusion and participation were measured through the number of visits from people outside the LTC and the number of recreational activities younger residents participated in. Thus, this study does not accurately represent how younger adults with disabilities experience or perceive social inclusion and recreational activities within LTC, as well as what they think alternative accommodations should provide. Further research is required to explore the actual perceptions and experiences of daily life in LTC by consulting with younger adults through in-depth methods that target specific health outcomes and quality of life.

Another study from Winkler et al. (2011), indicates that, although developing alternative community-based housing requires long-term changes, the lives of younger adults that moved out of LTC facilities were substantially improved through increased opportunities for specialized care and resources (Winkler et al., 2011). Younger adults who moved out of LTC were able to receive individualized funding packages used towards disability supports (e.g. supportive wheelchair seating, speech pathology, communication aids), and age-appropriate activities within their local communities (e.g. gym membership, taxi fare, tickets to a show). Through institutional changes and removing younger adults from LTC environments, experiences of health were influenced resulting in long-term change that could influence perceptions and experiences of aging. Through telephone interviews with health professionals and support workers, this study explores the positive and negative impacts of implementing a policy to provide alternative housing options for younger adults in LTC across Australia. Gathering a higher-level understanding of institutional and policy-focused changes to LTC is critical; however, the voices of younger adults with disabilities remain silent with little known about how the perceptions and experiences of health and aging for younger adults changed after leaving LTC.

For a Canadian perspective, Colantonio et al. (2010), conducted a secondary data analysis of medical records from the Ministry of Health Levels of Care within Ontario. Gathering information on the number of younger adults with TBI in LTC and their unique health care needs provides a new perspective for the structure of funding that each LTC institution is provided. A critical review of the current LTC under-funded resources and budgets indicates that processes of health and aging are likely to be influenced from a lack of active rehabilitation resources and specialized nursing staff (Colantonio et al., 2010). Contributing to a wider body of international research, this quantitative study offers a systematic review of the unique health care needs of younger adults with TBI living in Ontario LTC facilities (Colantonio et al., 2010). Through secondary data analysis, this study provides information on the types and levels of care required for younger adults with disabilities, while also directing future research to explore how the resources within LTC facilities can be utilized to promote health through specialized rehabilitative programs (Colantonio et al., 2010).

In addition to this quantitative research, a qualitative approach from Persson and Ostwald (2009) provides more detailed experiences of living in LTC for younger adults, specifically those with I/DD. Through interviews and focus groups, this study presents evidence that experiences of health for younger adults in LTC are characterized as the regimentation of life, freedom through participation in activities, and feelings of isolation (Persson & Ostwald, 2009). These individual experiences of health for younger adults in LTC were influenced by interpersonal relationships (e.g. with other residents, staff, and friends /family), as well as structural organization of the LTC institution (e.g. recreational activities, meal time/choice, and living arrangements with roommates). These results present a more in-depth perspective, while also representing the voices of younger adults with I/DD in LTC. Based on the experiences from

younger adults, future research should adopt similar interview techniques to compare and contrast the experiences of health and well-being in LTC in different settings.

Although the importance of improving the health status of younger adults with disabilities in LTC is well documented, the literature continues to represent a broad overview of specific bio-medical diagnosis and demographic characteristics of these individuals. This biomedicalization leads to a lack of significant psychological, social, and ecological information regarding the perceptions and experiences of health and aging among younger adults that live in LTC. Besides a study conducted by Persson and Ostwald (2009), qualitative research techniques are the least used in this area of research, despite the fact that little is known about it. As such, there is a need to apply qualitative research methodology to gather rich descriptive data. More specifically, adopting multiple and creative research methods would expand beyond traditional forms of data collection, such as surveys and secondary data analysis, that may not include people with disabilities meaningfully throughout the research process (McDonald, 2012; Povee et al., 2014). Future research should adopt creative research techniques, such as photovoice, known to work well with people with disabilities in a health care context as they experience health and aging.

Research Questions

This literature review leads to the overall purpose of this research study, which is to understand the perceptions and experiences of health and aging among younger adults with disabilities living in LTC in Halifax Regional Municipality (HRM). Data were gathered to address this purpose through answering three more specific research questions:

1. What are the perceptions and experiences of health and aging of younger adults with disabilities living in a LTC setting?

2. How are these perceptions and experiences of health and aging positively and/or

    negatively influenced by living amongst a relatively older population within the LTC

    setting?

3. How does the LTC institution promote positive and/or negative perceptions and

    experiences of health and aging for younger adults with disabilities?

These research questions gathered the perceptions and experiences of aging for younger adults

that live in LTC at multiple levels, which have allowed for an in-depth understanding of the

individual, interpersonal, and institutional factors that create or influence the health and aging

experiences of younger adults living in LTC. The significance of framing each research question

to address multiple levels within the social-ecological theory was to gather a deeper

understanding of this important and complex health phenomenon.

CHAPTER 3: METHODS

Study Methodology and Research Design

Given that the proposed research questions are exploratory, qualitative description

research methods were best suited to capture and represent the purpose and objective of this

study. Based on the existing gap in knowledge that has not yet captured the perceptions and

experiences of health and aging for people with disabilities, this exploratory research study

contributes data using inductive qualitative description methods. Inductive methodologies

include data that were gathered to provide a rich description of a research topic, specifically how

younger adults with disabilities describe their perceptions and experiences of health and aging in

a LTC facility. The purpose of providing a specific issue from the voices of participants' is to

reduce bias from a researcher's interpretation of an observed phenomenon (Sandelowski, 2010).

In the absence of an established grounded theoretical framework, and appropriate to qualitative

description, this research study gathered information on the who, what, when, and where,

through verbal description and visual images to represent the lived experiences of aging for

younger adults with disabilities (Sullivan-Bolyai, Bova, & Harper, 2005). As a method known to

explore and address a new area of research, qualitative description has potential to increase

awareness of pressing health care situations and provide clear information about the ways to

improve care (Sullivan-Bolyai et al., 2005).

By giving voice to younger adults with disabilities, qualitative description methods offer

a different approach that few studies have previously applied as, to date, the abundance of pre-

existing research focuses on the biomedical and epidemiological conditions of people with

disabilities through quantitative measurements (McAllister et al., 2013). This existing research

focuses on gathering data about people with disabilities without their active participation, instead

including family members, doctors, direct support staff, or management staff (Lehmann et al., 2013). While it is important to gather data from various stakeholders, a limitation of existing research is a lack of information known about the direct lived experiences from people with disabilities themselves.

Where little is known about the perceptions and experiences of health and aging for younger adults, and more specifically younger adults with various disabilities, participants were asked to describe their perceptions and experiences in more than one way. The voices of people with disabilities were gathered through one-to-one, in-person semi-structured interviews in addition to photovoice techniques. Photovoice methodology is a participatory research method that engages participants to take photographs of physical and social environments within their daily life while contributing to the collection and analysis of data to be used in the study (Povee, Bishop, & Roberts, 2014). Through participatory techniques, photovoice is also recognized as a method for including and empowering vulnerable populations, such as people with disabilities, to participate in, and contribute to, research and related outputs (Palibroda et al., 2009).

First, interviews focused on gathering information at one point in time through a cross-sectional study design. Open-ended interview methods are known to provide four main benefits of collecting qualitative data as outlined by Patton (2001): a) maintaining consistency between participant responses and direction of conversation; b) precise and concise interview guide provides effective time management; c) organizing data allowing for systematized analysis; and d) availability of original interview guide for future inspection and replication in future research. Aligning with the objectives and purpose of this research study, the evidence for using semi-structured interview techniques provides rationale for exploring the perceptions and experiences of health and aging in LTC.

Second, to accompany face-to-face interviews, photovoice methods were used to contribute additional data by gathering visual representations of participant experiences (Patton, 2001). The use of photovoice methods throughout research is known to provide three main benefits to the production of knowledge as outlined by Wang and Burris (1997): a) to enable people to record and reflect their community's strengths and concerns; b) to promote critical dialogue and knowledge about important issues through discussion of photographs; c) to reach key stakeholders and policymakers. Within the objectives of this study, photovoice methods provide useful information about the physical environment, and without being present to observe, the significance of any environment may be challenging for a researcher or an audience to understand.

Using multiple qualitative research methods, comprising face-to-face interviews and photovoice techniques, participants with various disabilities were able to provide details of experiences within the LTC facility both verbally and visually. This information is applied to understand a larger system in which younger adults with disabilities experience health and aging within various levels pertaining to policy, community, organizational, interpersonal, and individual networks. The theoretical framework that applies this systematic analysis is found within the social-ecological model (Brofenbrenner, 1977). The social-ecological model is primarily used to, "address the interdependencies between socioeconomic, cultural, political, environmental, organizational, psychological, and biological determinants of health and illness" (Stokols et al., 1996, p. 247). Within the context of this study, a social-ecological theoretical framework recognizes that individuals do not exist in isolation or in a vacuum, and that they are influenced by the network of structures as well as the relationships that exist around us (Boutin-Foster et al., 2013). Thus, to grasp a comprehensive understanding of health and health-related

topics, a systems-based approach is required to explore and describe the individual, environmental, social influencing factors (Lieberman, Golden, & Earp, 2013).

Ethics Approval

Before beginning this research project, ethics approval was required from both Dalhousie University and the LTC facility in which the study took place. First, ethics approval was granted by Dalhousie University on December 05, 2016 (see Appendix J). Following this approval, a project proposal and ethics application was submitted to the LTC facility for internal review. Approval was granted on December 16th, 2016. This letter of approval has not been included to protect the privacy and identity of the LTC facility.

Participants, Setting, and Recruitment

This study recruited 11 participants between the ages of 36 to 60, with a disability, and living within the same LTC facility in the Halifax Regional Municipality. The inclusion of 11 participants was sufficient to begin exploring the experiences and perceptions of younger adults with disabilities in one LTC facility, while also ensuring data collection was completed within one year. Participants were required to be the age of majority, which is 19 in Nova Scotia, and under the age of 65, the age at which individuals are characterized as an older adult and typically enter LTC facilities (Nova Scotia Community Services, 2008). One LTC institution within the Halifax Regional Municipality, was selected for the study for pragmatic reasons including time restrictions, travel accommodations, and feasibility of participant recruitment. The LTC institution selected offers different levels of individualized full 24-hour nursing or minimal residential health care services for residents (Department of Health and Wellness, 2015). The LTC facility selected is one of the larger institutions within the HRM, and provides various

facility based professional health care services, transportation, full service menu for all meals, housekeeping, and individualized health care support teams.

Based on the proposed methods of data collection, including both interview and photovoice techniques, participants were included if they could engage in verbal communication. To accommodate verbal communicational skills of participants, a support worker or peer was able to be present during the initial meeting and following interview to clarify conversation between participant and researcher. In addition to accommodating for verbal communicational skills, a support worker or peer was also able to assist during the process of taking pictures, with direction from participants as to which images to capture. In summary, inclusion criteria for recruitment included: a) participants must be between the ages of 19 to 65, b) participants communicate verbally (with or without a support person), c) participants are their own legal guardian, d) participants consent to be audio-recorded during interviews.

Additionally, to respect and protect the confidentiality of medical records, information on official diagnosis of disability was not used as inclusion criteria, rather this information was communicated from participants in the first interview. Although there were no specific inclusion criteria for diagnosis of disability within this study, it is known that younger adults with a disability typically move into LTC due to lack of appropriate housing and health care services (Colantonio et al., 2010). The purpose of including diagnosis of disability was to ensure appropriate medical information were included within the study for consistency and comparison to the extant literature. Inclusion of a gender balanced sample was sought throughout the recruitment process. This purposeful sampling strategy ensured that participants represented the target population, as the LTC facility communicated there were 49 females and 30 male younger adults living in LTC at the time of the study (Personal communication, October 7th, 2016). This

sampling strategy is common for qualitative description methods that aim to gather data from fewer participants but allow for information-rich cases to provide data on a common experience (Sandelowski, 2010).

After research ethics approval was provided from Dalhousie University and the LTC facility, the recruitment process began. During the recruitment process, a phased screening process was applied to ensure the sample of 11 younger adults represented a homogenous population of which perceptions and experiences of health and aging were compared. A phased screening process required recruitment staff from the LTC facility to first reach out to a potential sample of participants between the ages of 19 to 30. The purpose of this was to ensure potential participants were contacted and a sufficient sample of younger adults was achieved, allowing data collection to remain within the youngest age range. The phased screening process of recruitment was organized to contact younger adults between the ages of 31 to 40, then 41 to 50, and finally 51 to 64, until a sufficient sample was achieved.

Participants were first approached for recruitment by a project-assigned LTC internal liaison staff member. Based on the set of initial inclusion criteria (i.e., age, ability to communicate verbally, acting as legal guardian, and consent for audio-recording), a list of potential participants were provided a recruitment handout (Appendix B) outlining what the project was about, how they were being asked to participate, and how they could potentially benefit. To reduce the risk of coercion, the recruitment handout was provided to potential participants by other health professionals at the LTC facility (i.e., physiotherapists, occupational therapists, recreational leisure representatives). Only those potential participants that met the inclusion criteria were provided a recruitment poster, of which was determined by the internal liaison. Importantly, the initial recruitment stage began with the internal liaison from the LTC

facility and, at this point, the identity of the potential participants remained confidential. The initial correspondence with an internal LTC staff member acted to protect the identities of participants that did not wish to be included in the research study. Information was only provided to the lead researcher if the potential participant was interested in participating in the project and provided permission to the internal liaison to share information with the researcher. Contact information was used to arrange the first meeting between the participant and the researcher. The first session started with an outline of the proposed study, as well as gathering written or verbal informed consent. If consent was provided, then session 1 of the study was started and data collection began during the first interview.

Data Collection

Participants engaged in two interview sessions in a comfortable location of their choice inside the LTC facility. Although participants were able to choose a comfortable location, the immediate health care needs of each participant influenced the private location chosen, in close proximity to staff or resources. The only requirement of the interview setting was to ensure the environment was conducive for hearing participant and researcher verbal communication and to ensure audio-recording of conversations allowed for adequate transcription. The use of two qualitative research methods involved two sessions with participants, outlined below, occurring within a one-week time period, to collect photovoice and in-depth interview data.

Session 1. After consent was gathered, a methodological guide to applying photovoice techniques from Palibroda et al., (2009) was used. This included an outline of the utility and use of photovoice methods within research. Participants were provided a clear description of what photovoice is and how they would be asked to engage in photovoice methods, in the form of operational instructions (Appendix F). Participants decided whether they wished to use their own

digital camera or electronic device (i.e. cellphone or tablet) that could take photos. Participants that did not have their own device were provided a digital camera. Following the photovoice instructions, participants were provided one week to take photographs and select 5 to 8 final photographs representing their individual, interpersonal, and institutional perceptions and experiences of health and aging (i.e. environments or activities within the LTC facility). Based on recommendations from a practical guide to photovoice methods, previous researchers recommend following a structured technique of including under 10 photographs per participant, proving most effective for data collection and analysis (Palibroda et al., 2009). To facilitate the process of taking photos over the span of a week, participants received a handout as a reminder of the three levels within the social-ecological model (Appendix G). Although participants were provided a guide to taking photos, there were no instructions given to include a certain number of photos representing each theme.

Pertaining to data collection during the first session, one-to-one semi-structured interviews gathered information on individual, interpersonal, and environmental factors that described and influenced the perceptions and experiences of health and aging. The interview guide (Appendix H) was structured using the first three levels within the social-ecological model. More specifically, interview questions were organized according to individual, interpersonal, and environmental aspects of health and aging within the LTC facility. The semi-structured interview guide was used for each interview to ensure a high level of consistency among the questions asked to participants, and to ensure all questions adequately answered the primary research questions. In addition to the semi-structured guide of interview questions, probing questions were used to gather greater detail of participant responses (Kvale & Brinkmann, 2009). This open-ended interview format ensured participants were given ample time to respond to

questions, and to ensure participants had an opportunity to share additional information prompted by the initial interview questions.

        Session 2. Approximately one week from the first session, participants were asked to discuss and describe each of the 5 to 8 photographs from digital form in a second semi-structured interview. At this time the cameras were returned and a digital copy of the photographs were collected from participant's personal electronic device, and stored on a secured USB drive from the researcher. The selected photographs that participants included in the study supplemented interview questions, as participants were asked to describe and explore the meaning and significance of each image. An interview guide of questions facilitated conversation about the photographs, to ensure sufficient and comprehensive data were collected (Appendix I). Upon completion of interviews, audio-recordings of interviews were loaded onto a secure computer and transcribed, removing any identifying information.

Data Analysis

        Interview and photovoice transcripts were coded and analyzed, with emergent themes identified. These themes emerged as reported patterns in the data, based on techniques from Braun and Clarke's six phase analytic method (2006). More specifically, thematic structures were achieved by a) familiarity of transcripts, b) generating initial codes, c) grouping and re-grouping of codes, d) search for identified themes, e) organization of thematic map to review, and f) definition of themes (Braun & Clarke, 2006). This approach is recognized for its flexibility of theoretical and epistemological approach, and the inductive formation of codes, categories, and themes that are grounded within the data (Braun & Clarke, 2006). An advantage of thematic analysis aligns with the aims of this research project to provide rich and detailed, yet complex description of data (Braun & Clarke, 2006). Importantly, the social-ecological

theoretical framework was applied during the analysis of research results as themes were organized according to individual, interpersonal, and environmental aspects of health and aging among these younger residents of LTC. Using the social-ecological model, data were grounded and analyzed based on the understanding that health and health behavior associated with the experiences of aging are socially conditioned (Lieberman et al., 2013). Delineating the experiences of health and aging that emerge within the data while capturing the details of younger adults' lives presents a challenging task. As such, the social-ecological framework provides an effective and efficient way to describe the interconnections between a bottom up and top down understanding of health and aging within LTC environments. During the six-phases of thematic analysis, the underlying ideas and assumptions of participant experiences were described and interpreted by the primary researcher. To ensure credibility and validity of the data analysis, coding was cross-referenced by the primary researcher, supervisor, and one other supervisory committee member to ensure data analysis trustworthiness of results (Boyatzis, 1998).

Researcher Details and Reflexivity

As a Masters of Arts in Health Promotion Candidate, this research study comprises the required thesis component. The primary researcher remained involved and responsible for all research processes including development, data collection, analysis, and write-up, and dissemination. This research study was supervised by Dr. Brad Meisner, Assistant Professor in Dalhousie University's School of Health and Human Performance. Additional supervision was provided by committee members Drs. Lori Weeks and Natasha Spassiani. The analysis of data and credibility of research results were confirmed with the assistance of this supervisory committee.

The area of research focusing on younger adults aging within LTC was largely developed from personal, academic, and future career interests of the primary researcher. Before the development of this research project, and upon completion of courses at the graduate level, the primary researcher obtained adequate skills and knowledge within an advanced research methods course and an independent study project. These experiences provided a strong foundation of knowledge in the subject matter of aging and disability as well as the methods/methodology that were relevant for this study. In addition to academic knowledge, the primary researcher gained two years of employment experience working with people of varying ages with I/DD. This experience provides the primary researcher with the practical skills, abilities, and sensitivities, required for conducting interviews with a marginalized population.

Ethical Considerations

There were various ethical considerations addressed within the design of this study based on Dalhousie University's Research Ethics guidelines on research involving humans. Additional considerations were made based on the LTC facility's internal research ethics procedures required to conduct research with residents in LTC. To ensure participants were provided a choice on how they wish to provide consent, both written and verbal consent forms were offered. Each participant was reminded that any identifying information would be omitted from transcripts and results, through assignment of participant numbers or pseudonyms, to guarantee privacy and confidentiality. Participants were also reminded that participation in this study was completely voluntary, and if at any point in time a participant decided to withdraw from the study then all of their data would be removed from the study up until one week after the interview was conducted as, after that point, data would be analyzed and synthesized into the results.

Ethical concerns of photovoice. The use of photovoice methods offers a unique benefit of supplementing meaningful discussions with participants. While promoting participatory research methods and including participants in the meaningful collection of data, some limitations were placed against participants throughout the process of selecting photographs for final research results. Due to the nature of collecting photographs within photovoice techniques, participants were made aware of the ethical considerations of including identifying themes that reveal the identity of the LTC facility, such as personal/identifying information or people. To ensure participants are aware of the ethical considerations of taking photographs in the environment of the LTC facility, careful instructions were provided during Session 1 of the study (Appendix F).

If participants were to include personal/identifying information or people within photographs, they were made aware that due to the privacy and confidentiality policy of research involving humans, as described within Tri-Council Policy Statement (TCPS, 2010) mandate, certain information would be withheld from dissemination of research results. These photos could only be used in private interviews discussing the significance of the photograph. To protect the identification of individuals or groups within publications or other means of dissemination, the photographs to be included in research results must follow the confidentiality and privacy policies of the LTC facility (TCPS, 2010). Therefore, photovoice images included within the dissemination of research results or made available to the public through published manuscripts do not reveal personal information about the LTC facilities or images of any person.

Ethical considerations of interviews. During interviews, there was an ethical concern for risk of discussing sensitive topics arising from the experiences of participants. It was discussed prior to the start of this research study, and stated at the beginning of the consent form,

that counselling services were available within and outside the LTC facility for participants to seek additional support. To ensure participants had access to additional resources, a discrete print-out of resources was supplied at the time of the interview to all participants, for example hotline numbers and locations of local clinics that offer counseling and mental health support. As well, it remained the responsibility and ethical obligation of the primary researcher to report any signs of abuse or trauma that were disclosed during interviews. Participants were reminded they could withdraw at any point in time or take a break or skip a question during the interview without any consequence.

After completion of the interviews, audio-recordings were loaded onto a secure, password and firewall-protected computer to be transcribed. At the point of transcription any identifying information was removed. Transcribed interview data were stored securely through password-protected electronic files. Once transcripts were complete, audio-recordings were stored on an encrypted hard drive securely stored in the supervisor's office on Dalhousie University campus. Only the primary researcher and supervisory thesis committee had access to transcripts upon request. Consent forms were stored securely and separately from the audio files at Dalhousie University. Upon completion of this study, hard copies of transcripts were shredded and electronic versions stored on an encrypted hard drive for a five-year period, after which all records are to be destroyed.

Benefits and risks of including people with disabilities as participants. To include younger adults with various disabilities throughout the process of interview and photovoice techniques there were various ethical considerations to address. Reasonable accommodations were arranged to be made for the potential varying communication abilities of participants, such as the length of interview or the time of day that interviews occurred. In agreement with LTC

visitation hours, participants were able to choose a time for interviews that best fit their schedule and personal needs. For participants that wished or required a support worker or peer (i.e. friend or family member), then those individuals were also required to sign a confidentiality agreement. To ensure the purpose of this research project was addressed through adequate interview questions, a semi-structured interview guide written in lay language was submitted for ethics approval (Appendix H). A benefit of creating a semi-structured interview guide is so that questions could be re-worded and revised during an interview or throughout the research process based on feedback provided by participants.

In addition to the risks, there were various benefits for younger adults to participate in this research project. Beginning with the research design, both photovoice and interview techniques are shown to empower participants to share personal experiences through story-telling, irrespective of the positive or negative orientation of research results (Palibroda et al., 2009). The very nature of qualitative description offered participants an opportunity to participate in the process of gathering data and contributing to the analysis of results.

This research study was also created with the intention of benefiting younger adults that live within LTC. When this research project was designed, additional efforts were taken to ensure the purpose of research questions are founded upon a topic that is meaningful and relevant to the lives of younger adults with disabilities living in LTC facilities over extended periods of time. Creating an appropriate research project provides participants with a benefit of using the research results to educate key stakeholders within the LTC institutions about their positive and negative experiences. Results from this study could also be used to strengthen the efforts of local advocacy groups, such as Independence Now Nova Scotia, organized by younger adults living in LTC facilities across HRM (INNS, 2015). Sharing the experiences of younger

adults in LTC within an academic platform provides additional evidence to policy makers to influence higher-level community and socio-political change within LTC regulations.

Dissemination of Results

Sharing the results of this study are important in advancing the development of age-appropriate health care solutions for younger adults in LTC within Nova Scotia. As outlined on the consent form, participants decided to remain in contact, via email, in-person, or mail, to be provided with a one-page research summary in an effort to disseminate future research results. These participants decided how they would like to share the results of this study, for example, with peers, family, LTC staff, or LTC management. To protect the anonymity of participants within the LTC institution, group-level results versus individual results were shared with participants and a presentation made to the LTC facility staff. A presentation of results is also planned to be shared at an annual LTC research conference in 2018.

Results will also be disseminated through publishable manuscripts following the submission of this final document. Reaching a larger academic and professional audience to provide knowledge on the lived experiences of health and aging for people with disabilities has exposed some realities this marginalized population experience, that many younger adults with disabilities in LTC do not have an opportunity to share. Dissemination to the larger public has begun in collaboration with a local organization called, Independence Now Nova Scotia. This organization was created and is operated by younger adults with disabilities in LTC. Results have been available to members of Independence Now Nova Scotia to utilize during advocacy meetings with public officials and health administrative boards. By working alongside an HRM organization, this study can help contribute to the advancement of age-appropriate health and health care policies in LTC within Nova Scotia.

Chapter 3 Summary

     Chapter 3 provides a detailed outline and description of the purpose for this research methodology, design, theoretical framework, methods, and ethical considerations for this study. Each stage of this research design contributes to the purpose of this study, which is to give voice to younger adults with disabilities by including them within the meaningful collection of data. To accomplish this goal this study applied a flexible qualitative description framework, allowing participants to share their stories visually and verbally with little interpretation required from the researcher. To achieve this, photovoice methods were paired with traditional interview techniques to provide participants with control over the information that was shared. Thus, photovoice techniques aimed to strengthen and compliment data gathered throughout interview methods. Based on the complexity of this research design, there were various ethical considerations to be recognized through accommodations to safeguard against potential risks for participants, LTC facilities, and all other persons that were affected by this study. Upon completion of the study, research results were disseminated to participants, LTC facilities, and made available through public presentations and peer-reviewed publishable manuscripts.

CHAPTER 4: RESULTS

Participant Characteristics

A total of eleven participants volunteered to share their perceptions and experiences of health and aging through in-depth qualitative interviews and photovoice. All eleven participants lived within one LTC facility selected for this study, which was located within Halifax Regional Municipality. As part of the phased screening process of recruitment, all eleven relatively younger adult participants fell within three age range groups from 31 to 40, 41 to 50, and finally 51 to 64. Of the eleven participants, one participant fell within the age range 31 to 40, four participants within 41 to 50, and finally six participants within 51 to 64. The average age of participants was 49, comprising three male and eight female participants. All participants self-identified with experiencing a disability and described experiences of their diagnoses including, but not exclusive to: Multiple Sclerosis; physical disabilities (i.e., quadriplegia, degenerative and/or genetic diseases); intellectual and developmental disabilities; and Cerebral Palsy. Participants had experience and identified having lived within the LTC facility for an average of three years, ranging from as low as one year to as high as eight years in LTC. To protect the identities of participants, detailed information for specific diagnoses of disability and number of years having lived in LTC were omitted from results. Rather, to provide context for the use of direct quotations of perceptions and experiences of participants, the following table presents participant characteristics including participant number, age, gender, and number of years having lived in LTC (i.e., grouped as 1 to 2; 3 to 4; and 5 or more). Throughout the results chapter, direct citations of quotations will include a participant number, age, and gender.

Table 1: Participant Characteristics

Table 1: Participant Characteristics

Participant #	Age	Gender	Years Lived in LTC
1	36	Female	(3 − 4)
2	46	Female	(3 − 4)
3	52	Male	(3 − 4)
4	49	Female	(1 − 2)
5	53	Female	(1 − 2)
6	52	Male	(5 or more)
7	43	Male	(3 − 4)
8	54	Female	(5 or more)
9	50	Female	(1 − 2)
10	60	Female	(1 − 2)
11	54	Female	(5 or more)

Presentation of Results

Interviews and photovoice methods were effective in uncovering an abundance of rich and detailed data on the experiences of health and aging for younger adults with disabilities in LTC. Data from participant interviews will be presented within three sections, as they are categorized according to the research question they address. Section one discusses the experiences and perceptions of health and aging of younger adults with disabilities living in a LTC setting. Section two discusses how these perceptions and experiences of health and aging are positively or negatively influenced by living amongst a relatively older population within the LTC setting. Lastly, section three discusses how the LTC environment supports negative and positive perceptions and experiences of health and aging for younger adults with disabilities. Data from interviews are further organized into emergent themes and sub-themes. In addition to answering three research questions, experiences and perceptions of health and aging for younger adults are applied to the first three levels within the social-ecological model including individual, interpersonal, and environmental level relationships. A summary of the social-ecological model will be presented to illustrate how data pertaining to each of the research questions fits within

each level of the model, and how the framework overall is used to characterize interconnected relationships between all three levels.

Thematic Structure Research Question One

Within research question one, five central themes emerged regarding the perceptions and experiences of health and aging of younger adults with disabilities: Perceptions and experiences of disability and health; aging as a state; aging as a process; fear of aging; and avoidance of aging discourse. Within these themes, participants described individual perceptions and experiences of health and aging separately, but also through interconnected ways. The themes and their associated sub-themes for research question one are presented in Figure 1.

Figure 1. Thematic Structure Research Question One
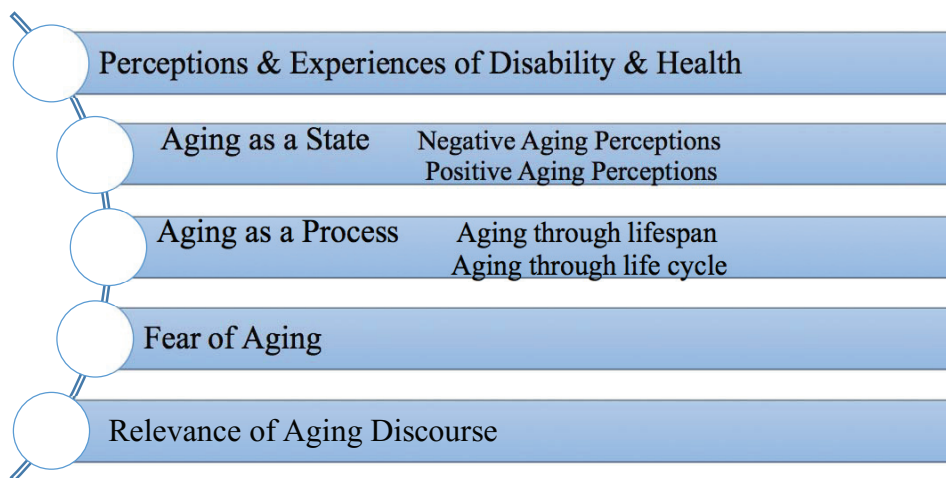
1. **Perceptions and Experiences of Disability and Health**

When asked to describe perceptions and experiences of health, participants simultaneously included perceptions and experiences of their disability through impairment. More specifically, participants discussed how their health and wellbeing were influenced by experiences of impairment. Although perceptions and experiences of health and impairment were

described as two distinct concepts, the discussion of one concept often proceeded to the discussion of the second through interconnected ways.

All eleven participants described perceptions and experiences of health through living with a disability. Participants began describing their experiences of disability through diagnosis and severity of symptoms. For example, multiple participants' experiences of M.S. were described as maintaining conditions of chronic pain, or decline in ability and mobility. Although experiences of diagnoses and severity of individual disabilities varied, each participant discussed the complex relationship between positive and negative perceptions and experiences of health through disability. For example, one participant's positive experience of health is described as, *"I'm doing really well, my doctor is blown away with how well I'm doing, like everyone is different. Some people are in a wheelchair in here if they have [diagnosis] and I can walk around and stuff"* (P07, 43, M). A second participants' perception of health and disability is illustrated as, *"what health means to me is… when people are sick, and when people have disabilities. That's what health means to me"* (P09, 50, F). Overall, participants' experience of a life-long impairment was reflected in their understanding of health and disability through complex and interconnected ways. Through experiences with a genetic disorder, Participant 4 described, *"health means a lot to me. It's very complicated thing to have. You have a lot of learning with your health, and with me, because of my disability and my health, I have to take it day by day"* (49, F).

Some participants (n=4), identified how experiences of health are influenced by living with a disability over time. For example, when discussing what comes to mind about health one participant described, *"disabilities, that's what comes to mind. What disabilities are going to get harder, what disabilities are going to stay the same"* (P09, 50, F). Overall, within this

understanding of health over time, participants described how their perceptions of health were influenced by knowledge of life expectancy for someone with their specific disability. Participants discussed their own perceptions and experiences of health and/or severity of symptoms based on knowledge of how one could expect to experience the progression of symptoms over one's lifetime. To illustrate,

> *"disability is a fact of life basically. Cause I know I'm going to get worse but I just take one day at a time… I know I'm 53 now, but getting up to 60 and 70 if I last that long because I've been told I have one to three years"* (P05, 53, F).

2. **Aging as a State**

Comparable to interconnected perceptions and experiences of disability and health, participants also described perceptions and experiences of aging through health. Similarly, perceptions and experiences of aging were understood independently from health; however, aging was discussed through connections to health status. Participant descriptions of various states of aging are broken down into two sub-themes including, negative and positive aging perceptions.

2. a. Negative aging perceptions. The majority of participants described aging through negative perceptions such as: decline; dementia or Alzheimer's Disease; and appearance of aging. To begin, perceptions of aging as decline were described through general characteristics of slowing down, going downhill, and having difficulty maintaining activities of daily life. For instance, one participant described aging as, *"you can't do stuff, when you get hurt it takes you longer to heal, and getting old you are slowing down and can't do things you could do before"* (P07, 43, M).

A second participant reflected upon similar negative perceptions of health and aging through decline by including a photograph of a wet floor sign. This photograph was described as, *"people are always warning you to 'be careful! Don't fall!' and you see those signs everywhere,*

like all the time. And I just thought it was important to show how you have to be careful when

you get older" (P10, 60, F).

Figure 2: Negative aging perceptions - Wet floor sign

Aging as a state of decline was described by perceptions of physical and biomedical

changes within older adults, as well as individual experiences of negative physical and

biomedical health changes. As described by Participant 9,

> *"when I found out last month when I went to my doctor, I found out I had a new health problem, and it made me think, now how many more am I going to gain, like health problems…, as far as I'm concerned, I feel that aging is very negative to begin. Because then there's your health. Your health is going to play a big part in aging"* (P09, 50, F).

In addition to decline, the majority of participants described how they perceived aging as a state

of dementia or Alzheimer's Disease. Many participants referred to dementia or Alzheimer's

Disease as a characteristic of older people, and a state one reaches in older age. As Participant 1

described,

> *"Getting older and praying to God you don't get dementia or lose your memory. I wouldn't like that… Yeah, I don't want to get older. Believe me, when I get older I do not want to have dementia. That would be crazy"* (36, F).

Beyond attributes of negative health status, participants also describe aging through

physical signs of appearance. When participants discussed aging, negative perceptions of

wrinkles, greying hair, and frail physique were commonly used as defining characteristics of

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older adults. For example, Participant 8 describes, *"I don't want the ego down. Your body is all wrinkled up, the grey hair, and you got no strength. You know it's a shame"* (54, F).

2. b. Positive aging perceptions. Although perceptions and experiences of aging were for the most part negative, participants also described positive perceptions and experiences of aging such as: leisure; loss of responsibilities; gaining wisdom; and defying age stereotypes. To start, many participants identified experiences of aging as part of leisure, and perceived older people have greater ability to enjoy daily activities. To illustrate,

> *"I think a lot of people that is older like me is starting to enjoy life more because they don't need the hassle of going out in a snow storm or going out in the cold. Or um, driving in the city on their own, or they can enjoy life more…they can get out and mingle with their friends. If they are in a home like this? They can still enjoy mingling with their family and friends. They can enjoy life. They can learn some more. They can see what happens in the future"* (P04, 49, F).

Positive perceptions of aging are also understood through experiencing loss of responsibilities. For instance, one participant described, *"well I suppose it's good not to have so many responsibilities anymore… Well when you raise children you have a lot of responsibilities. Like all the shopping, the cleaning, the cooking. Making sure they are safe, and taken care of"* (P10, 60, F). Further, positive experiences of aging were described through perceptions of gaining wisdom. As Participant 1 illustrates, *"well you get to learn everything you've learned as you grow older. Makes you smarter"* (36, F).

As participants identified many positive perceptions and experiences of aging, many participants identified how some older adults can defy social expectations of aging or of older people. When asked to describe being healthy in older age Participant 11 stated, *"I think it's just the health, I don't think it's aging, you can be ninety and still be in good shape"* (54, F). Participants generally identified that experiences of aging do not always exist through negative age perceptions, as illustrated by one participant as, *"I know the ladies are older than me, and I*

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think they've got more spunk that what I have. I think that's just what your body ends up feeling when you get older" (P11, 54, F). Overall, participants understood aging is not defined as a linear experience, and further described how people should expect to experience unique processes of aging influenced by their status of health. To illustrate, Participant 9 described aging as a complex and individualized experience, *"I find growing older could mean that everything could stay the same or everything can change. Like everything can change in a flash. Like it's different for everybody. Growing older is different for every person here"* (P09, 50, F).

3. **Aging as a Process**

Although perceptions and experiences of aging are understood through positive and negative representations, participants also described perceptions of aging as a process most individuals can expect to experience. Within this process, aging was generally described as part of one's lifespan, experienced from birth to death; and lifecycle, a continuous cycle from infancy to old age and reverting to an infancy-like state.

3. a. Aging through lifespan. Many participants described aging as an inevitable process of living that people can expect to experience over their lifespan. Participants discussed aging over one's lifespan through either positive or negative perceptions, and also described how individual experiences are unique for everyone. To illustrate, one participant described aging through the lifespan as,

> *"I mean, you know you can't stop being old, cause if you stop being old then you might as well stop living... That's part of life, that's part of who you are. That's part of the cycle that you have"* (P07, 43, M).

Aging over one's lifespan was also perceived as an experience of living another day. Participant 8 described, *"well every day, or every time you have your birthday, you are getting older. That's the way I look at it. Um, age is just another day"* (54, F).

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Aging was also described across the lifespan as a process characterized by chronological age. When describing aging across different stages of life, chronological age was used as an indicator of reaching age specific milestones. To illustrate, one participant characterized aging as an experience of reaching birthday milestones,

> *"well, like I said, you are going to get old down the road, you can't help that. You know the grey hair and the wrinkles, and ugh, that's facing the facts. I mean, like I said I'm going to turn 55. But that's not like 80 or 100. But I mean you got to face it, someday maybe soon or later you are going to get old… [I feel] young, and when I get up to 80 or 90, I don't think 90, but um, I will think back I had a good life"* (P08, 54, F).

3. b. Aging through lifecycle. Although aging was understood across one's lifespan, aging was also described through lifecycle; one continuous cycle from infancy to older age, and from older age reverting to experiences of infancy. Aging through lifecycle was discussed through distinction of experiencing a second childhood, with perceptions of older adults becoming infantilizing. Participant 10 describes the experience of seeing older adults re-enter infancy as, *"I see it as a lot of people going into second childhood. And that's why I thought the diapers were significant"* (60, F). To illustrate, Participant 10 included the following photo,

Figure 3: Aging through lifecycle – Diapers
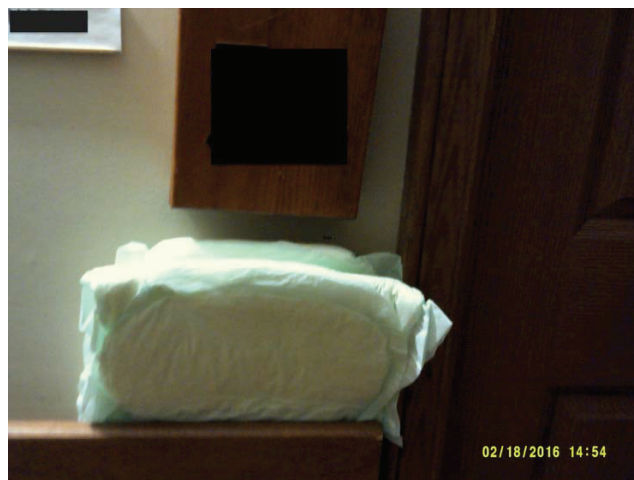
Other participants attribute aging through lifecycle as the return of poor health experiences from infancy to when one reaches older age. To illustrate, one participant described

her fear of experiencing aging by returning to similar experiences of poor health she can remember during infancy,

> *"I haven't been able to move since I got back and being in the hospital is another thing. That's another form of aging I think… because I feel myself when I was younger, I was in the hospital a lot and it goes through my mind is that going to happen as I get older? I'll be in the hospital more or what? I'll go right back to the beginning… But I just hope it doesn't start all over aging when I hit my 60s, cause it's scary"* (P09, 50, F).

4. Fear of Aging

Although positive perceptions and experiences of aging were discussed, overall negative perceptions and experiences of aging led to discussion of fear towards aging. Fear of aging was mainly described through perceptions and experiences of illness, disease, and death. Participants described feeling scared and fearful of their own experiences of aging leading to death. One participant illustrates, *"So, it's hard growing older, it really is, and it's scary too… cause as you grow older you get closer to dying. And that's pretty scary. But anyways, it's going to happen anyways"* (P09, 50, F). Fear of aging was also described interchangeably with worsening health conditions, *"makes me scared, cause I know I'm going to get older. There's not much I can do about it. I have birthdays so. I take every day one day at a time cause I know I'm going to get worse cause every year since I've had [diagnosis] I've eventually got worse"* (P05, 53, F).

Overall, discussions of fear towards aging could also be understood through uncertainty and unknown expectations of aging. Several participants discussed fearful perceptions towards aging based on lack of knowledge towards what to expect as they age. As illustrated by one participant,

> *"as I grow older I would like to keep up to date on changes, and what happens as you get older and…like I know none of that, and that scares me. That I don't know what to look for getting older… people should talk about it more, people should have a little understanding with each other"* (P10, 60, F).

5. Relevance of Aging Discourse

Following perceptions and experiences of fear towards aging, participants described aging as having little relevance to their experiences or self-perception as a younger adult. Several participants (n=5) described having rarely discussed aging or typically avoiding these conversations with other LTC residents. Younger adult participants also described not having given the topic of aging much thought, based on their identity as younger and youthful in comparison to the older population in LTC. For example, when asked about perceptions of aging one participant described, *"no, I haven't given it much thought"* (P02, 46, F). A second participant said, *"no, I always thought I was going to be young"* (P04, 49, F). Additionally, when asked whether aging is a topic of discussion, one participant described, *"no, cause I find a lot of people don't want to talk about it. Like a lot of residents don't want to talk about getting older, and even the staff. I feel they don't want to talk about it"* (P09, 50, F). Lastly, the perceived irrelevance or avoidance of aging was discussed when participants described the unlikeliness of reaching a chronological age where they would experience aging and thus avoid thinking about it. This is illustrated by one participant as, *"I don't think about growing older. Because um, of the people around me, they are old. The average is 90. I won't make it to be 90… so yeah, I don't think about growing older"* (P02, 46, F).

Thematic Structure Research Question Two

Within research question two, participants described how interpersonal relationships influenced their perceptions and experiences of health and aging. Following individual perceptions and experiences of health and aging, participants described positive and negative relationships with older residents and family; and how these relationships shaped what they think and feel about health and aging. The themes and their associated sub-themes for research question two are presented in Figure 4.

Figure 4. Thematic Structure Research Question Two

Relationships with Older Residents
- Negative Perceptions and Experiences
- Positive Perceptions and Experiences

Relationships with Family
- Negative Perceptions and Experiences
- Positive Perceptions and Experiences
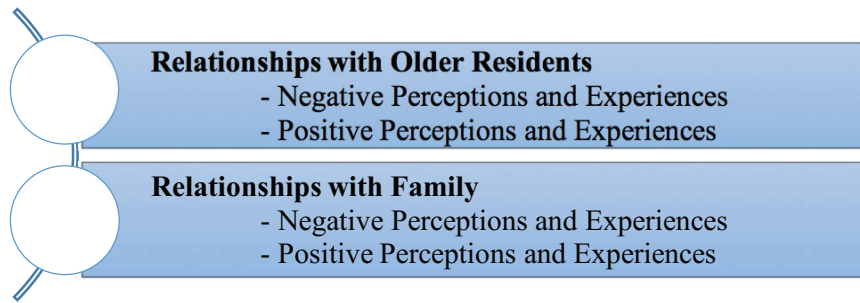
1. **Relationships with Older Residents**

When asked to describe perceptions and experiences of health and aging, participants discussed interpersonal relationships with older residents. Participants discussed how living amongst older adults and sharing relationships shaped their individual perceptions and experiences of health and aging. Characterizing these relationships, two sub-themes emerged as negative and positive perceptions and experiences.

1. a. Negative perceptions and experiences. Many participants described how relationships with and/or living amongst older residents experiencing poor health influenced negative perceptions of health and aging. Participants described how seeing older residents experience activities of daily living, such as taking medication during meals, negatively influenced what they thought about health and aging. Through experiences living with older adults, negative perceptions of health and aging are described by one participant as,

> *"well I see some people take more pills but I don't really take a lot of pills. I just take one pill in the morning. And I see a lot of old people take a handful of pills. And then I see what they are dealing with later on in life and I'll probably have to deal with too cause I'm a smoker. So I do want to keep up cause I don't want that to happen"* (P07, 43, M).

Overall, some participants discussed what they think and feel about their own health and aging has been influenced by seeing negative experiences of health amongst older residents over time. As Participant 9 states, *"there are a lot of people here I became friends with, and just*

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watching them grow older it's hard for me to know if I'm going to be as easy as they are or

harder" (50, F).

While living amongst an older population participants discussed what they think and feel towards seeing dementia or Alzheimer's Disease. For example, one participant describes how her friendship with two older residents experiencing Alzheimer's Disease has negatively influenced her perception of health and aging. To illustrate,

> *"Since I've been around these two women I find that it has shown me a very scary thing of growing older. Just knowing I could lose my memory. And when I have the health problems I have already it can make a big difference in life. So, I wouldn't really want to develop what they have"* (P09, 50, F).

From living amongst an older population, participants discussed negative perceptions of health and aging through seeing older residents experience declining health over time. Participant 1 described her negative experience of seeing declining health amongst older residents as, *"Yeah, I don't like seeing it because I know for a fact when a resident gets sick and they are sick for a long time. That tells me they are on their way out. Which is scary"* (36, F). Interpersonal relationships with older residents were also described as, *"one thing that upsets me is seeing old people fall. That upsets me. And when you get old, when you get up to 80 or 90 that's when you lose your balance and you fall. And that's a damn shame"* (P08, 54, F).

Beyond progression of declining health, participants described negative perceptions of health and aging when experiencing older residents pass away. As participants developed relationships with older residents they described how difficult it became to think about the number of older residents that would die in LTC. To illustrate, Participant 9 described, *"being here and seeing all these people that are older. I know they are all going to die off on me. And that scares me. I've already lost four friends here"* (50, F). Participants also described how living amongst older residents, typically moving into LTC at the end of their life, influenced how

they felt about developing relationships. When asked to describe how they felt living with older

residents, Participant 10 said,

> *"Oh, I mind it. I'd rather be with younger people. I mean when you stop and think about the*
> *reality of it. Oh, my best friend is ninety-eight years old. They could die tomorrow you know!*
> *Like it's not a good idea to make too close of an attachment with these people"* (60, F).

Negative perceptions of health and aging were also described through self-reflection

when participants described fear of sharing similar experiences of aging as older residents.

Participants described seeing stereotypical images of older residents in LTC and feared they

would become a similar image of older residents as they age themselves. As described by one

participant,

> *"When I see people just sitting in their wheel chairs looking around and talking about this*
> *one and that one. And saying well jeez I should be that or looking like that or looking like*
> *this. And I'm laughing at myself because I'm thinking you guys were like me when I was*
> *young. And when I sit down I am thinking to myself I am going to be like these guys when I*
> *am going to be older"* (P04, 49, F).

Perhaps out of fear or apprehension, participants described how they shared little in

common socially with older residents. Through negative perceptions of interpersonal

connections with older residents, many participants described experiencing negative social

interactions. To illustrate, *"it's too hard for me as the younger generation to talk to these people*

because I don't know what to say to them. I don't know how to interact with them" (P04, 49, F).

Overall, participants described having few friends or relationships with older residents, and

found it difficult to engage in meaningful age appropriate conversation. As described by one

participant, *"yeah, I have a lot more in common with friends that are younger. Now with a forty-*

year age gap the conversation is minimal. So, you just go through the pleasantries" (P02, 46, F).

A second participant illustrates, *"yeah cause the way I talk with younger people or people my*

age compared to older people, I can't talk as much. Um, well I talk about certain things like sex

or whatever that I can't with the older people" (P05, 53, F).

From these negative perceptions of living with older residents and a lack of interpersonal connections, participants described what they thought about living with residents closer in age. As described by one participant,

> *"if I lived with younger people I think the noise level would be greater, and there would be more laughing, more conversation. I think that would be good. I have nothing in common with someone years my senior, so you just talk about the weather, simple things"* (P02, 46, F).

Perceptions of health were also described as being influenced by living with older residents versus residents closer in age to participants. Participant 5 described, *"when we carry on with young people, you find your health gets better. I find that anyways. The older people I find I get along with better in my strategy are funny and carry on and stuff like that"* (53, F).

1. b. Positive perceptions and experiences. Although interpersonal relationships are largely negative, participants also described how relationships with older adults positively influenced perceptions and experiences of health and aging. Living with older residents helped to reveal that health and aging are not always defined through negative experiences. Seeing positive experiences of health and aging are illustrated by one participant as, "*like I see a lot of healthy people that are older and they can get up and go around*" (P11, 54, F).

Participants also described how positive relationships while living with older residents influenced what they think and feel about living in LTC. Positive experiences of living with older residents were characterized through enjoyment of activities and friendship. One participant described:

> *"when her and I get together and we go for a cup of tea downstairs, we go for walks downstairs, we talk about people. And when she gets angry and mad, I'll talk to her about it. And like we complement each other, I know she is older than me but we do a lot of complements to each other"* (P04).

In addition to enjoyment of daily activities with older residents, participants also described how they felt when socializing with older residents. When asked to describe how they felt socializing with older residents Participant 8 stated, *"I love talking to people. I socialize a lot and the stories*

they can tell you, it's unreal. I mean imagine your grandfather telling you a story. Yeah, it's

great" (54, F). Although relationships were described through experiences of companionship,

many participants described how their relationships with older residents became an experience of

living with family. To illustrate, Participant 4 described:

> *"do I want to live anywhere else but here? No. Because I wake up every morning and I see*
> *my family. I see all the people that live here are my family… There's a lady, she's in her*
> *eighties, she's a spitfire. She is comical, she is funny, she's my leaning board. If I need*
> *something, or someone to talk to, other than my mom on the phone. I go out and talk to her*
> *and we laugh, we cry, and we say things that not normal people say [laughter]. And she*
> *keeps me going because of her, of her disability and her well-being. She keeps me going*
> *big time"* (49, F).

A second participant also described his experience of living with older residents in LTC as his

support system, *"cause I ain't have no family that bother with me ever since I've been here. So*

ugh, I have more friends then" (P03, 52, M). To illustrate further, Participant 3 continued to

describe his positive relationships with older residents as:

> *"oh I am social with all these people. There is a hundred and one or hundred and three-*
> *year-old woman over there, I always talk with her every day and make her laugh. I said*
> *how's my new mother? And I had her laughing today, I said you know this was adopted,*
> *this is my birth mother now? I had them laughing their heads off over there"* (52, M).

2. Relationships with Family

In addition to relationships with older residents, relationships with family emerged as a

central theme for research question two. Beyond relationships shared within LTC, participants

discussed how relationships with family outside of LTC influenced what they think and feel

about health and aging. Two sub-themes emerged as negative and positive perceptions and

experiences of health and aging.

2. a. Negative perceptions and experiences. Several participants described how their

relationships with family negatively influenced perceptions of health and aging. Based on a

family member's negative experience of health, participants discussed how relationships with

family negatively influenced what they think and feel about health and aging in LTC. For

example, negative experiences of family members living with dementia or Alzheimer's disease

contributed to negative perceptions of health and aging while living amongst older residents with

dementia or Alzheimer's disease. As described by Participant 6,

> *"I think the thing is, I looked after my wife's grandmother when I was living in the States*
> *and she had dementia really bad. And she ended up dying a couple years ago. And I just*
> *don't want to see anybody in that state and I don't want to be in that state. It's too hard to*
> *care for"* (52, M).

A second participant also described how negative experiences with her grandmother

experiencing Alzheimer's disease influenced how she thinks and feels about her own processes

of health and aging, *"Believe me, when I get older I do not want to have dementia. That would be*

crazy. My grandmother, she has dementia and Alzheimer's. I called my grandmother and she

goes I'm a grandmother but I'm not your grandmother! She totally forgot" (P01, 36, F).

In addition to experiences of dementia or Alzheimer's Disease, participants described fear

of experiencing similar negative health conditions as family members. How participants felt

about their own health and aging were negatively influenced by seeing negative experiences of

health as family members grow older. For example:

> *"I'm scared I'm going to be just like her because of all these health problems that she had. I*
> *was not an alcoholic but I did a lot of things, and a lot of things have happened to me, and*
> *now that I am going to be 50 I am not looking forward to as I am getting older because of her*
> *health, her well-being"* (P04, 49, F).

2. b. Positive perceptions and experiences. In contrast to negative perceptions and

experiences, participants also described positive relationships with family. When describing

experiences of living with older adults, participants often discussed positive experiences of

health from memories doing similar activities with family. Positive relationships with family

were described as having a positive influence on the perceptions and experiences of health for

participants in LTC. To illustrate, one participant described how the experience of doing puzzles

in LTC reminded her of the relationships she shared with her mother, along with the positive

memories of doing puzzles with her mother. Participant 9 illustrates her positive experience of

health by doing puzzles and how this fond memory highlights a positive relationship she shares

with her mother:

> *"It sort of has a lot of different things, doing puzzles does. It calms you down, it relieves the stress, it gets your mind off things. I've enjoyed them all my life and it reminds myself of my mother, when I was stressed out we would sit down together and do a puzzle together. Even though we are in two different age brackets, we enjoyed doing puzzles together"* (50, F).

Figure 5: Positive Perceptions and Experiences – Puzzles

In addition to positive activities with family, participants described how positive memories

eating with family influenced positive experiences of health while living and eating in LTC.

Participants described how eating comforting meals influenced their positive perceptions of

health while living in LTC. For instance, one participant described positive perceptions of health

based on a memory of her grandmother making a healthy meal of soup, salad, and sandwich. As

illustrated:

> *"Well I remember my grandmother um, when I was younger my grandmother always made soup and sandwiches, and I remember every once in a while she would make salad, she would toss salad. I can still remember those days cause I can remember sitting in her little house and eating sandwiches while she was making the salad or eating the salad while she was making the sandwiches. It makes me feel like they care enough to do meals like this, make meals like this"* (P04, 49, F).

Thematic Structure Research Question Three

Within research question three, participants described how the environment of LTC influenced their perceptions and experiences of health and aging. Following individual and interpersonal perceptions and experiences, participants described how the environment of LTC influenced what they think and feel about health and aging. Two central themes emerged as environmental characteristics supporting negative health and aging, and environmental characteristics supporting positive health and aging. These themes and their associated sub-themes for research question three are presented in Figure 6.

Figure 6. Thematic Structure Research Question Three

Environmental Characteristics Supporting Negative Health and Aging
- Aging in institutional care
- Loss of privacy
- Inconsistencies with staff

Environmental Characteristics Supporting Positive Health and Aging
- Benefits of LTC programs
- Receiving care
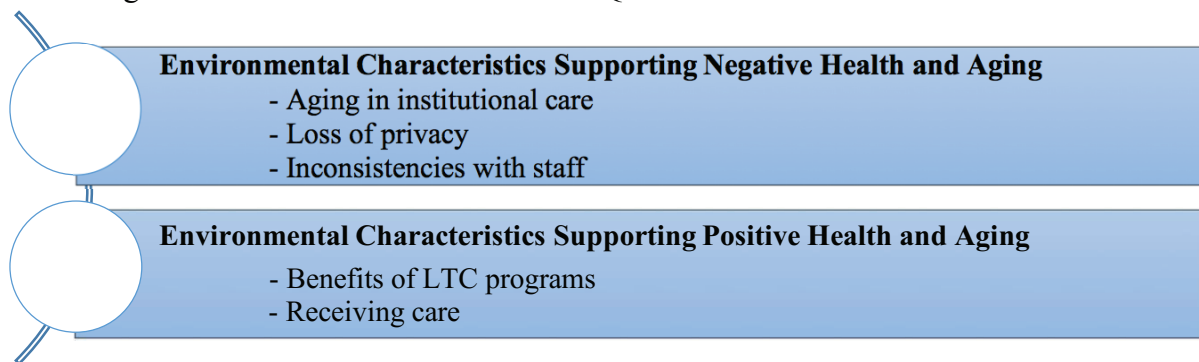
1. **Environmental Characteristics Supporting Negative Health and Aging**

When asked to describe perceptions and experiences of health and aging, participants described negative characteristics of living within the environmental of LTC. In addition to individual and interpersonal levels of health and aging, participants discussed how experiences of living in LTC negatively influenced what they think and feel about health and aging. Characterizing these environmental relationships, three sub-themes emerged as: Aging in institutional care; loss of privacy; and inconsistencies with staff.

1. a. Aging in institutional care. Living within an environment characterized

by a largely older population was described by participants through largely negative perceptions and experiences of health and aging. Many participants discussed LTC as an environment where people go to die, and how this influenced negative perceptions and experiences of health and aging within institutional care. To illustrate, Participant 2 described:

> *"It's dismal. I'm just treading water it feels. It feels like I'm just waiting to die like everybody else. There is no ... at the last stop and it's saddening. You see so many people pass away. I went out one day last week and one of the residents died at my table. That's upsetting to see. Because that's where we are all heading. So now we've got a conveyor belt happening. And you know this is the last stop"* (46, F).

Although some participants clearly identified how the LTC environment influenced negative perceptions and experiences of aging, other participants faced challenges trying to describe this complex experience. For example, one participant described:

> *"When I'm in the mood to talk to younger people and carry on with them. Like, older people don't bother me but it's just, it's like an environment that I don't like to be in. I mean it's not that it bothers me, but it's just, you feel the different environment so, don't get me wrong I don't mind older people. But it's just sometimes it's not feasible"* (P05, 53, F).

Through identifying negative perceptions of aging within LTC, participants also described how LTC was organized and why it was created as an institution of care. Participants shared how LTC was structured and created for older residents through examples of having limited access to kitchen amenities or private bathrooms with bathtubs. Overall this led participants to understand how the environment was contributing to negative perceptions and experiences of health and aging. As described by one participant:

> *"They don't really have it organized for younger people cause when they put the place together and made their policies and so on they were thinking of older individuals. Now when you are trying to come up with ideas on how to entertain someone who is 90 years old and not able to feed themselves, it's going to be completely different than somebody like me"* (P10, 60, F).

Within discussion of the structure of LTC, participants described negative perceptions and experiences of health and aging through programing. As participants discussed programming within LTC, it was described how certain activities, such as bingo or dances, negatively

influenced their perceptions and experiences of health and aging. An example of negative

perceptions of aging through experiences participating in LTC programming was described as:

> *"We go to the dances, but the music they play is so old. It is depressing. It makes me feel*
> *like I am really old already. Cause the music they play is old music. They need to play*
> *some young music something in the millennium. So, it just depresses me, I tend not to go*
> *down to the dances anymore"* (P02, 46, F).

Participant 2 also included a photograph to represent her negative experiences going to

dances, as shown in Figure 7.

Figure 7: Aging in institutional care – Old music

A second participant shared a similar negative experience of going to the dances and listening to

music:

> *"When they have their dances and their musical presentations and so on I find that it's*
> *geared more towards the older people. And it's not music that I want to listen to. They've*
> *got a thing up now for the swinging 60s. I was a little girl in the 60s. I didn't start listening*
> *to music until the 70s and they don't do that. They don't play that kind of music"* (P11, 60,
> F).

In addition to negative experiences and perceptions of programming within LTC,

participants that had lived in LTC for five or more years described how their negative

experiences progressed over time. As illustrated by one participant, "*But when I got here I loved*

it, I thought wow this place is great. I moved from floor to floor. And ugh, it just was very nice. When you are being here for five years you get kind of sick of it, I think. You need to see the outdoor life (P08, 54, F). Represented through a photograph in Figure 8, one participant described how their negative experiences and perceptions of health and aging were influenced by living within LTC over time. As described, *"we don't do nothing on this floor anymore. Nope. I just sit in my room more or less. You either sit in your room or, the only time you get out is if you go yourself. They had one worker one time tell us to go back to our room"* (P11, 54, F).

Figure 8: Aging in institutional care - Boredom
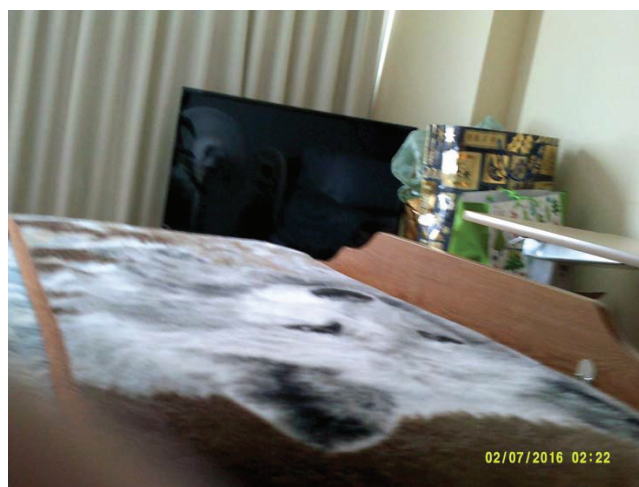
1. b. Loss of privacy. Within the environment of LTC, participants commonly discussed how they felt a loss of privacy upon moving in. Although participants discussed how LTC was created and organized to support older residents, they described how their perceptions of health and aging were negatively influenced by losing all sense of privacy. As one participant described living in LTC, *"it stresses me out! I'm like get out of my room! I'm like can I have any quiet time for myself and every single time I shut the door someone is knocking on the door. And they go, Oh, are you ok? And I'm like, I'm fine, leave me alone"* (P01, 36, F). A second participant described their loss of privacy with older residents in LTC as, *"and then when you have*

somebody that won't stay out of your room, they are always in your room, this person is. Like

last night she walked in on me when I was half naked, which becomes very frustrating, so it's

hard to get through to her" (P09, 50, F). As represented through a photograph of a mechanical

bath lift, one participant described their negative experience of being seen naked by staff as a

complete loss of privacy.

Figure 9: Loss of privacy - Bath lift
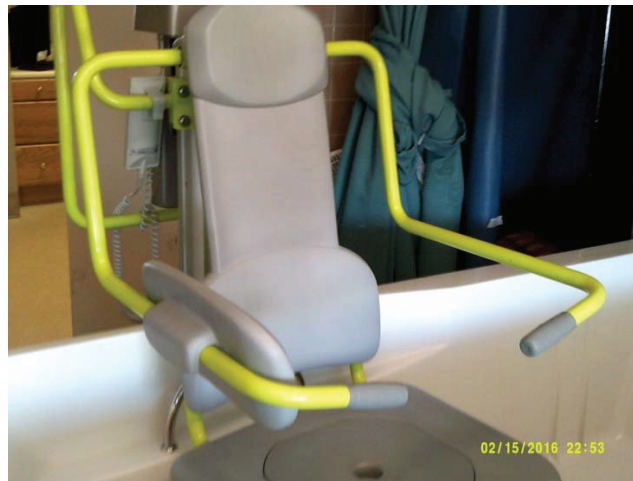
As represented by this image above, Participant 10 described:

> *"I wasn't even 60. I can give myself a bath for crying out loud. I don't need three people attending me in the bathroom. I didn't have a lot of privacy when I first moved in. Somebody walks in, opens my door and stands there to talk to me, watching me on the toilet. I just closed the door I was so disgusted. You know it's my room, right? That's what they keep telling me. But they don't treat it as such. They are getting there now, they are starting to understand that I like my privacy cause it upset me to bad one day I cried all day"* (60, F).

1. c. Inconsistencies with staff. In addition to characterizing institutional care,

participants described how inconsistencies between LTC staff influenced negative perceptions

and experiences of health and aging. As part of living and receiving care within LTC,

participants described how their perceptions and experiences of health were negatively

influenced by staff. As described by one participant, *"Well living here can be very interesting*

and it can be very frustrating. It just depends on what goes on each day. Like the group that's on

today I find it very hard with the staff working, I can't always get the help I need. Now on the shift tomorrow I can get the help I need" (P09, 50, F). Through these negative perceptions and experiences with staff, some participants described how they would avoid specific staff working. As described by Participant 3, *"nope I don't bother with them too much. I just stay in my room and go downstairs. Some of them are ok. Some I don't get along with right? Yup. I always thought that, I found some of them were mean"* (52, M). Overall, negative perceptions and experiences with staff led participants to describe how their health within LTC was negatively influenced. As illustrated by Participant 2, *"there are a couple I don't care for. I call them the necessary evil. They've been here the longest. So, we need to get them taken out and new staff put in place. Yeah, the longevity of somebody working at [LTC] um, leaves them to be more callous and less sympathetic to your needs"* (46, F).

2. **Environmental Characteristics Supporting Positive Health and Aging**

Beyond these negative perceptions and experiences in LTC, participants continued to describe positive perceptions and experiences of health and aging within the environment of LTC. Of these positive perceptions and experiences, two sub-themes emerged; Benefits of LTC programs; and receiving care.

2. a. Benefits of LTC programs. Within LTC environments, participants discussed how their experiences and perceptions of health and aging were positively influenced by recreational programs. Being provided something to do was discussed by participants as, *"they always have something going on. Like they have bowling, they have the young generation group, which I really like because it is with people around my age. And they have a lot of activities go on here. It's up on my wall and I go to a lot of them"* (P09, 50, F). Positive perceptions and experiences of health through LTC programming were represented within photovoice as enjoyment of

weaving, illustrated in Figure 10.

Figure 10: Benefits of LTC Programs - Weaving
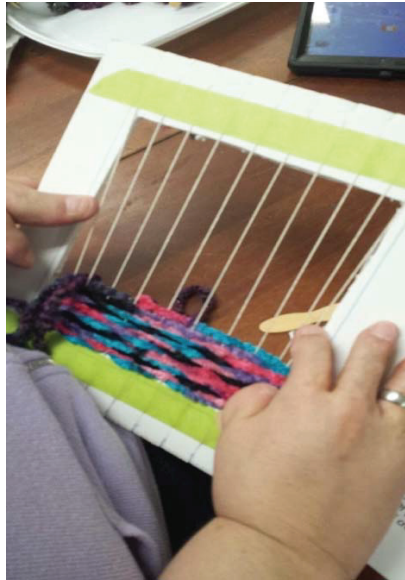
Participant 4 included this image to discuss how LTC programs positively influenced her

perceptions and experiences of mental health over time. To illustrate:

> *"they are good for your mental health because you are out and among friends and laughing a lot and talking to people and you are healthy, in a healthy way. And plus, emotional health is very good as well because it makes you happy and makes you feel good when you do crafts or listen to music"* (49, F).

LTC programs and activities were also described to have a positive influence on the experiences

of physical health for participants. One participant represented their positive experience of health

and aging through a photo of the gym in LTC.

Figure 11: Benefits of LTC Programs – Going to the Gym

Figure 11: Benefits of LTC Programs – Going to the Gym
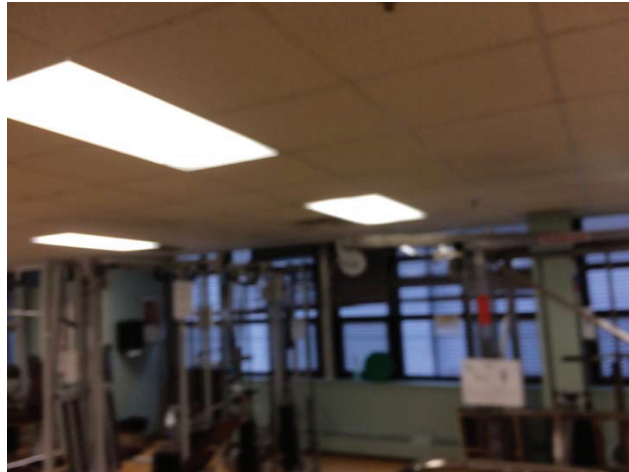
As further described, *"one thing I do well is I go to the gym and I go to Tim Hortons every day. Every morning. And it's positive, I do it to build muscles. I do enjoy going to the gym"* (P07, 43, M). While living within the environment of LTC, participants described the importance of having programs and services available without leaving the building. As illustrated by one participant, *"yeah, it improves my health when I can go down to the hairdressers. It's a positive image, it gives me independence"* (P02, 46, F).

      2. b. Receiving care. As part of living and receiving care within the environment of LTC, many participants described how receiving care influenced their positive perceptions and experiences of health and aging. When describing positive experiences of receiving health care, participants discussed how they felt comfortable within the environment. Represented through a photo (omitted from results due to identifying information) of one participant's room, she described, *"and you know different things like that are meaningful to me. And when I'm in my room I don't feel like I am in a hospital or in [LTC Institution Name]. I feel like I am in my room, like this is my home. This is what I feel comfortable with. If I didn't have all this surrounding me I'd be miserable so"* (P04, 49, F). Participant 4 continued to describe overall general experiences of living and receiving care in LTC as, *"sometimes being here at [LTC Institution Name] can be*

very challenging at times because we don't have a whole lot to deal with. But, yet it can be a

blessing at times because we have a lot of good staff that deals with it" (P04, 49, F). Living in

LTC was also experienced positively as, *"everything we need is right here, so I think it's the best*

place for me to be. Yeah, [LTC Institution Name] has most of things going on. You can go to the

bank, you can go shopping" (P02, 46, F). Overall, positive experiences of receiving care and

living in LTC for younger adults were largely generalized through perceptions and experiences

of health as, *"well I think this is a good place to be if you have a disability. Like people are here*

to take care of you. So, that's a good thing about being in here, you can get help" (P01, 36, F).

Summary of Results within Social-ecological Model

Throughout the detailed account of results in this chapter, data pertaining to each of the

three research questions provides rich description of the individual, interpersonal, and

environmental perceptions, experiences, and contexts of health and aging for younger adults

living in LTC. For research question one, data represented the individual level perceptions and

experiences of health and aging for younger adults. Although health and aging were defined

through largely negative perceptions and experiences, the relationships between and among these

constructs were complex and interconnected. For research question two, data represented how

the interpersonal level relationships between participants and older residents and family

members influenced the perceptions and experiences of health and aging for younger adults.

Through these relationships understandings of health and aging emerged as complex constructs,

interconnected with both negative and positive perceptions and experiences. Lastly, for research

question three, data represented how the environment of LTC influenced the perceptions and

experiences of health and aging for younger adults. Participants shared how living within an

institutionalized environment, represented through environmental factors and characteristics, influenced their perceptions and experiences of health and aging.

Overall, data within each research question contribute to multiple levels within the social-ecological model, representing important and complex relationships of health and aging. Data pertaining to the levels within the social-ecological framework contribute to a system of relationships that exist in a bottom up and top down direction. For example, when participants described interpersonal relationships with older residents, they simultaneously included how the environment helped to shape these relationships, further influencing individual level perceptions and experiences of health and aging. Figure 12 represents this network of relationships, as illustrated through separate yet connected levels within the diagram. Although data within each level represented a different relationship, each level does not exist in isolation, and is influenced by the relationships within and between each level.

Figure 12: Social-ecological Model
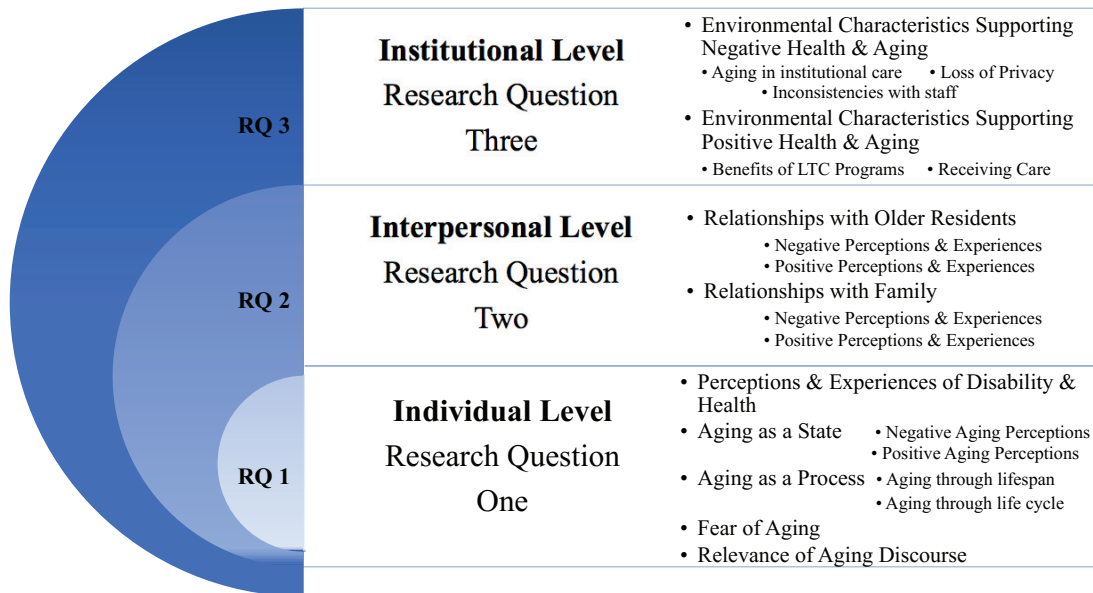
CHAPTER 5: DISCUSSION

Introduction to Discussion

The following chapter will discuss how major findings within the results contribute to the overall objective of this research study, which was to explore the perceptions and experiences of health and aging among younger adults with disabilities living in LTC. The discussion of findings will be organized similar to the presentation of research results, structured within three research questions, three levels of the social-ecological model. The use of the social-ecological model has shown to be an effective framework to represent the complex processes of health and aging for younger adults in LTC who participated in this study. This study considered the relationship within and between individual, interpersonal, and environmental level factors; and how these levels operate from bottom-up and top-down directions. Provided the complexity of these relationships, the social-ecological model provides a useful framework to organize and understand results within various perspectives of existing literature, which will be discussed in the following three chapter sections.

Discussion of Findings

Research question one: Individual level perceptions and experiences. Individual level perceptions and experiences of health and aging revealed findings that were anticipated based on review of the extent literature. Overall negative and positive perceptions and experiences of aging were consistent with previous research that represents predominately negative age perceptions of younger adults (Levy 2003; Meisner & Levy, 2016). The discussion of aging through positive or negative stereotypes indicates younger adults understand processes of aging that are consistent with negative conceptions of aging, such as frailty and decline, along with positive conceptions of aging, such as gaining wisdom as well as leisure time and activities in

older age (Levy, 2009). Although age perceptions and experiences were predominately negative, participants also included discussion of positive aspects of aging. How participants understood age stereotypes is consistent with research exploring how perceptions of older adults are comprised of both positive and negative traits (Cuddy & Fiske, 2002).

While perceptions and experiences of health and aging were consistent with previous literature, this study adds to existing research by contextualizing health and aging through perspectives of disability discourse. Although diagnosis of disability does not define lived experiences for younger adults' (Spassiani & Friedman, 2014), experiences of impairment through limitation in daily activities were key factors influencing individual perceptions and experiences of health that ultimately linked to perceptions of aging. For instance, participants discussed how their experiences of poor health and impairment influenced how they perceived what their processes of aging would be over time. Processes of aging for people experiencing disability have gained interest as topics of research, given that people with disabilities can expect to live longer with a higher quality of life than observed in previous generations (Ouellette-Kuntz et al., 2015; Spassiani et al., 2016). Results from this study begin to explore what younger adults think and feel about their health and aging are linked to their experiences of health and aging. As existing research focuses predominately on biomedical conditions of aging with a disability (Haveman et al., 2010; Krahn et al., 2006), this study demonstrates how younger adults' perceptions of their health and aging are also important when evaluating how younger adults perceive what current and future experiences of health and aging will be. A comparison between positive and negative participant experiences of impairment were interconnected with what they thought and felt towards their own processes of health and aging. Participants with a relatively positive perception of their health and disability spoke more positively about aging, and what

they anticipated experiences of aging would be. Examples of self-perceptions of health and aging were found within results from Participant 3, 7, 9, and 10. These observations of self-perceptions within health and aging are not new, as these concepts are evident throughout research exploring internalization of self-perceptions of aging (Levy, 2003; 2009). Additionally, this study represents similar findings to that from Burke at al., (2014) that indicate when older adults with I/DD perceive aging positively, they also give high ratings of personal health. The present study contributes to the discussion of existing evidence linking how one thinks and feels about their processes of aging earlier in life influences how individuals experience aging in later life (Levy, 2003; 2009).

Interestingly, beyond constructs of health and aging through the life span, participants also described perceptions and experiences of aging through lifecycle. Lifecycle was understood as returning to similar experiences of infancy as one reaches older age. Compared to the life course, fewer studies have explored aging through the lifecycle perspective (Grassman, Holme, Larsson, & Whitaker, 2011). Participants conceptualized this explanation by reflecting upon experiences of poor health in younger age and fear of continuing to experience similar negative status in older age. Concepts related to aging through lifecycle are known, such as theories of infantilizing older adults (Marson & Powell, 2014); however, research has not yet fully explored how perceptions of aging change over time. Given research has explored how perceptions of aging influence behavioral and physiological health outcomes (Meisner & Levy, 2016), experiences of time outlined by the chronosystem, provides a new approach within stereotype embodiment theories of aging.

How perceptions and experiences of health and aging at a younger age can influence health outcomes in later life can be represented through the chronosystem within the social-

ecological model (Neal & Neal, 2013). The chronosystem underlies how social-ecological systems (i.e., individual, interpersonal, and institutional) change over time, contributing to different patterns of relationships within and between each level of the social-ecological framework. Applications of the social-ecological model most often characterize complex relationships at one point in time however, the chronosystem reflects patterns of change within and between each level of the framework over time (Neal & Neal, 2013). Therefore, what younger adults think and feel about their health and aging was understood through the social-ecological model as a snap shot in time. While this study captured individual experiences of younger adults at one moment in time, it was evident younger adults' perceptions and experiences of health and aging were affected over time through patterns of change within individual, interpersonal, and institutional relationships. Research has yet to apply a longitudinal approach of understanding how perceptions and experiences of health and aging are affected over time. This study indicates, in terms of study design, the importance of exploring how multiple levels within the social-ecological model interact to affect change within individual level experiences over time.

　　　　Research question two: Interpersonal level perceptions and experiences. Through interpersonal relationships, perceptions and experiences of health and aging continued to be discussed in complex and interconnected ways. The findings included detailed examples of the relationships younger adults shared with older adults, providing context to why they understood health as sometimes independent from aging. By seeing older residents in their 90s continuing to be in 'good shape', younger adults understood people can be in good health at an older age. Through interpersonal relationships, younger adults learned processes of health are independent from aging, and experiences of aging are not inextricably linked within negative stereotypes.

Characterizing perceptions and experiences of aging as an individualized process, rather than through generalized and predominantly negative age stereotypes, is not a new finding (Lehmann et al., 2013; Janicki et al., 2002). While this study supports previous research that identifies health and aging as individual processes, it was unexpected interpersonal relationships would exist as a facilitator for deconstructing younger adults' perceptions of age stereotypes.

An interesting finding indicated how younger adults shared a deeper understanding of positive perceptions of health and aging through relationships with older residents. Based on the extent literature and the pervasive negative representations of older adults in the environment of LTC, it was expected younger adults would provide mostly negative perceptions and experiences of living with older residents (Dobbs et al., 2008; Persson & Ostwald, 2009; Taylor, 2014). Similar positive interpersonal relationships between younger and older adults was explored within a qualitative study with people experiencing Intellectual Disability in Ireland (Burke et al., 2014). Results presenting positive interpersonal relationships from this present study, and Burke et al. (2014), strengthen evidence within the stereotype embodiment theory (Levy, 2009). Stereotype embodiment theory indicates interpersonal relationships are strong facilitators for priming negative or positive age stereotypes between younger and older adults. Therefore, within an environment that places younger and older residents together, findings indicate the importance of exploring interpersonal relationships that facilitate positive perceptions and self-perceptions of health and aging for younger adults over time.

Relationships with older residents and family also influenced how younger adults described perceptions of aging and age stereotypes through chronological age. Participants discussed the influence of chronological age within their perceptions of age stereotypes. Depending upon chronological age, participants described behavior that could be expected for

someone that is 55 versus 85. Recent research within the field of aging explores perceptions of personality characteristics and behavioral changes of older adults within a certain chronological age (Kornadt, 2016). In addition to age stereotypes, Kornadt (2016) provides evidence that social role expectations are rooted within interpersonal relationships influencing how older adults should behave at a specific chronological age. For instance, younger adults learn through interpersonal relationships what typical behaviors look like for someone aged 70 or 80.

It is also interesting how younger adults referenced chronological age in relation to their own experiences of health and aging throughout this study. Participants understood, through relationships with older residents, how they wouldn't reach an older age comparable to the majority of older residents, based on life expectancy for someone with disability. Through discussion of the chronological age differences between themselves and older residents, participants distanced themselves and described an inability to relate to experiences of older residents in LTC. Existing research explores the notion of aging self-relevance, where younger adults avoid shifts in age identity and reject an awareness of their advancing age (Meisner & Levy, 2016). Within the context of younger adults rejecting a shift in age identity, it was interesting how participants referenced their shorter life expectancies without perceiving their experiences of aging as advancing at a faster pace given the fewer number of years they could expect to live. All eleven participants were under the age of 65, yet some of their individual experiences of health and aging were comparable to experiences of older residents, some even over age 80. Regardless of overall poorer experiences of health, participants clung to their chronological age as membership of youthful in-group identities. Given the lifespan of people experiencing disability remains shorter than someone without a disability (Bowers et al., 2014), this study demonstrates how perceptions and experiences of chronological age may be an

important factor influencing the health and aging for younger adults with disabilities. Through the social-ecological model, younger adults' perceptions and experiences of chronological age were shaped through interpersonal relationships with older residents and family while living within the environment of LTC over time.

Research question three: Institutional level perceptions and experiences. Within institutional level perceptions and experiences, participants discussed how the social space and systems within LTC shaped what they think and feel towards health and aging. Overall, participants characterized negative experiences of living in LTC through awareness of the LTC environment. Within a facility that is created for providing health care and housing services for a population of relatively older and sicker residents, participants described experiencing a lack of belonging. Participants characterized the LTC environment as quiet, boring, and without privacy. These findings are consistent with existing research exploring perceptions of LTC environments, of which characterized the LTC environment as isolating, restrictive, and reinforcing of dependency and decline (Dobbs et al., 2008; Guse & Masesar, 1999). These findings indicate an interesting dynamic between individual and environmental level perceptions and experiences of health and aging. While participants described the environment of LTC, it was evident these perceptions were interconnected with and even shaped by, negative individual level perceptions of age stereotypes. This bottom-up relationship, from individual to environmental, indicates how the LTC environment can support or challenge perceptions of health and aging that individuals held before moving into LTC. Applying these findings within the social-ecological model, the relationship within, between, and among levels is reciprocal, as individual-level perceptions and experiences of health and aging were influenced through higher level interpersonal and environmental relationships. This represents the complexity of perceptions and experiences of

health and aging for younger adults in LTC as the environment did not indicate a mere top-down relationship of factors that shape individual-level experiences.

Participants that discussed more positive perceptions of health and aging were also more likely to characterize the environment of LTC through benefits of programming and receiving care. This presents a barrier for LTC facilities providing care to younger adults, as participants that discussed negative perceptions of aging were also more likely to characterize the environment as depressing, with a lack of programming, and loss of privacy. When evaluating the experiences of participants in LTC, findings suggest individual perceptions of health and aging may affect how younger adults experience living in LTC. While LTC facilities do not determine whether individuals hold positive or negative perceptions of health and aging upon moving into LTC, existing research has shown LTC facilities can attempt to support positive experiences for younger adults through social space (interpersonal relationships) and structural organization. For example, a study by Persson and Ostwald (2009) explored experiences of younger adults in LTC and indicated that interpersonal relationships (e.g., with residents, staff, and friends/family), and structural organization (e.g., recreational activities, meal time/choice, and living arrangements with roommates), were facilitators of positive or negative experiences of health. This research begins to explore how health care settings, such as LTC facilities, can be used to support or deconstruct age stereotypes (Meisner & Levy, 2016).

In addition to environmental characteristics of LTC, participants discussed how characteristics of the structural organization influenced their perceptions and experiences of health and aging. When participants discussed moving into LTC, it came as a shock how they were placed within rooms that were shared amongst older residents on each floor. Participants described how the structural organization of the facility, in which they were placed within a

specific room and floor, influenced what they thought about health and aging. It was a concern of participants that the original structure and organization of rooms (i.e., shared bedrooms or washrooms with older residents) in LTC had not been changed to accommodate a group of younger residents, such as placing younger adults on one floor. Research from Colontonio, Howse, and Patel (2010) provide similar evidence that LTC facilities lack appropriate resources and budgets to adapt the structure of facilities to accommodate the number of younger adults residing in care. Considering the relatively unchanged structure of LTC facilities, participants experienced how facility-wide policies guiding specialized health care and housing were no longer applicable for the population of younger adults moving into LTC. The absence of age-appropriate policies were perceived and experienced through restricting meal and bed times, or limited access to kitchen amenities. Beyond specialized LTC programming exclusive for participation from younger adults, it was unclear to participants how the facility adapted the structural organization to provide specialized policies, care, and housing for younger adults.

Summary of the Social-Ecological Model

Through discussion of major findings, multiple interacting levels of individual, interpersonal, and environmental factors were represented as they influence the health and aging for younger adults in LTC. Using the social-ecological framework, this study explored perceptions and experiences of health and aging for younger adults with disabilities and living in LTC. Earlier studies exploring the health of younger adults in LTC contributed to individual and interpersonal level understandings, indicating health of younger adults is complex and involves multi-level analysis (Persson & Ostwald, 2009). This study builds upon previous research and contributes a new health promotion lens aimed at deconstructing multiple factors and relationships that influence health and aging for younger adults in LTC. Not only was this multi-

level framework effective at organizing and presenting data within complex relationships and processes of health and aging, this multi-level framework contributes to broader understanding of biopsychosocial aspects of health and aging that require multi-dimensional approaches. As illustrated by existing research in this field, the nature of exploring perceptions and experiences of younger adults in LTC inherently involves multiple levels of the social-ecological framework (Persson & Ostwald, 2009).

By the very nature of younger adults receiving health care and housing accommodations in LTC over longer periods of time than their older LTC resident peers (Statistics Canada, 2011b), it is important for researchers to consider how multi-level relationships are affected over time. Research of aging perceptions, focusing on stereotype embodiment theory, provides extensive evidence of influence of age stereotypes and health-related outcomes over time. Age stereotypes are shown to be internalized through culture (top-down), and during one's life span (over time) (Meisner & Levy, 2016). As such, the relationships individuals share, and the environments in which they exist, are critical factors when exploring how individual health and aging processes are positively and/or negatively influenced by age-related perceptions and experiences.

The relationships influencing health and aging within, between, and among the levels of the social-ecological model have been discussed, and applications of which are well represented throughout extent literature of health and health-related topics in research (Lieberman et al., 2013). Although applications of the social-ecological model are effective at characterizing relationships through a snapshot in time, little research explores experiences of aging focuses on how these multi-level relationships progress over time (Satariano, 2006), as shown through Bronfenbrenner's chronosystem (Neal & Neal, 2013; Warner, Schaie & Schooler, 1989). Given

perceptions and experiences of negative age stereotypes are shown to strengthen over time, the length of time younger adults live in LTC may predict different relationships between individual, interpersonal, and environmental levels of the social-ecological model. The conceptualization of time within the chronosystem adds another level describing how patterns of social interactions change between and within individuals and their environments (Neal & Neal, 2013). Research has yet to consider longitudinal approaches to individual, interpersonal, environmental relationships characterizing how health and aging progress over time for younger adults in LTC.

Study Strengths and Limitations

To achieve the objectives of this study, two qualitative research methods were used to gather the perceptions and experiences of aging within each level of the social-ecological framework. These two key aspects of the study offer significant strengths. First, the use of multiple qualitative research methods, with the purpose of including younger adults with disabilities meaningfully throughout data collection, both photovoice and interview techniques were used. A strength of combining these methods were to engage younger adults through participatory research while also providing a dynamic understanding, through words and images, on experiences of health and aging among younger adults in LTC. The design of the study intended to promote institution-based health initiatives of conducting research alongside younger adults with disabilities.

Photovoice methodology provided an effective tool to facilitate discussion, where participants were in control of eliciting topic of conversation when presenting each photograph. Although photovoice was successful, with eight out of eleven participants having participated with selecting five photographs, there were many challenges that emerged with photovoice methods in the LTC environment. Beginning with ethical concerns of photovoice in the

environment of LTC, many restrictions were placed upon participants to protect the personal/identifying information of people or the facility. Therefore, many photographs of LTC specific programming and photos with residents or staff were omitted from results and included as data gathered through interviews. The restrictions that were placed upon participants created limitations towards reaching the effectiveness of participatory research methods. While participants were still included in the meaningful collection of data, and photovoice data were included within results, future research involving LTC environments may face similar challenges and limitations.

Second, a strength of using the social-ecological model within a health promotion context was to explore how different structures of life influence individual-level health phenomena in this case, perceptions and experiences of health and aging in LTC. As a framework, the social-ecological model is best understood to characterize larger structures that shape the health and well-being of individuals. As such, the social-ecological model has a strong foundation within fields of public health, health promotion, and health psychology (Engel, 1981; Lieberman et al., 2013) offers a new approach to research on this topic.

Although there are many benefits and strengths of using two qualitative research methods and a multi-level research design, there are also various limitations that have impacted this study. Beginning with the research design, the purpose of this study was to gather the perceptions and experiences of younger adults that have the ability to communicate verbally, or with the assistance of a translator. While a strength of this study is to include the voices of people with disabilities, this study excludes a portion of the population that communicate non-verbally. Further research will be required to explore a larger proportion of the population of younger adults with various abilities, for instance non-verbal individuals that reside in LTC facilities.

Additionally, with time limitations, there are various challenges that impact the feasibility of collecting a larger sample of data. Due to time constraints imposed when applying to multiple ethics boards, one LTC institution was selected and ethics approved, alongside approval from Dalhousie University. Characteristic of most exploratory qualitative research projects, results from this study will pertain to the perceptions and experiences of younger adults in a localized area in this case, people who live within a LTC institution in suburban HRM. Gathering data from this target population may generate a sample that is not highly transferable to younger adults in LTC facilities across Canada. As such, future research could compare the experiences of younger adults that live within LTC facilities, both publically and privately operated, across Canada.

In addition to recognizing results are gathered from a sample that is not highly representative of other groups, it is important to comment how participants had only lived in LTC for an average of three years. Therefore, it is likely that results from this study pertain to the perceptions and experiences of younger adults that have recently moved into LTC. Reflecting on the average length of residence for participants in LTC is important when comparing perceptions and experiences of health and aging over time. Within a framework of the social-ecological model, the interconnections between individual, interpersonal, and environmental relationships may have a greater effect on the perceptions and experiences of health and aging for younger adults over time. This study was unable to compare the perceptions and experiences of health and aging between younger adults that had lived for short versus long periods of time in LTC.

CHAPTER 6: CONCLUSION

Summary of Project

Given that earlier studies on this topic contribute to individual-level understandings of living in LTC for younger adults, the novelty and importance of this research study was found in its focus on multiple, interacting levels that shape health and aging for younger adults living in LTC facilities. Existing research has not yet explored how living in LTC from an earlier age or for longer periods of time influences individual, interpersonal, and institutional level experiences of health and aging for these relatively younger adults in LTC. Through creative and useful methodological approaches for a specific population within a unique environment, the purpose of this project was to generate an innovative and valuable perspective creating new knowledge on younger adults' experiences and perceptions of health and aging in LTC. Using the social-ecological model as a guiding framework, the focus on individual, interpersonal, and institutional factors that create and shape these experiences and perceptions provides, for the first time, a deeper and more comprehensive understanding of the complex experiences of health and aging in this setting and context. Using this multi-level approach provides new and important information and creates a more complete picture capturing various structures and systems that impact the lives of younger adults in LTC.

Relevance to Health Promotion

Through a health promotion lens, this study explores health and aging for younger adults in LTC based on principles of reducing health disparities and achieving equity in health (World Health Organization, 1986). Adding to this small yet growing field of research will continue to build evidence towards a demand for re-orienting health care policies and services that affect processes of health and aging for younger adults in LTC (Spassiani et al., 2015). Within the

results of this study, younger adults shared the importance of making structural changes to re-orient health care services in LTC. Overall, younger adult participants made five recommendations for the LTC facility including: 1) placing younger adult residents closer in proximity (i.e. one floor or wing) within the facility; 2) improving access to kitchen amenities outside designated mealtimes; 3) increasing number of private bathrooms and use of private bath tubs; 4) increasing number of staff providing care to residents during morning and evening times; reducing restricting morning and bedtime routines; and 5) increasing variety of programming activities available to younger adult residents. From these suggested recommendations, it is clear including the voices of younger adults with disabilities provides important information. Further, application of this information is significant for LTC facilities looking to improve how health care policies and services are structured for younger adults requiring health care services for longer periods of time.

Although this study embedded the social-ecological framework to organize and understand perceptions and experiences of health and aging, general themes focused on the importance of health care services, and housing accommodations for the health and well-being of marginalized populations, such as people with disabilities. While this is a relatively new area of research, this is not a new reality for younger adults in need of appropriate housing and health care services (Curry 2015). Meeting the health care and housing needs for younger adults with disabilities remains a key priority area for Nova Scotia. Challenges to providing adequate housing accommodations for younger adults with disabilities will continue to rise as the population of older adults steadily increases and provincial investments for affordable housing remain in slow progress (Nova Scotia, 2017).

Action to provide housing solutions for older populations has recently developed under Nova Scotia's provincial plan called Shift (2017). This provincial agenda aims to provide funding for improvements within public housing, including repairs and renovation to LTC institutions (Shift, 2017). While this shift in health promotion within politics is underway, it is critical plans for repairs and renovation include all voices of residents living within LTC facilities. As a growing population of residents within LTC include younger adults with disabilities, it is critical the voices of this marginalized population are represented and included within the decision-making processes to re-orient health care services (World Health Organization, 1986). During this critical shift in attention to key issues of adequate housing, improving health, and long-term investments to community planning. It is significant research continues to explore how health and aging are influenced by housing accommodations in LTC.

Improving the health and well-being of older adults in Nova Scotia has been initiated through policy action within Shift (2017). This new political bill is significant and represents a shift towards health promotion strategies in policy. Unfortunately, a similar action plan addressing the housing and health care needs of younger adults with disabilities has not been provided by the provincial government within Nova Scotia. A recent release of news reports in April 2017 raise concern Nova Scotia is moving too slowly and fails to provide long-term solutions, without taking the health care and housing needs for this marginalized population seriously (CTV News, 2017; Global News, 2017). As plans move forward to repair and renovate public housing for aging populations, attention must also focus on incorporating plans for a proportion of LTC residents that are younger and require different levels of care. With the promise of funding for more LTC facilities to offer increased numbers of beds to care for older and sicker adults in end of life; it is critical there is an action plan to promote long term health

care and housing accommodations for younger adults with disabilities that are placed within LTC facilities.

A health promotion perspective within this study contributes to approaching change through multi-level collaborations between researchers, community partners, and policy makers. This study contributes to strengthening collaborative relationships between researchers and community partners, specifically champion community liaison within LTC that have helped to facilitate this research. Community liaisons within the LTC facility chosen for this study expressed a genuine interest in collaborating with researchers to make change that serves to benefit residents and staff within LTC. Establishing collaboration and engaged scholarship between these stakeholders will move effort towards building healthy public policy, supportive environments, and reorient health services to improve long term health of younger adults with disabilities (World Health Organization, 1986).

Recommendations for Future Research

Future research exploring the perceptions and experiences of health and aging should build on the strengths discussed within this study. Considering the predominately quantitative nature of health research involving people with disabilities and age-stereotypes, it is recommended that future research continue to adopt qualitative methods. Within the application of qualitative methods, it is significant that future research applies similar creative and non-traditional methods to gather new and important data representing the voices of younger adults with disabilities. The effectiveness of methods, such as photovoice used within this study, offer creative and participatory research methods to meaningfully include participants within the collection and analysis of data. Additionally, the social-ecological model has shown to be an effective framework to represent the complex processes of health and aging, and future research

would benefit from conceptualizing this framework to understand multi-level relationships. Following a handful of studies that have begun to explore experiences of younger adults in LTC, a gap in knowledge exists comparing and contrasting experiences of younger adults across similar locations. Future research should consider comparing experiences of younger adults between more than one LTC facility, across or within different regions. Comparing the experiences of younger adults across more than one facility would also provide the opportunity to consider how living for longer periods of time in LTC influences the perceptions and experiences of health and aging.

Given that negative age stereotypes are shown to contribute to health-related concerns and poorer health outcomes (Meisner & Levy, 2016), future research should focus on exploring age stereotypes through interpersonal relationships in LTC. Although age-stereotypes are explored for groups of younger and older adults separately, the environment within LTC presents a unique opportunity to explore how age stereotypes exist in a relatively closed environment through intergenerational relationships. Research has not yet explored whether the presence of younger adults in LTC reinforces negative self-perceptions of aging for older residents, or how older residents are influenced by living amongst a population of younger adults.

Overall, this project aimed to understand, and hopefully bring attention to, the experiences of younger adults with disabilities in LTC. Using a health promotion approach, this study explored how LTC facilities influence the perceptions and experiences of health and aging for younger adults. Research has not yet explored how LTC facilities provide age-appropriate care that meets complete health and health care needs of younger adults. While the objective of this research study was new and important, it is equally valuable to recognize its methods and how they meaningfully include younger adults as active participants.

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APPENDIX A

Recruitment Guide for LTC Liaison

Inclusion Criteria
- Participants are between the ages of 19 to 65 and live within LTC [facility name].
- Participants able to communicate verbally (with or without a support person)
- Participants are their own legal guardian
- Participants consent to be audio-recorded during interviews

Recruitment of participants will be determined through 4 Phases. The recruitment process will begin within Phase 1 whereby participants between the ages of 19 to 30 will be chosen as potential participants. Participants that agree to be approached by the lead researcher will then be provided more information. When approximately 10 participants have consented to participate in the study then recruitment will stop and the remaining phases will not continue.

Phases of Recruitment
- Phase 1: 19 to 30 years of age
- Phase 2: 31 to 40 years of age
- Phase 3: 41 to 50 years of age
- Phase 4: 51 to 64 years of age

Research Project Summary:

This study will explore your experiences and perceptions of health and aging. You will be asked to take part in two interviews with the lead researcher (Brittany Barber) as well as take pictures. This study will involve two meetings over two weeks, and will take on average an hour of your time. The interview will ask you to discuss and describe what you think and feel about health and aging. After the first interview you will be asked to take around 5 to 8 photos to represent what you think and feel about health and aging. The second interview will occur after one week and will ask you to select and discuss each photo.

Potential Research Participants

If you are interested in participating in this study, the lead researcher (Brittany Barber) will be in contact with you. If you give me permission, I will provide her with your name on a list of potential participants. By agreeing to be contacted by Brittany, you are not agreeing to be part of the study, and can decide later if you wish to participate. Your participation will be kept private and confidential. Choosing whether or not to take part in this research is entirely your choice. There will be no impact on the care you receive in this facility if you decide not to participate in this research project.

Younger adult residents:

lets talk about living in long-term care

Are you living in LTC and are younger than 65?

Would you like to share your experience of health and aging in long-term care?

If so, you might be interested in participating in a research project with Brittany Barber, a Master's student from Dalhousie University.

For more information, talk with Manager of Social Work, or contact Brittany Barber at (519) 777-9665

Younger adult residents:

What is the project all about?
We are interested in exploring what younger adults think about their own health and aging while living in long-term care. Researchers are interested in what you think about health based on individual, social, and institutional factors in long-term care. By exploring this topic, the researcher hopes to (a) find out more about how younger adults experience health and aging while living in a long-term care setting and (b) gather information to improve future policies and programs within long-term care.

Who can take part?
We are looking to talk to 10-12 residents who are:
a) under 65 years of age, b) are willing or able to communicate verbally (with or without a support person), c) are their own legal guardian, d) agree to be audio-recorded during interviews

What does your participation involve?
Residents who agree to participate will meet with the researcher twice. Each meeting can be expected to take around 1 hour of your time. The first meeting will involve an interview where you and the researcher will discuss what you think and feel about health and aging. After the first meeting you will be asked to take around 5 to 8 photographs to illustrate what you think and feel about health and aging. During the second meeting we will discuss the photographs and describe what each one means to you.

What's in it for you?
By participating in this study, you may receive a sense of satisfaction for sharing your experiences and contributing to knowledge about this important topic. You may also receive a sense of satisfaction by contributing knowledge towards future changes within long-term care to improve quality of life for younger adults.

INFORMED CONSENT FORM - WRITTEN

Project title: Experiences of Aging: Younger Adults with Disabilities in Long-Term Care
Facilities

Lead researcher:
Brittany Barber, Dalhousie University, School of Health and Human Performance

Other researchers
Dr. Brad Meisner, Dalhousie University, School of Health and Human Performance
Dr. Lori Weeks, Dalhousie University, School of Nursing
Dr. Natasha Spassiani, Trinity College Dublin, Adjunct

Funding provided by: Nova Scotia Health Research Fund, Nova Scotia Graduate Scholarship

Invitation
You are invited to take part in a research study being conducted by researchers at Dalhousie
University as part of my Masters in Health Promotion program. Choosing whether or not to take
part in this research is entirely your choice. There will be no impact on the care you receive in
this facility if you decide not to participate in the research. The information below tells you about
what is involved in the research, what you will be asked to do and about any benefit or risk that
you might experience.

You should discuss any questions you have about this study with Brittany Barber. Please ask as
many questions as you like. If you have questions later, please contact Brittany.

Purpose and Outline of the Research Study
The purpose of this study is to gather information about the experiences and perceptions of
health and aging for younger adults with disabilities in long-term care. Researchers are interested
in how your experiences and perceptions are influenced by individual, interpersonal, and
institutional factors in long-term care. By exploring this topic, the researcher hopes to (a) find
out more about how younger adults experience and perceive health and aging while living in a
long-term care setting and (b) gather information to improve policies and programs within long-
term care in the future.

Who Can Take Part in the Research Study
You may participate in this study if you currently live in long-term care. Everyone that
participates must be between the ages of 19 to 65, diagnosed with a disability, and able or willing
to communicate verbally in English with the researcher. You are encouraged to have a support
person (support staff, peer or family member of your choosing) assist during the interviews
and/or while you take pictures. You will be responsible for selecting this person. There will be
approximately 10 people taking part in this study.

What You Will Be Asked to Do
This research study will ask you to take part in a face-to-face, one on one interview with the lead researcher. If you agree to be part of this study, both interviews will be audio-recorded. The interview will ask you to discuss what you think and feel about health and aging while living in LTC. Interviews will take place over two meetings approximately one week apart. Each meeting will last around one hour in length and will take place in a private space. The first meeting will include an interview, during which you will be asked questions about what you think and feel about health and aging. After the first meeting you will be asked to take around 5 to 8 photographs to illustrate what you think and feel about health and aging. When we meet again during the second meeting you will be asked to discuss the photographs and describe what each one represents to you.

How to Obtain Results
We will provide you with a one-page summary of results when the study is completed. You will be asked if you would like to receive results after the study by providing your contact information, such as email/mailing address. You can get more information about this study by contacting the lead researcher on this consent form.

Possible Benefits, Risks and Discomforts
A benefit of participating in this study includes an opportunity to share your experiences of living in long-term care.

There is potential risk that LTC residents and staff (beyond the internal liaison) may know you are involved in a research study. If individuals in LTC see you taking pictures, then your involvement in this study will not be completely anonymous; however, all details of the study and data collected will remain confidential, private, and will be anonymized.

Due to the risk of discussing sensitive topics surrounding your health and aging, you may experience emotional and/or psychological distress. Additional external resources, found within a handout, and internal support from social workers will be available for counseling services.

How your information will be protected:
Steps will be taken to ensure your identity and privacy are protected throughout this study. It is important all information is kept confidential to protect the identities of yourself, the facility and other people present. Meetings will take place in a private location at the long-term care facility. Your name will not be used in any documents or publications and participation in this study will remain confidential from any persons. All information gathered during the interviews will be stored on a password protected file on a computer, and only myself and supervisor will have access to it. Information will be stored securely in a locked space at Dalhousie University for 5 years and then will be destroyed.

If You Decide to Stop Participating
Please feel free to leave the study at any time. If you decide to stop participating at any point in the study, you can also decide whether you want any of the information that you have contributed to be removed or if you will allow us to use that information. You can also decide for

up to one week after the second interview if you want us to remove your data.

Protection for Persons in Care Act
Based on the Adult Protection Act and the Protection of Persons in Care Act, there are laws in place to prevent and respond to the abuse of adults in long-term care. In the case that any signs of abuse or trauma are discussed during the interviews I will be held responsible to report and contact Adult Protection Services by phoning 1-800-225-7225.

Questions
We are happy to talk with you about any questions or concerns you may have about your participation in this research study.
Please contact Brittany Barber (519-777-9665) (brittany.barber@dal.ca) or Dr. Brad Meisner (902 494-1158) (brad.meisner@dal.ca) at any time with questions, comments, or concerns about the research study.
We will also tell you if any new information comes up that could affect your decision to participate.

If you have any ethical concerns about your participation in this research, you may also contact Catherine Connors from Research Ethics, Dalhousie University at (902) 494-1462, or email: ethics@dal.ca

Signature Page

Project Title: Experiences of Health and Aging: Younger Adults with Disabilities in Long-Term Care Facilities

Lead Researcher:
Brittany Barber, Dalhousie University, School of Health and Human Performance

I have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered. I understand that I have been asked to take part in two interviews that will occur at a location acceptable to me, and that those interviews will be audio-recorded. I understand direct quotes of things I say may be used without identifying me. Do you consent to the use of photographs in the results of this study, without identifying you, people around you, and the place that you live?

I agree to take part in this study. My participation is voluntary and I understand that I am free to withdraw from the study at any time, until one week after my second interview is completed.

_____   _____   _____
Name   Signature   Date

I wish to be contacted after this study is complete with a copy of the results

 ☐Yes ☐No

Via Email _____

In-person at my home   ☐Yes ☐No

Via Mailing Address _____

DALHOUSIE UNIVERSITY

INFORMED CONSENT FORM - VERBAL

Project title: Experiences of Aging: Younger Adults with Disabilities in Long-Term Care Facilities

Lead researcher:
Brittany Barber, Dalhousie University, School of Health and Human Performance

Other researchers
Dr. Brad Meisner, Dalhousie University, School of Health and Human Performance
Dr. Lori Weeks, Dalhousie University, School of Nursing
Dr. Natasha Spassiani, Trinity College Dublin, Adjunct

Funding provided by: Nova Scotia Health Research Fund, Nova Scotia Graduate Scholarship

Invitation
You are invited to take part in a research study being conducted by researchers at Dalhousie University as part of my Masters in Health Promotion program. Choosing whether or not to take part in this research is entirely your choice. There will be no impact on the care you receive in this facility if you decide not to participate in the research. The information below tells you about what is involved in the research, what you will be asked to do and about any benefit or risk that you might experience.

You should discuss any questions you have about this study with Brittany Barber. Please ask as many questions as you like. If you have questions later, please contact Brittany.

Purpose and Outline of the Research Study
The purpose of this study is to gather information about the experiences and perceptions of health and aging for younger adults with disabilities in long-term care. Researchers are interested in how your experiences and perceptions are influenced by individual, interpersonal, and institutional factors in long-term care. By exploring this topic, the researcher hopes to (a) find out more about how younger adults experience and perceive health and aging while living in a long-term care setting and (b) gather information to improve policies and programs within long-term care in the future.

Who Can Take Part in the Research Study
You may participate in this study if you currently live in long-term care. Everyone that participates must be between the ages of 19 to 65, diagnosed with a disability, and able or willing to communicate verbally in English with the researcher. You are encouraged to have a support person (support staff, peer or family member of your choosing) assist during the interviews and/or while you take pictures. You will be responsible for selecting this person. There will be approximately 10 people taking part in this study.

What You Will Be Asked to Do

This research study will ask you to take part in a face-to-face, one on one interview with the lead researcher. If you agree to be part of this study, both interviews will be audio-recorded. The interview will ask you to discuss what you think and feel about health and aging while living in LTC. Interviews will take place over two meetings approximately one week apart. Each meeting will last around one hour in length and will take place in a private space. The first meeting will include an interview, during which you will be asked questions about what you think and feel about health and aging. After the first meeting you will be asked to take around 5 to 8 photographs to illustrate what you think and feel about health and aging. When we meet again during the second meeting you will be asked to discuss the photographs and describe what each one represents to you.

How to Obtain Results

We will provide you with a one-page summary of results when the study is completed. You will be asked if you would like to receive results after the study by providing your contact information, such as email/mailing address. You can get more information about this study by contacting the lead researcher on this consent form.

Possible Benefits, Risks and Discomforts

A benefit of participating in this study includes an opportunity to share your experiences of living in long-term care.

There is potential risk that residents and staff (beyond the internal liaison) may know you are involved in a research study. If individuals see you taking pictures, then your involvement in this study will not be completely anonymous; however, all details of the study and data collected will remain confidential, private, and will be anonymized.

Due to the risk of discussing sensitive topics surrounding your health and aging, you may experience emotional and/or psychological distress. Additional external resources, found within a handout, and internal support from social workers will be available for counseling services.

How your information will be protected:

Steps will be taken to ensure your identity and privacy are protected throughout this study. It is important all information is kept confidential to protect the identities of yourself, the facility and other people. Meetings will take place in a private location at the long-term care facility. Your name will not be used in any documents or publications and participation in this study will remain confidential from any persons. All information gathered during the interviews will be stored on a password protected file on a computer, and only myself and supervisor will have access to it. Information will be stored securely in a locked space at Dalhousie University for 5 years and then will be destroyed.

If You Decide to Stop Participating

Please feel free to leave the study at any time. If you decide to stop participating at any point in the study, you can also decide whether you want any of the information that you have contributed to be removed or if you will allow us to use that information. You can also decide for up to one week after the second interview if you want us to remove your data.

Protection for Persons in Care Act
Based on the Adult Protection Act and the Protection of Persons in Care Act, there are laws in place to prevent and respond to the abuse of adults in long-term care. In the case that any signs of abuse or trauma are discussed during the interviews I will be held responsible to report and contact Adult Protection Services by phoning 1-800-225-7225.

Questions
We are happy to talk with you about any questions or concerns you may have about your participation in this research study.
Please contact Brittany Barber (519-777-9665) (brittany.barber@dal.ca) or Dr. Brad Meisner (902 494-1158) (brad.meisner@dal.ca) at any time with questions, comments, or concerns about the research study.
We will also tell you if any new information comes up that could affect your decision to participate.

If you have any ethical concerns about your participation in this research, you may also contact Catherine Connors from Research Ethics, Dalhousie University at (902) 494-1462, or email: ethics@dal.ca

VERBAL CONSENT SCRIPT

Do you have any questions or would like any additional details about the study?
[Answer question]

Do you understand that you are being asked to take part in two interviews that will occur at a private location of your choosing?
[Answer question]

Do you consent to both interviews being audio-recorded?
[Answer question]

Do you consent to the use of direct quotations of things said during interviews, without identifying you?
[Answer question]

Do you consent to the use of photographs in the results of this study, without identifying you, people around you, and the place that you live?
[Answer question]

Do you agree and understand that participation in this study is voluntary and you are free to withdraw from the study at any time, until one week after the second interview is completed?
[Answer question]

Do you wish to be contacted after this study is complete with a copy of the results?
[Answer question]

Do you want to receive results via email , in-person, or through your mailing address?
[Answer question]

DALHOUSIE UNIVERSITY

CONFIDENTIALITY AGREEMENT

Project Title
Experiences of Health and Aging: Younger Adults with Disabilities in Long-Term Care
Facilities

Lead Researcher
Brittany Barber, Dalhousie University, School of Health and Human Performance

Other Researchers
Dr. Brad Meisner, Dalhousie University, School of Health and Human Performance
Dr. Lori Weeks, Dalhousie University, School of Nursing
Dr. Natasha Spassiani, Trinity College Dublin, Adjunct Dalhousie University

You have been asked to support this person throughout a research study taking place over 2 weeks and 2 sessions. The first session includes an interview. After this interview you may be asked by the person you support to help with taking approximately 5 photographs. The second interview will take place one week later to discuss the photographs that were taken.
 In agreeing to assist this person you agree to:

1. Keep all the research information shared confidential by not discussing or sharing the research information in any form or format (e.g., pictures, conversation) with anyone other than the *Researcher(s)* and person you are supporting.
2. Agreeing to keep information confidential does not prevent you from reporting the health, life, or safety concerns of individuals.
3. You are being asked to assist during the conversation between the researcher and person you are supporting; only to clarify the words that are spoken and not to contribute or add information on behalf of the person supported.
4. Understand that all information regarding the people and setting in LTC will be kept private, confidential, and will be anonymized when the results of this study are complete.

_____   _____   _____
(Print Name)   (Signature)   (Date)

APPENDIX F

Guide to Introduce Project, Photovoice, and Aging Theme

(The following information will be discussed with each participant.)

Researcher Introduction:

My name is Brittany Barber and I am working on a project to complete my Master's degree at Dalhousie. If you want to, I am here today to discuss with you a very important topic, your experiences of health and aging while you live in long-term care. I am interested in this topic from previous experience working in a group home with people that experienced various disabilities. Would you like to hear more?

Research Project Summary:

To participate in this study, we will ask you to take photographs that tell a story about your health and aging. You will also be asked to have a conversation with Brittany Barber in-person to discuss what you think and feel towards health and aging while living in LTC. You will be asked to explain what you think and feel towards health and aging during two interviews. After the first interview you will be asked to take around 5 photographs of things that represent how you think and feel about health and aging. We will talk about these photos during the second interview.

Photovoice:

- Photographs will be used to show how you experience your health and your aging process while living in LTC. Photographs can be used to tell a story through images. When you take a picture, you are representing what you think or see about a topic. After you take this photograph you will discuss what the image means during the second interview. The photographs that you take can be of anything. There is no right or wrong way to take photographs for this study, as you are describing your own experiences and thoughts.
- When you are taking photographs, you can write down or record notes to remind yourself later why you took the photo. It might help to keep track of what you are thinking or feeling when you take each photograph.
- While you are taking pictures you can ask someone for assistance, if you wish. If you do get assistance, you will be the one to decide which things to photograph and talk about why you decided to include each photograph in the study.

Healthy and Aging:

- This study will focus on what you think and feel about health and aging. There is no right or wrong answer, this study is interested in finding out what health and aging means to you.

- To begin, you will be asked to take pictures within your home in LTC to illustrate your personal experiences of health and aging, your relationships that shape how you think or feel about health and aging, and the place you live. The photographs that will be included in this study will provide other people with a better understanding of how you experience health and aging within a long-term care home.

Expected Timeline:

- After today we will meet again within 1 week. Each meeting will require around 1 hour of your time, although more or less time will be available, if you wish. You will be asked to choose a second time for us to meet to discuss the photographs.

Session #1: During this meeting you learn about the project and how you would be involved in taking pictures and discussing health and aging – if you decide to participate in the study. Your involvement in this project is completely voluntary, and verbal or written consent will be gathered today, if you're willing to participate. We will discuss whether you would like to use your own camera to take pictures or if you would like to use a camera provided for you. You will receive a handout of instructions to help remind you of things to photograph over the next week. The second meeting will be scheduled in about one week, and you will be asked to share the **5 to 8** photographs by explaining what they mean.

Session #2: A second meeting will occur in about one week from today. We will talk about the photos you have taken and discuss the story behind each photograph. You will be asked to choose 5 to 8 photographs, but there is no limit to the number of photographs that you can take. The photographs that are selected for discussion will remain digital during this meeting. At the end of this meeting, I will ask if you would like to remain in contact to receive the research results. Please ask any questions, and discuss any issues or concerns, that you may have throughout the entire research process.

Research Results: The results of this research project will be shared and discussed with you once the project is completed. A one-page summary of the results can be delivered through mail or in-person. When the results of this project are available to you, you can share it with anyone you wish, including friends, family, or staff.

Ethical Considerations:

- It is important the privacy of everyone that lives or works in the facility must be protected. It is important all information is kept confidential to protect the identities of yourself, the facility and other people. The location and identity of the facility must also be protected. This means that images that identify people or the place you live cannot be included in the results. All pictures can be used during private discussions, to help illustrate your story and help to discuss your experiences; however, only the discussions will be included within the results of this study.

Supplementary Questions Related to Photovoice:

-   Will you require a digital camera be provided to you, or would you like to use a camera you already own? (e.g., cellphone or electronic device with a camera)? If you choose to use your own camera, then the photographs must be transferable to a secure USB. If you require the use of a camera, then more instructions will be shared on using the camera.

Photovoice Handout for Participants

This handout will help remind you of the three themes that you are asked to take photographs of.

You are asked to take pictures of:

1. **What you think and feel about aging**

2. **Relationships with people**
   a. **How do people shape your aging?**

3. **Place you live**
   a. **How does LTC shape your aging?**

Semi-Structured Interview Guide for Sessions 1 and 2

Interview Guide for Session #1

Demographic Questions

- How old are you?
- What gender do you identify with?
- Do you identify with having a disability?
  Probe: (If Yes) Can you explain more about your experience of disability?
- How long have you lived in this facility?
- Where did you live before you moved here? How long did you live there?

Questions Regarding Individual Perceptions of Health and Aging
- Can you describe what 'health' means to you?
- Can you describe what 'aging' means to you?
- Can you describe what 'disability' means to you?
- Is what you believe about aging shaped by something in your life?
  Probe: Can you explain more?
- Who do you think about when you think of growing older?
  Probe: What do you think about their experience is/was positive or negative?
- Did you think about aging before you lived in this facility?
  Probe: How has this changed?
  Probe: Why do you think this has changed?
- Are your thoughts towards aging or growing older changing over time?
  Probe: How are they changing?
  Probe: Are they changing since living at [name]? How?
- What would you say are some bad things about aging or growing older?
  Probe: Why are they bad?
- What would you say are good or bad things about aging or growing older?
  Probe: Why are they good?
- Are your thoughts towards health changing over time?
  Probe: How are they changing?
- Do you think your experience of disability has shaped your experiences of aging?
  Probe: How are they shaped (or not shaped)?

Questions Regarding Interpersonal Relationships with Older Residents and Staff
- Do you spend a great deal of time with other residents at this facility?
- Do they influence your experiences of health and/or of aging?
  Probe: How?
- Are they close in age to yourself, or older?
- Do you have friendships with any older residents?
  Probe: Why or why not?
- How do you feel about living with older residents?

Probe: Does that influence what you think and feel about your health?
Probe: Does that influence what you think and feel about aging?
- How do you feel about living with people that are similar in age?
    Probe: Does that influence your experience of health?
    Probe: Does that influence your experience of aging?
- Do you have friendships with any of the staff here?
    Probe: Are they close in age to yourself?
- Does the age of staff members impact your experience of living in the facility?
    Probe: How?
- Do you talk about aging or growing older in conversation with anyone?
    Probe: Are these conversations negative or positive?

Questions Regarding the LTC Institution
- What opportunities do you have to participate in activities that are offered by the facility?
    Probe: Does this influence your experience of health?
    Probe: Does this influence your experience of aging?
    Probe: Are these activities created specifically for younger residents?
- How would you describe your experience of living here?
    Probe: Are these experiences negative or positive?
    Probe: How? Why?
- Do you feel there are changes that could be done in the setting to change your experience of health and aging?
    Probe: How would these changes affect your experiences of health and aging?
- How does living in this facility impact how/what you think about aging?
    Probe: Would living in a different facility change your experience of health and aging?
- Is the facility created to meet the physical health care needs of younger residents that live long-term in this facility?
    Probe: Does the facility meet psychological/emotional health care needs? Social?
    Probe: Are there any changes you think could be made to the facility for younger residents as they age?

APPENDIX I

Interview Guide for Session 2

Ongoing Consent:
Before we begin, do you agree to continue participating within this interview to discuss the photos you have taken? If so, do you have any questions since we last met?
[Answer question]

Photovoice
- What do we see in this photo?
- Why did you include this photograph?
- Does this photo represent what you think and feel about health? How?
- Does this photo represent what you think and feel about aging? How?
- Which theme from the handout does this photo represent?
- Does this photo represent a positive or negative image? Why?

Questions Regarding Involvement in the Research Project

- Can you describe your experience of being involved in this research project?
  - What did you like about this project?
  - What did you dislike?
- Was the topic of aging within a long-term care facility important to you?
- Would you recommend the process of taking photographs again to a future researcher?
- What would you want someone to do differently next time?

APPENDIX J

Ethics Approval Dalhousie University

DALHOUSIE UNIVERSITY
Research Services

Health Sciences Research Ethics Board

Letter of Approval
December 05, 2016
Brittany Barber
Health Professions\Health & Human Performance

Dear Brittany,

REB #: 2016-3984

Project Title: Experiences of health and aging: Younger adults with disabilities in long-term care

Effective Date: December 05, 2016
Expiry Date: December 05, 2017

The Health Sciences Research Ethics Board has reviewed your application for research involving humans and found the proposed research to be in accordance with the Tri-Council Policy Statement on *Ethical Conduct for Research Involving Humans.* This approval will be in effect for 12 months as indicated above. This approval is subject to the conditions listed below which constitute your on-going responsibilities with respect to the ethical conduct of this research.

Sincerely,

Dr. Tannis Jurgens, Chair

TCPS2 Core Certificate

PANEL ON RESEARCH ETHICS
Navigating the ethics of human research

TCPS 2: CORE

Certificate of Completion

This document certifies that

Brittany Barber

*has completed the Tri-Council Policy Statement:
Ethical Conduct for Research Involving Humans
Course on Research Ethics (TCPS 2: CORE)*

Date of Issue: **28 September, 2015**

Participant Resources for Mental Health Support

Halifax Regional Municipality

Mobile Crisis Intervention Service
(902) 429-8167

MH Services Bedford –Sackville
(902) 865-3663

MH Services, Dartmouth
(902) 466-1830

Community Mental Health, Halifax
(902) 454-1400 or 454-1440

Mental Health Services, Hants
(902) 792-2042 Emergency

Emergency Assessment, QE11
(902) 473-3104 Emergency

CMHA- Halifax –Dartmouth Branch
(902) 455-5445

SSNS HRM Chapter
(902) 462-8658

Healthy Minds Cooperative
(902) 404-3504

Self-Help Connection
(902) 466-2011

Empowerment Connection
(902) 404-3445