

“I FEEL LIKE I JUST DON’T QUITE FIT IN”: WORKING-AGE ADULTS
WITH A PHYSICAL DISABILITY SHARE THEIR EXPERIENCES
IN RESIDENTIAL CARE

by

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ABSTRACT

This study explores the perceptions of working-age adults with a physical disability who often face unique challenges while living in a residential care facility designed for a geriatric population. It is apparent that by addressing psychosocial needs and providing appropriate health care services to adults with a physical disability, strengths and challenges of these residents can be highlighted and recommendations made to improve upon experiences within residential care. In this study, I sought to answer the question: how do working-age adults with a physical disability experience living in a residential care home designed for a geriatric population?

Utilizing a qualitative narrative method, eight adults between the ages of 22 and 59 participated in a face-to-face audio taped interview, during which they shared stories of their personal experiences living in a residential care home designed for seniors. The concerns and experiences of the participants in this study clustered into the following key themes: (1) admission stories, (2) coping and adjustment, (3) relationships, (4) institutional culture and environment, and (5) hope. Subthemes included experiences of grief and loss, loss of autonomy and choice, changes in family relationships, relationships with staff and older residents, social support and advocacy and perceptions of “fitting in.”

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INTRODUCTION

Approximately 10% of clients in geriatric residential care are under the age of 60 years old and in recent years, this percentage has continued to rise. Though a great deal of research has been conducted with long-term care clients over age 65, little is known about the experiences of residents who are working-age and residing in a geriatric residential care facility. This exploratory, qualitative research study aimed to reveal how young adults with a physical disability experience living in a residential care facility designed to meet the needs of a geriatric population.

Personal Interest

My research question arises directly out of my own experiences working with adults who have a physical disability. As a health care social worker in both residential and acute medical settings, I had an opportunity to work within the micro, mezzo and macro levels of the health system. Through my varied work experience, I developed an interest in the experiences of clients who live in a government-funded residential care facility, as that has been the setting for a significant portion of my social work experience thus far. I worked closely with several middle-age adults in residential care, and witnessed firsthand the many challenges they face in self-advocacy and attempting to navigate through the health care system. Young residents face many unique challenges not shared by residents over age 65, as the services in most nursing homes are designed specifically for a geriatric population. I feel a strong affinity for working with residents who do not fit into the conventional definition of a nursing home resident, and the opportunity to learn more about the experience of this group of residents was appealing because I felt it could provide an opportunity to influence policy within Fraser Health.

During the proposal phase of this study, I had several conversations with colleagues who agreed that speaking to working-age residents in residential care would be a worthwhile research project, and this is a topic that has not yet been explored in depth within Fraser Health. I was made aware of a research project that took place several years ago to determine what was and was not working for residents under the age of 65 in Fraser Health residential care facilities, but after contacting several people to discuss the project, it appeared to be impossible to locate any detailed information or the report that was compiled to summarize the findings. I was able to collect some information from several of the staff who had participated in the data collection, but it appeared that this information was not going to have any further use. I found it disappointing that Fraser Health did not make the data more readily available or use the data to inform policy changes with the health authority. It appeared that the data had been collected for the purpose of determining if the health authority should create a facility for young residents, but it seems that there are no further plans for this potential project.

In my work experience as a social worker in acute and residential care, it became apparent that advocating for clients to be as involved as possible in making the choice to move to residential care is extremely important, and the move to a nursing home should be seen as a last resort once all other care options have been exhausted. Unfortunately, not all clients are involved in the residential care admission process; occasionally health professionals and family start this process without the client's knowledge and input. My experience also indicates that once a client is admitted to a residential care facility, there is often a lack of social support and little value is placed on maximizing independence, and this can be upsetting and isolating to residents who do not fit into the milieu.

I feel a professional obligation to assist clients to voice their opinion and concerns in order to help staff improve the services being offered, and hopefully improve upon the quality of life of these residents. It appears that because working-age adults living in a nursing home are a small group, their unique needs and requests are often overlooked or dismissed by staff as being unreasonable. Additionally, the small size of this group in proportion to the overall population within residential care can also contribute to their concerns and needs being overlooked, as geriatric residential care services are primarily designed to meet the needs of older clients rather than working age clients.

My work experience also indicates that social workers are the ideal professional to assist these clients within a setting that has little freedom or choice, as the very core of social work values includes advocacy and client-centred practice. The practice of social work in residential care can be a frustrating experience, as the role frequently involves large amounts of paperwork and administrative duties, which limits the time available to work directly with the residents. I found that much of my time employed as a social worker in residential care was spent completing tasks that would have been better suited to the skills of other professionals, such as clerical staff, and very little was spent with the residents. The staff who work in residential care attempt to be resident-focused whenever possible, but often the health care team listens more to the wishes of family members or other professionals than to the resident themselves. Advocating for the residents is often met with resistance by the facility management and other staff members due to the institutional culture in long-term care. My hope in pursuing this research is to highlight a number of strengths and concerns of younger residents who live in a geriatric care facility, and impart information that can assist with informing future policy.

Organization of the Thesis

This thesis has six chapters. Chapter 1 outlines the theoretical framework of the study including the definition of disability, disability and human rights, anti-oppressive practice theory, and role theory. Chapter 2 comprises a literature review of the traditional and more current literature on areas related to this topic, including the history of the disability movement in Canada, research with people who have a disability, autonomy and choice in residential care, relocation stress, social work in a residential care setting, quality of life of residents, current nursing home demographics, and the policy that informs long-term care in British Columbia.

In Chapter 3, I discuss the methodology that was used to carry out this study, including the sampling method, interview procedures and ethical considerations. Chapter 4 reports the findings of the study. I begin this chapter with a brief description of each participant who was interviewed in order to provide a more human “face” to each participant. The findings unfold according to the five main themes identified in the data: 1) admission stories, which outline how each participant came to live in a geriatric residential care facility, 2) coping and adjustment, 3) relationships, 4) institutional culture and environment, and 5) hope. I presented the understanding each participant has of their situation using direct quotations from the interviews.

In Chapter 5, the discussion, I connect the findings that arose from the study to the literature review and theoretical framework. In Chapter 6, the conclusion, I outline the potential contributions of this work to social work practice, social work research, education for social work students and other health professionals, and my reflections on the interviews and research process. I then identify policy implications for increased

understanding of the experiences of working-age clients who have a disability and other possible care options that could be provided in place of residential care. I conclude by suggesting some areas of future research for this topic.

THEORETICAL FRAMEWORK

This study is informed by the concept of disability from a human rights and social justice perspective, the social model of disability, elements of anti-oppressive practice, and the ways in which role theory influences one's sense of well-being and life satisfaction. Social work theory outlines how we relate to others and helps ensure that effective services are being provided, and theory in social work is an attempt to explain social situations and relationships in a useful way (Payne, 1997). The use of theory when working with clients who have a physical disability is essential in order to develop effective social work interventions.

Defining Disability

The concept of disability has been defined medically, socially, economically and politically. Disability is defined by the Americans with Disabilities Act as “a physical or mental impairment that substantially limits one or more major life activities beyond the range of a typical human being” (Thun, 2007). Individuals may also be deemed to have a disability if they are considered disabled based on group standards or guidelines. Types of disability may include physical, sensory, and cognitive or intellectual impairments. Psychiatric disorders and various types of chronic disease may also be considered to be disabling (Thun, 2007).

A disability may occur over the course of a person's lifetime or be present from birth (Statistics Canada, 2001). The concept of “disability” is specifically defined by legal statute in some jurisdictions; however BC's Human Rights Code contains no specific definition. In British Columbia, the characterization of a specific problem or condition as a

disability under human rights legislation will depend on the facts and circumstances of each case (Birnbaum & Mosher, 2008). In general, the legally defined concept of disability for human rights purposes indicates a physiological state that is involuntary, has some degree of permanence, and impairs the person's ability to carry out the normal everyday functions of life.

There are several main approaches to the social and scientific formulations of disability. The biomedical approach sees disability as a consequence of biological conditions, whereas the functional approach views disability as an impairment of functional abilities and capacities (Rioux & Valentine, 2006). The environmental approach views disability as a consequence of environmental factors and service arrangements, so disability becomes a result of a person's interaction with their environment. The human rights approach sees disability as a consequence of social organization and relationship of each individual to society.

The social model of disability indicates that systemic barriers, negative attitudes and exclusion by society are measurements of disability in society (Wendell, 1996). This model specifies that a person can only be considered "disabled" when society fails to take into account individual differences and needs. An example of this is outlined by Harlan and Robert (1998) who discuss the social construction of disability in a work environment, and how some employers resist making reasonable accommodations, because they want to maintain power and control within the work environment. Societal arrangements and expectations make essential contributions to how disability is understood and created,

therefore the concept of disability cannot be defined in purely biomedical terms (Wendell, 1996). Disability can include a physical limitation, ailment, social construct, perceived limitation, or a combination of these things to form a socially constructed disability located in society, rather than the individual themselves (Birnbaum & Mosher, 2008).

Rioux and Valentine (2006) explain that theory is essential to understanding the meaning and social construction of disability because it has had an impact on the development of laws and social policies. A critical disability theory approach assumes that human rights and equality provide a foundation for understanding the systemic barriers and oppression experienced by people with disabilities in Canada. The pattern of discrimination and inequality remains entrenched in society even in light of positive steps towards equality.

Human Rights and Disability

Thun (2007) describes the history of disability rights in Canada and highlights the legislation that has been integral in bringing the movement forward. Human rights legislation broadly encompasses laws that have been created to prevent discrimination, and the Universal Declaration of Human Rights was the first document to address this concept (Rioux & Valentine, 2006). The United Nations definition of disability is considered to be a function of the relationship between people and their environment (Wendell 1996). Recent estimates indicate that approximately 10 to 20% of the world population has a disability, but Canadian data ranges from estimates of 13% to 31% depending on the source and definition of disability (Statistics Canada, 2001). Regardless

of the actual numbers, it is clear that people with disabilities comprise a significant segment of the population.

The rights-based approach to disability encourages viewing people with a disability as “subjects of the law”, and the aim is to empower people who have a disability. The legal perspective of disability rights promotes active participation in political, economic, social, and cultural life while still providing accommodations for any difference in ability (Rioux & Valentine, 2006). This approach is based on international human rights standards and anti-discrimination legislation such as the Canadian Human Rights Act (Birnbaum & Mosher, 2008). People with disabilities are equally entitled, legally and ethically, to all economic, political and social rights in Canada, although these rights are not always enforced.

Human rights refer to the basic rights and freedoms to which all humans are entitled, as outlined in the Universal Declaration of Human Rights (Birnbaum & Mosher, 2008). Some of the issues commonly described as basic human rights include civil and political rights, such as equality before the law, as well as social economic rights, including the right to basic human needs such as food and safety, as well as the right to education and the right to employment. The United Nations General Assembly adopted the Universal Declaration of Human Rights in 1948 as a stand against oppression and discrimination (Rioux & Valentine, 2006). The Declaration, written shortly after World War II, marked the first time that the rights and freedoms of individuals were documented and outlined in detail. The Declaration was also the first recognition of human rights and

freedoms internationally, and it continues to influence human rights activism and legislation all over the world (Rioux & Valentine, 2006).

People with disabilities have historically been invisible and excluded from many aspects of mainstream society. There have been many segregated schools, separate housing and specialized transportation for people with disabilities of all ages, most of which were created on the assumption that people with a disability were incapable of coping with society and most major life activities (Wendell, 1996). People with disabilities have been prevented from participating in many aspects of mainstream life; and frequently viewed as people in need of protection, treatment, and assistance rather than people entitled to human rights. They have been denied equal access to the basic rights and fundamental freedoms to which every human being is entitled (Birnbaum & Mosher, 2008). However, a dramatic shift has occurred in recent years, such that people with disabilities are viewed as a group entitled to equal rights. The Canadian Charter of Rights and Freedoms was an important legal document in Canada to ensure this recognition was written into the highest law in the country, and has also assisted in shaping provincial human rights legislation (Birnbaum & Mosher, 2008).

In many societies of the world, including countries that have a relatively high standard of living, people with a disability often encounter discriminatory practices, which prevent them from exercising their rights and freedoms, and make it difficult to participate fully in the activities of society. The human rights perspective of disability advocates full equality for all members of society, regardless of age, gender, ability, race or culture (Birnbaum & Mosher, 2008; Thun, 2007). The disability rights debate is not about the

enjoyment of specific rights. Rather, it is about ensuring the equal enjoyment of all human rights, without discrimination, by people with disabilities. The non-discrimination principle helps make human rights relevant in the specific context of disability (Thun, 2007). Four core values of human rights law are of primary importance within the context of disability: the dignity of each individual, the concept of autonomy or self-determination, equality for all regardless of difference in ability; and solidarity, which requires society to promote and support the freedom of individuals with disabilities by providing appropriate social supports (Birnbaum & Mosher, 2008).

Working-age adults who experience chronic illness and disability frequently encounter unique challenges related to advocacy and service delivery that are not addressed by current services. Additionally, navigating through the health care system can be a challenge for any client who is experiencing illness, but for a client who is already part of a marginalized group, it can be extremely challenging. The use of human rights and anti-oppressive practice theory can assist in developing and evaluating social work interventions with working-age adults who have a physical disability in various health care settings.

Disability and Anti-Oppressive Practice

Anti-oppressive practice is generally understood in Canadian social work theory as a term encompassing a variety of practice approaches that seek to challenge and change expressions of oppression and domination and maximize the potential of social work to promote social justice (Dominelli, 2002). The health care system creates an environment that can be described as oppressive, due to many obstacles and barriers developed from

middle and upper class value systems. The medical model is based on a hierarchal and patriarchal model of power and control. It is essential to work with clients within this system and advocate for essential services while highlighting socioeconomic concerns and barriers from a structural perspective (Mullaly, 1997). Social workers in various health settings can utilize a framework of anti-oppressive practice and human rights in order to assist clients to focus on their strengths rather than their challenges. An anti-oppressive framework is particularly useful for exploring the nature of work with working-age clients with a disability in nursing homes, because it lends value to the concept of client as expert on their own situation.

Anne Bishop (2002) discusses the basic common denominator of oppression to be power and hierarchy, where one group exercises power over another in order to achieve a desired outcome. In the current medical system, doctors and other medical professionals exercise power over the client's treatment, care plans and interventions, resulting in the clients having little or no power over their situation. Social workers are the ideal professional to advocate for the client's right to have input and a voice in their own situation, and help the interdisciplinary professional team to view clients as an expert in their own lives. The strengths perspective assumes that all individual strengths, such as talents, capacities, knowledge, and resources exist in all individuals and communities. Advocacy for client rights and adequate resources is a core value of social work practice which recognizes the importance of including an analysis of material resources, as well as existing social structures that may contribute to client oppression.

Many health care environments including hospitals and residential care facilities maintain environments that can be described as oppressive, due to an expectation that clients must fit the services provided rather than designing services to meet the needs of individual clients. (Bishop, 2002; Dominelli, 2002). Certain clients may be seen as more deserving than others due to differences in class, age and gender (Wendell, 1996). These issues are frequently highlighted by the attitudes and judgments of those who work in the health system (Bishop, 2002). An anti-oppressive framework is useful for exploring the nature of work with working age clients in nursing homes, because it lends value to the concept of client as expert on their own situation.

Role Theory

Developmental role theory looks at the defined and expected roles that one will fulfill over their lifetime. There are several stages of the family lifecycle as outlined by Duvall (1977) starting with how a newly married couple will strive to establish a mutually satisfying marriage and likely consider parenthood while fitting into the family network of both spouses. The childbearing years establish a home for the parents and their children, if they choose to have children. The school-age years include helping children to fit into the community of school and their peer group. The teenage years precede sending the young adults into the world and maintaining a supportive home while balancing freedom with responsibility. This is also a time when parents will likely establish post-parental interests and spend more time as a couple pursuing activities independent of their children. Middle-aged parents rekindle the marriage relationship and begin to adapt to aging. The retirement years usually include adjusting to retirement and coping with bereavement while maintaining family relationships.

Clearly not all life courses will follow this exact pattern, but Duvall's (1977) framework provides a guide for what is typical in a western culture that values productivity and child rearing as typical and desired. This framework does not account for different family structures or childless couples, and also does not account for cultural differences. This framework also does not account for life changing events such as significant illness and how this affects the family. There is no one definition of "family" and the family lifecycle that is relevant across all cultures and family structures (Sigelman & Rider, 2003). It is also important to note that achievements typically associated with adulthood, such as marriage and child rearing, previously occurred earlier in the life cycle. It is more common in recent years to marry later, remain single into middle adulthood, dissolve a marriage or choose to remain childless.

Vandewater and Stewart (2006) discuss how theories of adult development can indicate that personality and social role development can be directly related to a perception of positive well-being. They also outline how Erikson's role theory indicates that those who successfully complete developmental tasks or milestones seen as societal norms can help one to feel increased self-esteem and life satisfaction. The perceived fulfillment of social roles can influence healthy adjustment and coping, particularly during the middle adulthood stage.

Defining middle adulthood in a developmental perspective is helpful when exploring the experience of an individual who may have life experiences that include "off-time" events not typically experienced by all people of that age group at that particular time (Rolland, 1999). It is imperative to consider how illness and disability can affect the

family unit and lifecycle, especially when this affects the spousal and parenting role or results in a member of the family residing separately from the rest of the family.

LITERATURE REVIEW

In my review of the literature related to this topic, I begin by clarifying the common terms used throughout the literature. Then I will discuss the disability movement in Canada, discuss possible research methods with participants who have a disability, and look at autonomy and resident choice within the long-term care system. I will touch upon the issues of relocation stress, and then I will discuss what is presently known about the quality of life of nursing home residents, as well as social work in the nursing home environment. I will discuss the policy that informs long-term care and briefly discuss the current demographics of nursing homes. Finally, I will narrow my focus to look at working age adults with a physical disability who reside in a nursing home facility and describe the gaps in the existing literature.

Current health care terminology contains many terms for a nursing home, and I have chosen to use these terms to describe the type of facility I am looking at, because these seem to be the terms most often used in the existing literature. Throughout my review of the existing literature, I use the terms “nursing home” and “residential care facility” interchangeably. Research from the United States often refers to 24 hour nursing care in a residential facility as a “nursing home.” In Canada, and more specifically the Vancouver area, most health care professionals refer to a nursing home as “residential care.” I opted not to use this term exclusively because it fits many kinds of residential facilities, including residential care facilities for children and teenagers. Health care professionals also often refer to clients as patients or residents; so again, I have chosen to use the terms “client” and “resident” interchangeably. A client can also be someone who is not yet residing in a nursing home facility.

History of the Disability Movement in Canada

Thun (2007) highlights the number of people in Canada who have a disability. Recent estimates indicate that approximately 10 to 20% of the world population has a disability, but Canadian data ranges from estimates of 13% to 31% depending on the source and definition of disability (Statistics Canada, 2001). These estimates typically do not include data from people living on First Nations reserves or people living in Canada's territories. Some research estimates that the number of people with a disability is much higher in remote and northern areas. Statistics Canada (2001) estimates the rate of disability to be 16.7% for adults age 45 to 64. Regardless of the actual numbers, it is clear that people with disabilities comprise a significant portion of the population.

Reported disabilities in Canada include physical, emotional, and psychiatric conditions, and it appears that disability of women is more highly reported (Statistics Canada, 2001). The five most commonly cited conditions related to disability include heart disease, back problems, arthritis, diabetes and orthopedic impairments, with women more frequently reporting these conditions than men (Olkin, 1999). Details of the majority of disabilities that are included in the statistical reports that shape legislation and policy, are based on disability that is related to activity limitations or conditions that affect activities of daily living, such as self-care and leisure activities. Activity limitations related to emotional and psychiatric conditions are common in adults between the ages of 45 and 64, according to the Canadian census information collected in 2001.

The nature of disability has been defined medically, socially, economically and socio-politically (Hayashi, 2007). The United Nations definition of disability is considered to be a function of the relationship between people with a disability and their environment

(Wendell, 1996). The structure of a nursing home discourages residents from independence and autonomy in their daily life, instead requiring residents to conform to a schedule for all activities of daily living. Disability is a restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being, and there appears to be a substantial gap between national, international and legal definitions of disability (Wendell, 1996). The concepts of disability, equality and citizenship are central to advancing the basic human rights of people with a disability (Rioux & Valentine, 2006).

Thun (2007) also reviews several landmark cases and explores how three key pieces of Canadian legislation have shaped the human rights movement for people with disabilities. The Employment Equity Act of Canada, the Canadian Charter of Rights and Freedoms and the Canada Human Rights Act have all been integral in shaping human rights in Canada. Additionally, each province or territory has their own legislation addressing human rights, such as the Human Rights Tribunals and the Citizenship Commission. The disability movement and human rights are directly linked. Although various research indicates that disability rights and equality under the law still fall short of ideal, there have been many active movements to assist with changing this fact. Current policy is based on valuing independence and promoting equal status for people with disabilities under the law (Hayashi, 2007).

Research with People Who Have a Disability

The field of social work requires more research directly involving people with disabilities, but the existing literature indicates further studies can pose some challenges due to lack of understanding of disability issues, lack of access to people with a disability,

the disempowerment and invisibility of many people who have a disability and communication barriers (Eckhardt & Anastas, 2007). Participatory action research has been suggested as a way to involve people with a disability and other disadvantaged groups to assist with the design and conduct of the research study. Eckhardt and Anastas (2007) also suggest use of qualitative research methods as a way of empowering research participants, so they can be involved in how their stories are analyzed and interpreted.

Accessibility is an important aspect to consider when designing a research study that will include participants who may have special communication needs, or accessibility needs such as access to a building where the interview is taking place or special communication devices (Statistics Canada, 2004). In order to reduce barriers to participation in research, those who conduct research must survey methods on how to best conduct research with people who have a disability, and involve those who will participate in determining accessibility needs prior to commencing research (Creswell, 2003).

Autonomy and Choice in Long-Term Care

Nursing home facility care is primarily based on the medical model, which focuses on the biological needs and functioning of each resident. Sacco-Peterson and Borell (2004) conducted a study on the daily life in a nursing home and found the nursing home routines often actually discourage residents from being independent. Additionally, nursing home culture often requires residents to overcome greater physical and cognitive challenges to maintain dignity and autonomy than if they were living independently. For example, residents are often encouraged to adhere to a schedule rather than maintain as much independence as possible within the nursing home setting in order to sustain a consistent schedule for the facility staff. However, in recent years there has been a shift in

the style of care being provided, and innovative practice such as the “Eden Alternative” are being promoted (Sacco-Peterson & Borell, 2004). The Eden Alternative seeks to reduce three common negative aspects of residential care facilities: loneliness, helplessness, and boredom (Roth, 2005). The Eden Alternative is a community-centered approach committed to “creating a human habitat where life revolves around close and continuing contact with plants, animals and children. It is these relationships that provide the young and old alike with a pathway to a life worth living.” (Roth, 2005). This approach is used within many facilities within British Columbia in various degrees.

Culture change is defined as a departure from the traditional model of care being provided that tends to focus only on physical needs (Ronch, 2004). Person-centered care allows an expansion of choice and autonomy in a setting where there is often little of either (Ronch, 2004; Roth, 2005). Linzer (2002) reminds us that it is important to honour clients’ autonomy while still promoting safety and attempting to minimize the risk of harm. If ethical issues arise in assessing care needs and clients refuse care, the resolution of these ethical conflicts is deeply influenced by client capacity. Linzer (2002) also notes that approximately 5% of people over the age of 65 in the United States will require institutional care at some point during their elder years. However, home care services have significantly reduced the need for formal nursing home care and people are able to remain in their homes longer. This has also helped to decrease the overall cost of institutional care services and provide more personal service to clients who wish to remain at home (Linzer, 2002).

Relocation Stress in Long-Term Care

The majority of existing literature on adjustment to residential care facilities is based on the experiences of older adults. Nevertheless, some of the findings are also applicable to younger residents who enter a nursing home environment. Brook (1989) outlines the four phases in the process of adjusting to living in residential care: disorganization, reorganization, relationship building and stabilization. The disorganization phase typically lasts for a period of one to eight weeks and is a direct result of dealing with a sudden move into a residential care facility and dealing with resulting losses related to this move. The reorganization phase typically lasts around two to three months and evolves when the resident begins to find new meaning in their life, increase problem-solving ability, and identify and express preferences related to their care. The relationship-building phase usually commences after about three months in a care facility and involves creating and maintaining connections with family, friends, staff and other residents. The stabilization phase usually commences around the six-month mark and adjustment to the care home environment is evident at this time. Residents often appear more outgoing and secure with changes at this phase, which will likely affect how they view their living situation. This model is helpful in understanding the adjustment process, but fails to acknowledge the outside factors involved in accessing residential care or what alternative services could be accessed in place of a care facility.

There are three phases associated with relocation to a nursing home setting: the pre-move phase, the move itself and the post-move phase (Jackson, Swanson, Hicks, Prokop & Laughlin, 2000). Move preparation and continued follow-up post-move helps to decrease the level of relocation stress experienced by clients (Lander, Brazill & Ladrikan,

1997). Relocation stress is defined as a state in which an individual experiences physiologic and psychological disturbances as a result of a physical transfer from one environment to another (Tickle, 1993). Residents can also experience significant depression as a facet of relocation stress. A move that is seen as voluntary, desirable and reversible, is more likely to be viewed as a positive experience than a move where the client has little or no choice and involvement with the move (Gass, Guastad, Oberst & Hughes, 1992). Health care providers need to ensure they are providing timely and accurate information in order to facilitate a positive relocation.

Residents and families report that participation in the process, ability to have input in the decision to relocate, and access to regular accurate updates of information were crucial in order to facilitate a successful relocation process (Nolan, Walker, Nolan, Poland Curran, Kent & Williams, 1996). Preparing the new resident and their family prior to the move is an essential part of the process and helps to ensure that there is collaboration between care providers in different areas of health service, and this is an essential role of social work in all areas of health care. The role of the residential facility is to collaborate with the current care providers as well as the potential resident to help plan and disseminate information prior to admission. An opportunity to visit the care facility prior to admission is also helpful in preparing the resident and their support system, as this often helps to decrease anxiety and provide a glimpse of what is to come.

Other useful strategies suggested by Krout and Wethington (2002) include the use of approaches such as a buddy system to link new residents with long-term residents, formal welcome activities such as sharing information about the new resident, increased communication with family members and the use of written information to ensure

accurate transfer of information. Additionally, Jackson et al. (2000) suggest the use of care planning and family conferences during the post-move phase in order to facilitate communication and address any concerns in a timely and appropriate manner.

Social Work in Nursing Homes

Social workers are an essential part of the health care team in nursing homes, and social work practice in nursing homes has only recently been extensively studied. The existing literature indicates that social workers in nursing homes are often frustrated and dissatisfied by their jobs (Parker-Oliver & Kurzejski, 2003; Vourlekis, Bakke-Friedland & Zlotnik, 1995). Social work responsibilities in a nursing home often centre on psychosocial well being, care planning, grief and loss, and admission and discharge planning (Koren & Doron, 2005). Unfortunately, many social work roles in nursing homes become laden with paperwork, and consequently less time is available to assisting residents to make decisions, provide counselling, and engage in care planning. There is an assumption that staff members know what is best for the resident, and that residents must fit into the plan we make for them, rather than fitting the plan to the resident, and this is an aspect of care that social workers can certainly address (Goffman, 1961; Meyers, 2006; Parker-Oliver & Kurzejeski, 2003).

Nursing home culture is often based on the medical model and can be rigid and problem focused (Meyers, 2006; Roth, 2005). The focus of care can often centre on what people are unable to do, rather than working from a strengths-based perspective. Bartlett and Baum (1995) show that often there is no follow up with clients after admission to a nursing home if a hospital social worker or discharge planner helped to arrange the admission. If there is no residential care facility social worker available, adjustment to the

nursing home may be even more difficult. Many residents reported being disappointed in the lack of support and follow up after admission (Bartlett & Baum, 1995).

Parker-Oliver and Kurzejeski (2003) highlight the need for social workers in nursing homes to have knowledge of gerontology and mental health. Research data from the United States indicates that up to 80% of nursing home residents have some form of psychiatric condition, the most common being depression. Ryff and Heidrich (1997) agree that depression is prevalent among middle age adults who have had a non-normative experience, such as serious illness or becoming disabled. The skills of social workers in residential care are essential in addressing issues of relocation stress, depression, adjustment and strengths-based care planning.

Quality of Life of Nursing Home Residents

There are several studies that consider the perceived quality of life of nursing home residents. Watt and Konnert (2007) looked at quality of life in nursing homes for two groups of residents, and tried to establish a connection between quality of life and health, social support and leisure activities. Measures of social support and leisure activities included frequency of visitors, presence of a confidant relationship, frequency of involvement in activities and frequency of leaving the nursing home. This study brought forward important information and demographics of the residents, such as highlighting that 10% of residents under age 65 are living in residential care facilities, but did not document the lived experience of each resident in a way that highlighted important themes within their experience.

Institutional policies and the nursing home philosophy of care are similar for both younger residents and residents over the age of 65 (Franks, 2004). Several studies have

highlighted some of the difficulties of institutional living for residents of all ages, and suggested that this is more apparent with younger residents, as placement in a nursing home is a non-normative experience for a middle-age adult (Ryff & Heidrich, 1997: Watt & Konnert, 2007).

Unique threats to quality of life of nursing home residents include being physically separated from loved ones, a possible decline in social support as a result of this, and a perceived loss of control (Franks, 2004: Watt & Konnert, 2007). Harris and Cooper (2006) state that approximately 60% of nursing home residents suffer from depression, and depression is often a key factor in the decision to pursue admission to a nursing home. Melrose (2006) tells us that depression is frequently overlooked in nursing home residents, and that many residents will deny depressive feelings yet emphasize somatic and non-specific complaints that may indicate depression as an underlying cause. Melrose (2006) estimates that 12-16% of nursing home residents suffer from major depression, and approximately 50% of residents have symptoms of mild to moderate depression.

Goffman (1961) details the dehumanization of institutions, including the nursing home, and suggests the atmosphere be revitalized, describing the setting as within the concept of a total institution. Most facets of life are carried out in an unnatural way within an institutional setting, and these activities of daily living are controlled by an authority external to the residents or inmates (Goffman, 1961). Ronch (2004) studied the struggle to change the culture of nursing homes and “humanize” care to make the environment less institutional. Ronch (2004) hypothesized that quality of life of the residents would improve when life inside a nursing home more closely resembles life outside a nursing

home, but the research data did not clearly show a correlation between these two factors. Further qualitative study may be effective in continuing to shape this theory.

Franks (2004) explored perceptions of quality of life of both nursing home residents and residents in an assisted living facility. “Assisted living” facilities provide housing and personalized health care, while maximizing independence and dignity. Previous research indicates that people of all ages attempt to avoid nursing home placement, so Franks (2004) hypothesized that residents in an assisted living facility would report a greater quality of life than residents in a nursing home. The findings did not show this however; residents in both assisted living and nursing homes reported a very similar perceived quality of life, with both group making similar statements about their quality of life. There appeared to be little difference in perceived life satisfaction between residents from each of the two different types of facilities.

Assisted living facilities are frequently marketed as more desirable than nursing homes and able to offer greater choice, privacy and autonomy. Residents who are admitted to an assisted living facility must fit very specific criteria and must be able to direct their own care, which is challenging for many residents who live in a residential care facility. Assisted living is a relatively new concept and many facilities are still changing their client demographics and admission criteria (Franks, 2004). It may not be realistic to compare nursing home residents to assisted living residents because most clients admitted to nursing homes would not fit the criteria for assisted living. Hospital discharge planners try to arrange the least intrusive measures and would likely not recommend a client for nursing home placement unless it was absolutely necessary (Meyers, 2006).

Potential government-funded nursing home clients also must qualify for a higher level of care under a risk assessment tool in British Columbia (Fraser Health, 2009). Additionally, a client with a chronic progressive illness such as Multiple Sclerosis would likely not qualify for an assisted living situation in most areas, as the admission criteria often excludes clients with a progressive illness. Many young clients with a progressive illness will be referred to a group home situation or residential care, rather than assisted living. There is some data available on working-age adults residing in a group home situation, but a great deal of this research is focused on adults with intellectual disabilities, rather than those with physical disabilities.

Nursing Home Demographics

There is little data available on working-age adult residents who live in nursing homes in Canada. The Minimum Data Set (MDS) assessment is one tool that is useful for obtaining demographic information, and the MDS is widely used in the United States. Miller (2007) states that the number of nursing home admissions for working age clients age 18-64 has increased from 10% to 12% in some areas of the United States over the past ten years. This increase is most significant between 2000 and 2004, according to data collected by the Minimum Data Set assessment. The MDS data from the United States also shows us that nursing home residents under age 65 are predominately male, of minority ethnic status and of low socioeconomic status. There appears to be a correlation between low socioeconomic status and likelihood of admission to a care facility, as clients who can hire private support services appear to be less likely to require admission to a care facility.

Resident demographic information collected by the Minimum Data Set (MDS) assessment tool in Alberta shows that residents under age 65 make up 10% of the nursing home population in the Calgary area (Watt & Konnert, 2007). There was no recent relevant demographic data available for British Columbia or the Lower Mainland area. Miller (2007) also states that 42% of the residents interviewed stated they felt very involved in the process of making the decision for nursing home admission. Working-age individuals are a growing segment of the nursing home population. Common conditions of younger residents in Miller's study included cardiac disease, diabetes, paralytic symptoms and a prior stroke. Miller's study also highlights how little attention is given in the existing literature to client involvement in the nursing home admission decision, and this research data shows that admission to a nursing home critically shapes the life of the person admitted.

Residential Care Policy in British Columbia

The policy that regulates nursing homes in Canada is both national and provincial in nature. All nursing homes must follow basic licensing standards in order to remain functioning. There are two types of nursing homes: government run "owned and operated" facilities (Fraser Health, 2008) and those owned and run by private companies. The funding for nursing homes in British Columbia is primarily from the government, although there are a number of nursing homes that are run by private companies and also receive government funding for a certain number of beds. Clients may access publicly funded nursing homes through each health authority and can often wait for months before being admitted to a publicly funded nursing home bed. The Fraser Health Authority developed an FAAB (first appropriate available bed) policy that indicates clients must

accept the “first available bed” in the region. This can result in clients being placed in a less than ideal setting, and there is little choice in facility unless one can afford to pay privately.

The Fraser Health Authority’s “First Appropriate Available Bed” policy was developed in 2003 to expedite the process of accessing residential care. Prior to this policy, potential clients were able to tour facilities and be placed on a wait list long before they needed to move into a care facility. However, the number of clients who required a care facility bed far surpassed the number of beds available, so this process was no longer feasible since it did not take into account a client’s level of need. Clients could choose to be on a waitlist for several facilities and would be admitted based on their waitlist date rather than their care needs.

The FAAB policy states that priority will be given to patients with the highest need and who are at the greatest risk if there were to remain in their own home. Clients who are deemed eligible for residential care are obligated to accept the “first appropriate and available bed” offered in their preferred geographic area. Depending on residential bed availability, specific care requirements, level of urgency and acute care facility congestion, clients may be required to accept a bed outside their preferred geographic area but still within the Fraser Health boundaries, which are from Burnaby to Boston Bar, as some specialized services are centralized in specific geographic areas (Fraser Health, 2009). An example of this would be ventilator-dependent clients who presently can only be accommodated at particular facilities. The policy also states that once a client is notified of an appropriate and available bed, they will be admitted within 24 to 48 hours.

The FAAB policy states that “following a comprehensive assessment of the clients using standardized assessment tools and in consultation with the family, interdisciplinary team and responsible physician, the client and family are advised to consider residential care as the client’s care meets the eligibility for publicly funded residential care” (Fraser Health, 2009). In reality, though residential care is based on need, these assessment tools are not fail proof, as they are designed to assess someone’s physical needs and do not reflect all the underlying factors that may need to be considered in recommending admission to a care facility, such as caregiver stress or lack of sufficient home support. A client who does not meet the standard criteria for residential care can be placed “by exception to this policy” (Fraser Health, 2009).

It is important to obtain an understanding of the process of residential bed access, as this is also the beginning of the process that admits young clients to residential care. Most of the residential care facilities in Fraser Health follow the process as outlined above, although some make exceptions based on compassionate grounds, such as significant distance from family. Despite this process, there has been no exploration of alternative services in many areas of Fraser Health. The Vancouver Coastal Health Authority has the George Pearson Centre, which is a residential care facility designed specifically for adults who have a disability, but there is no comparable facility within Fraser Health.

Conclusion and Research Question

As the number of working-age residents who live in residential care facilities continues to grow, the psychosocial needs of these residents needs to be addressed. When a working-age adult is residing in a facility designed for seniors, there is significant risk of

loss of autonomy and choice, especially in cases where the resident has limited social support. Working-age residents need to be given the opportunity to maximize their independence, explore alternative services and improve upon their quality of life. The existing literature shows a gap in knowledge about the experience of working age adults residing in a nursing home. Therefore my research question is: **How do working age adults with a physical disability experience living in a residential nursing home designed for a geriatric population?**

METHODOLOGY

My research question arose out of a desire to understand the experience of individuals who reside in a setting that is not specifically designed to meet their needs, one in which individual autonomy and choice is often not promoted or valued. This qualitative exploratory study sought to provide a venue for participants to share their experiences, concerns and suggestions about the residential care environment. My chosen mode of inquiry is a descriptive narrative approach, which tells the story of individuals while collecting data that consists of conversations or “stories” through the reconstruction of life experiences and situating them within a broader context (Creswell, 2007).

A descriptive narrative approach assumes that human beings organize their experiences of the world into narratives. Additionally, the stories that are told depend on the individual’s past and present experiences, values, and when and where these stories are told (Maxwell, 1996). The audience of a story can also influence what information is shared and when. This research design allows many aspects of the participant’s experiences to be explored in a way that allows for richness and breadth of the data, and also validates these experiences as being significant and valuable. The results of the study are therefore a combination of my own interpretation of the meaning of the experiences being shared and results of “member-checking” (Maxwell, 1996).

Sampling

I have been a member of a Fraser Health regional social work group for social workers who work in residential care facilities for the past two years, and though I resigned from my position in residential care during the data collection phase of this research, I was able to successfully utilize a third party recruitment method to recruit

participants. After obtaining Research Ethics Board approval through both the University of British Columbia and the Fraser Health Authority, I utilized my collegial connections through the regional social work group to recruit participants. I provided a copy of my recruitment poster (Appendix C) and invitation letter (Appendix B) to each Fraser Health facility social worker, and asked them to distribute the information to any resident within the facility who fit the recruitment criteria and would possibly be interested in participating in the study. Seven participants were recruited by this strategy and one participant was recruited by snowball sampling, as another participant shared the study information with her and encouraged her to participate. Potential participants initiated contact with me by email or telephone. Initially, I had twelve respondents, two of whom did not meet the recruitment criteria and two of whom later decided not to participate in the study, as it became challenging to set up a mutually agreeable interview time. I followed up with each potential participant either by telephone or in person depending on the functional abilities and preference of the potential participant.

I did not strive to find a statistically representative sample as my goal for this study was to convey a “flavour” (Mason, 2002) of the experiences, successes, and challenges faced by working-age residents who live in residential care. My initial goal was to conduct interviews with between eight and twelve residents of Fraser Health owned and operated residential care facilities, as I felt this would be a sufficient number of participants to gain a sense of “flavour.” I chose to exclude residents from facilities that were run by a private company due to the complexities involved in obtaining permission to conduct research within these facilities. I also assumed there would be similarities among owned and operated facilities that are run under the guidelines and funding of the Fraser Health

Authority, as standards are mostly consistent among these facilities. Furthermore, recruitment proved to be much less challenging in facilities where I already had a professional contact, as many of the social workers I spoke with were interested in my research project and willing to assist with recruitment.

The study recruitment criteria specified that participants had lived in a Fraser Health owned and operated residential care facility designed for geriatric clients for a minimum of six months at the time of the interview, in order to ensure richness of the data and sufficient time for the person to have adjusted to the care home environment. Two potential participants did not meet this criterion and thus did not participate in the study. Another participant had lived in residential care for only four months at the time of our initial contact, so we mutually decided to delay the interview for two months to allow him more time to adjust to the environment. Silin (2001) and Brook (1989) both state that it typically takes a minimum of four to six months to acclimatize to a new or changed environment. This timeframe will help to ensure that each participant has had sufficient time to adjust to the residential care setting and example of their lived experience to share during the interview.

The study criteria specified that participants must be between the ages of 19 and 60 years old, have a physical disability, able to communicate in fluent English, and be willing to participate in one or two in-person interviews of approximately 60 minutes each. Due to ethical concerns, I only interviewed residents who were able to provide voluntary and informed consent, and who were willing and competent to participate in the interview process. Most of the participants were able to independently read and sign the consent

form, and those who required assistance to do so were assisted by myself, facility staff or a family member to ensure they understood the study procedures and consent process.

The ages of the eight participants who were interviewed for this project ranged from 22 years to 59 years at the time of the interview. In my review of the literature, Ryff and Heidrich (1997) identified “middle adulthood” as being an age range from early to mid forties and upwards, so initially this appeared to be an appropriate age range for my participants as I had initially planned to focus the study on adults between the ages of 45 and 60. However, during the course of my recruitment, several residents who were younger than 45 years old expressed an interest in participating, and after consultation with my thesis supervisor, it was decided to include these participants as well in order to ensure richness of the data. These participants provided a unique and valuable perspective to the study.

Interview Procedures

In my initial contact with the potential participants, I outlined the purpose of my research, structure of the interview, consent procedures, and expected time commitment involved for participation in the project. Once the participant expressed an interest in being interviewed, I provided them with a copy of the consent form (Appendix D) and set up a mutually agreeable time and place for the initial interview. I had planned to conduct an initial interview of approximately one hour with each participant, keeping in mind that it may be necessary to conduct several shorter interviews rather than one longer interview, depending on the physical abilities and preference of the participant. Each interview was audio recorded and transcribed into a typewritten document for further analysis. At the start of each interview, I reviewed the rationale and background of the study, as well as

explained the consent for participation in the study and ask each participant to sign the consent form (Appendix D). I also explained that participation in the process is voluntary and participants may choose to cease participation at any time during the process. The interviews were semi-structured and open-ended questions were asked, following the interview guide (Appendix A). All participants were given an opportunity to review the transcripts and preliminary themes that I collected from the initial phases of data collection and provide feedback, though only two of the eight participants opted to do so.

Data Collection

I tried to be cognizant of any accessibility issues in order to allow any resident who met the pre-screening criteria to participate in the study. One of the significant accessibility issues that arose was that one participant's limited vision did not allow her to read the consent form, so we went through it verbally to ensure she understood the process. Additionally, all of the participants in this study had limited mobility and chose to be interviewed in the facility in which they lived. This presented some challenges with regards to confidentiality due to the close proximity of staff members and other residents. Most of the interviews were conducted in each participant's private room; however, two of the participants shared their room with another resident. In these cases, the interview was conducted in a private conference room or the social worker's office on a weekend when these spaces were available.

The interviews were designed to be relatively unstructured and conversational in nature. By self-disclosing my experiences working within the health system, motivation for doing this research and reasons for my personal interest in this topic, I believe this helped the participants to see me as a potential ally and allowed me to develop a genuine

rapport with participants. I feel this also increased the richness of the data, which helped to guide my interpretation of the themes. The majority of interviews lasted approximately 45 minutes, and each interview was tape recorded and transcribed in its entirety.

Data Analysis

The data analysis process of the research began shortly after I conducted my first interview. After the interview was transcribed in its entirety, I reviewed each transcript individually in order to search for potential themes and significant statements. My initial plan for data analysis involved simultaneously collecting and analyzing the interview data. This proved to be valuable in that the initial data I collected contained themes that I had not previously considered and challenged me to reconsider the wording of some of my interview questions. An advantage of starting the analysis while I was still in the process of completing interviews was that I was able to make small adjustments to some questions, such as what each participant would change about their living situation, based on data and insights from previous interviews.

I began formal data analysis with thorough readings of the transcribed interviews by highlighting recurrent and significant statements. I began to identify recurring topics of discussion among the transcripts and identify preliminary groupings. Next, I grouped related statements under broad categories and reorganized the statements within the categories to generate sub-themes. From this process, I was able to define themes that capture the experience of being a working-age adult who is living in a geriatric nursing home.

Validity

Validity cannot be determined through objective measures or statistical tests in qualitative research (Maxwell, 1996). I employed several techniques to demonstrate the validity of my study. I am giving voice to my research participants by allowing them to guide the interviews through the use of semi-structured interview questions, and by quoting them verbatim in my final paper. The participants assisted me in guiding the focus of the interview and in several cases, led into topics I did not anticipate. I completed a review of the existing literature relevant to my study in order to ensure I will be able to place the results of these interviews within the existing body of knowledge. In the personal interest section of the thesis, I discuss my motivation for doing this particular research, and I have considered some of the ways in which my previous experiences and biases could influence my findings.

The process of requesting a participant's feedback regarding data and research findings, called "member-checking," is extremely important in assuring that participants' meanings have not been misinterpreted (Maxwell, 1996). Two of the participants opted to read over the interview transcript and my preliminary data analysis prior to writing up the final analysis. Soliciting this feedback from my participants helped to ensure that their experience has been captured within the data analysis and context of quotations. I anticipated doing follow-up interviews with participants who required a shorter timeframe for the initial interview to clarify what had been discussed in the first interview, but none of the participants felt this was necessary.

Once I completed the preliminary data analysis, I summarized my findings and delivered this information to participants, soliciting feedback. Unfortunately, only two of

the participants responded. The participants who took part in this stage of the research agreed that the themes I had identified captured their experiences. Both reviewed the excerpts of each interview I used in the thematic analysis. I shared a draft of my initial findings and both communicated they were satisfied with how I had interpreted their words.

Ethical Considerations

Permission to conduct this study was obtained from the University of British Columbia Behavioural Sciences Committee for Research and Other Studies Involving Human Subjects (Appendix E), as well as the Fraser Health Authority Research Ethics Board (Appendix F). All participants received a copy of the consent form, which was explained prior to commencing each interview and signed by the participant. The names of the participants were kept confidential and all names and identifying information was removed from both the written transcripts and final results of the study. The audio recordings and written transcripts were kept in a locked cabinet for the duration of the study, and access to the documents were limited to the researcher and primary research advisor. Interviews were conducted at a time and location of the participant's choosing and interviews were conducted in a private location such as the participant's private room or a private conference room.

Participants

A total of eight adults, four men and four women, participated in this study. All participants lived in a care facility owned and operated by the Fraser Health Authority in the Greater Vancouver area at the time of the interview. Details about the participants' characteristics are summarized in Table 1, and brief descriptions of the participants follow

in the form of a personal narrative. Pseudonyms have been randomly assigned by the researcher in order to maintain the confidentiality of the participants.

Table 1: Characteristics of Participants (N=8)

Participant	Gender	Age at time of interview	Length of time living in residential care	Age at time of admission to residential care
Ken	Male	56 yrs	6 months	56 yrs
Pamela	Female	59 yrs	1 year	58 yrs
David	Male	57 yrs	1.5 yrs	56 yrs
Jack	Male	53 yrs	2 yrs	51 yrs
Kimberly	Female	22 yrs	2.5 yrs	19 yrs
Randy	Male	36 yrs	3 yrs	33 yrs
Lisa	Female	58 yrs	3 yrs	55 yrs
Rebecca	Female	57 yrs	6 yrs	51 yrs

Ken

Ken has lived in a residential care home for six months. He was diagnosed with Multiple Sclerosis several years ago and now uses a wheelchair to mobilize. Ken is married to his wife of 30 years and they have two children. He lived at home with daily home support services until a hospital stay of nearly a year due to a recurring infection and pain management issues. He stated that he decided he would move into a care facility due to his wife’s increasing caregiver stress.

Pamela

Pamela moved into a residential care facility after her husband, who was her caregiver, passed away. She has lived in a care facility for just over one year and hopes to return to living independently in the community. Pamela does not have any children or close family.

David

David is married and has two children. He has lived in a residential care facility for 18 months. David has a rare neurological disease that affects his mobility and energy, so he spends most of his time in bed watching television and surfing the internet.

Jack

Jack is a 53 year old man who has lived in a residential care facility for two years. He is in a common-law relationship and has three grown children who live in another province. Jack has Multiple Sclerosis and previously worked as a computer technician.

Kimberly

Kimberly is a 22 year old Asian woman who has lived in a care facility for two and a half years. She was diagnosed with Multiple Sclerosis several years prior to her move to a care facility and she spent nearly a year in the hospital before moving into the care facility where she now lives. She has a supportive family and states her mom has been her primary source of support during her illness.

Randy

Randy worked for an electronics company and in construction before an accident resulted in paraplegia. He spent a long period of time in hospital and a physical rehabilitation facility prior to moving into a residential care facility. Randy is single and has one sister, an uncle and his mother who are very supportive.

Lisa

Lisa is a 58 year old woman who identifies her family background as including First Nations ancestry. She has lived in a residential care facility for three years. She describes herself as “feisty” and frequently questions the policies in the facility. Lisa’s

family visits but not frequently. Lisa is single and does not have any children, although she states she is quite close to her niece.

Rebecca

Rebecca has lived in a residential care facility for six years, after a severe stroke left her unable to walk. She is married and has one son and many supportive friends.

Rebecca describes herself as a hopeful person and very social.

FINDINGS

A diverse range of topics arose during the course of the research interviews. The participants spoke about their journey prior to moving into a care facility and these personal narratives have been included in order to provide context and give a fuller picture of the lives of each participant. The following main themes and numerous sub-themes emerged from the research data. These themes are (1) admission stories, (2) coping and adjustment, (3) relationships, (4) institutional culture and environment, and (5) hope. Some of the subthemes that emerged include experiences of grief and loss, loss of autonomy and choice, changes in family relationships, relationships with staff and older residents, social support and advocacy and perceptions of “fitting in.”

For the purpose of this section and the discussion section, I sequenced the themes to capture the experience of living in a residential care facility designed for a geriatric population. These themes create a powerful picture of the complex experience of being an adult with a physical disability who lives in a care facility that has not been specifically designed to meet the needs of non-geriatric clients. The quotations in the following sections are taken directly from the transcribed interviews, and some of these excerpts have been slightly edited for clarity and conciseness where necessary. All potentially identifying information has also been removed from the data.

Many of the participants spoke about what their life was like prior to moving into a residential care facility and the events that led up to this occurrence. The following personal narratives provide context and a fuller picture of the lives of the participants prior to presenting the themes of the research study. Participants spoke about how illness and disability affected their lives and how their lives changed after moving into a residential

care facility. It is important to note that all of the participants in this study acquired a disability or illness in adulthood rather than having experienced a disability from birth or childhood.

Personal Narratives: How Did I End Up Here?

Rebecca describes what her life was like prior to her move into residential care:

My life before was very, very busy. I worked full time and I had a black lab dog that was the love of my life. And I would walk him for a good 45 minutes in the morning before I went to work and then I would walk to work. I worked in a meat store at that time, a fresh meat store, high end. It was a really good place to work. The employers were terrific and in fact have become very good friends over the years. I still miss my dog and I miss running a home. I love to bake and cook and entertain which of course none of that can be done in here. When I was 52 I had two severe strokes, which took away my ability to walk and the ability to use my left hand. And my husband still works but his job entails that he travels out of the province for long periods of time. We did try home care, 24-hour care at home, but we weren't really blessed with our choice of homemaker unfortunately, and we had some severe problems with her. So just to have ease of life, I guess, without confrontation and worry, my husband and I decided this was probably the best place for me while he still works. And I agreed to that. (Rebecca)

Randy moved into residential care after an accident:

I had a bad experience with drugs. Um, did some crystal meth and eight days after I did I had a flashback and jumped out of a high rise ten stories high. So I've been tied up with that now for the last three and a half years. Almost four years. So now I'm here in care but I was in [the hospital] before that. I stayed there for five months and I stayed at [a physical rehabilitation facility] for five months and then I came here. (Randy)

Ken was living at home with his wife and two children when he developed the early stages of Multiple Sclerosis. He relays how it became challenging to remain living at home with his family:

I have a wife and two children. One just turned 25 and one will be turning 19 in August. The older one, he took it pretty hard. He moved out after I was diagnosed. The youngest one, I had to move into another room because my wife works. I couldn't sleep in the same room as her anymore. So the younger one moved in the room with me for two years in case I needed anything, which was quite noble of

him to do that. And, um, I was getting along fine. I had great home care. I mean, they were right part of the family. And then this illness started coming up, so I was in the hospital for awhile and then I moved into [the care facility]. (Ken)

Pamela spoke about the difficulties of making the decision to move into residential care after her husband passed away unexpectedly:

It was like it wasn't even my decision. Everyone in the hospital said this is the only place you can go and my sister agreed with them. I waited in the hospital [for months] before I finally moved, and when I did it was almost a relief because I knew where I would be living. I wanted to go back home, but there was no one to help me anymore. I didn't even have time to grieve after my husband died because all the staff kept asking me questions for the [residential care] assessment. (Pamela)

Kimberly had been in the process of moving out on her own when she became ill:

When I got sick, well what happened was, my family, we were all living together and then my dad and my grandma wanted to move back to [Asia]. So my dad and my mom and my grandmother were all moving back. My mom came back here to help me move into an apartment – me and my brother. And then when she came she saw me hospitalized and ever since she hasn't been able to go back. She's been taking care of me ever since. If I wasn't here, it would be hard for my mom to take care of me herself at home and stuff. Mom and my brother came and took a tour of [the care facility]. Yeah. And then they said, 'This place seems like the best place.' So we applied for it because at the time, I wasn't as healthy as [I am] now. When I first came here, you know, like I could move my arm and hands and stuff but I wasn't able to move my legs or anything like that. (Kimberly)

These personal narratives provide context to the participants' experience of illness and the decision to move into a care facility, and the information is important to help understand the journey from home to hospital to a residential care facility. All of the participants in this study spent time in an acute care hospital prior to moving into a residential care facility for geriatric clients. Some participants also had home support services prior to moving and several had lengthy stays in a physical rehabilitation facility.

Several participants also shared their thoughts about the transition from hospital to a residential care facility and the information, or lack of information, they received during the process of planning for their care needs:

No, actually I didn't have a tour beforehand. I just, my doctor recommended it and [my husband and I] both agreed. I didn't really know what to expect, but I figured it would be just another part of the hospital really. I came from the hospital to here and I figured it was just an extension of the hospital. I knew it was primarily older people. And I've only ever lived in a government subsidized residence. I have never lived in a private care facility, which I understand is different. (Rebecca)

Pamela was aware she would be moving into a care facility, but said it was still a shock when moving day arrived:

I didn't have a chance to say anything because I was up in the hospital. And they said to me, 'Okay, we're going to over to residential care' I said, 'When?' She said, 'Right now.' So it was like no warning. I just...I knew eventually it would happen but not just like that. That was kind of...awful. I was enjoying the hospital. They never stopped me from going out and doing things so...it was okay there. The only relief was that I finally knew where I would be living. (Pamela)

Doctors encouraged several of the participants to move into a care facility. Ken shared how his doctor recommended he consider moving into a care facility from the hospital instead of returning home to live with his family:

My doctor said to me, 'What are you going to do now when you get home? Your son, he's in school. Your wife is gonna be at work. You're leaving your family right now.' And I didn't really think about it until I got home and I thought, now I've left all the people that meant so much to me in the hospital. I don't have them anymore. So I have a new family now here in [the care facility]...and I'm loving it. (Ken)

Jack moved into a residential care facility when he was unable to remain at home due to limited home support hours:

A nurse came to the house and she said that they couldn't send in any more support staff because it was too expensive. I offered to pay for more and she said it didn't work that way. We would have had to hire a private company and it was too much money. I thought there would be another way, but when I went to the

hospital, they said it was either private [home] care or a nursing home. I refused to go to a nursing home but here I am. (Jack)

Relationships

Relationships were a predominant theme that emerged over the course of the interviews. Subthemes under this category include: relationships with family, including spousal relationships, relationships with children and social relationships with friends and extended family. Participants also spoke about relationships within the facility, including their relationships with older residents and care facility staff.

Relationships with Family

Several participants spoke about their extended family and how their relationships have changed since they moved into a residential care facility. Pamela shared how her siblings frequently promise to come and visit but rarely do: “My family keeps saying, ‘Oh we’re going to bring you up some pictures.’ Yeah, yeah. They don’t keep promises. That’s the way they are.” (Pamela). Randy spoke about how his family visits frequently and are a source of support for him since he has lived in a care facility:

But I’ve got my sisters and my uncle and my mom and that so that’s good. Yeah my sister, my one sister comes and my mom comes all the time. And my uncle comes every couple weeks too. He comes out and stays with my mom on the weekend. (Randy)

Ken shares how his family dynamics changed when his son moved out right before he moved into the care facility:

Yeah well I left a good place. I left a nice house, um, all done up for me. My wife and my children lived there too. But then when I got really ill, the oldest one moved out. I guess it was time for him to move out. (Ken)

Changes in Relationship with Spouse

Rebecca shared that it can be a challenge to maintain the relationship with a spouse after moving into a care facility:

You have to consciously work on relationships in here if you're still married, you know. It's been very different for me, but it's been very different for him as well. I have to keep that in mind. He is ready to retire and I'm sure he did not visualize himself having a handicapped wife when he decided to retire, if he thought about it at all. It just changes everything. My relationship with my husband can be strained at times just because of his time constraints and because I have *so* much time on my hands. I want to be home and I want to be with him more than he can handle. And that's unfortunate but it's not something a married couple should have to go through. When he's in town he comes every day to see me and sometimes twice a day. Today he came up and brought lunch and he will come back tonight for awhile for another visit. We'll go and have coffee together over at Tim Horton's and maybe take a stroll around the block. He strolls and I ride. So you have to consciously work on relationships in here if you're still married, you know. It's been very different for me but it's been very different for him as well. I have to keep that in mind. (Rebecca)

Ken reflected on how his relationship with his wife started to change even before his move into a care facility:

I didn't have a choice about moving. My wife had had enough. She couldn't take it and I couldn't do it to her. 'Cuz I seen what was going on with her. And it wasn't the girl that I married. I mean it's just not...I married my best friend. And that wasn't her anymore. She was so upset with everything going on. But then, like I say, I got sick and she just couldn't take it anymore. She's not leaving me. She's still with me. She'll never leave me. And that's the great thing about her. She's on top of everything. (Ken)

David's wife visits daily and they try to maintain their relationship and daily interactions the way they were prior to David's move into as residential facility:

My wife visits every day, sometimes twice a day. She comes in the morning before work and she sits with me while I eat breakfast, then she comes by after work and we talk about the news. On weekends my children visit but my wife is always here too. She brings me what I need and calls me from work on her lunchtime to chat. (David)

Changes in Relationship with Children

Four of the eight participants in this study have children, and all spoke about how moving into a care facility changed the relationship they had with their children, particularly in a parenting role. It is of importance to note that all of the children ranged in age from late teens to early twenties. Most were still living in the family home when their parent moved into a care facility. Ken shared how he feels like he is missing out on parts of his son's life and he wishes he could be more involved:

But [my wife], she's also got her own life too. And she's got an 18 year old boy and she's got to make sure that he's on the straight and narrow, and if he needs a ride anywhere she's always doing that. Or... he's got his driver's license but trying to get him a vehicle, that's what I miss because I would be part of that, and I'm not part of that, and my wife don't know how to buy a car. She's never had to. But I've got a lot of friends and they'll look out for her so hopefully everything will be okay. (Ken)

Social Relationships

Rebecca described how her friends are a source of support for her, though they sometimes have strong opinions about how she should live her life:

I have some very dear girlfriends who live quite close and one of them comes in every Wednesday afternoon with her dog. I really enjoy their visits and I look forward to their visits. I have another girlfriend that has two small dogs and she comes in on a regular basis to see me. [pause] Um, my friends are always trying to tell me what would be good for me [laughs]. And I am on some pretty heavy duty narcotics for pain and I have one friend who is convinced I am going to become addicted and end up on the street somewhere. So she's always nagging me about that. (Rebecca)

Not all social relationships remain the same after one moves into a care facility. Pamela shared how she doesn't socialize with her friends outside of the facility very often anymore:

It's just something I have to adjust to because I'm used to getting up at home and going uptown and going out for coffee, go to the mall. But now I can't. I'm so

used to going out and meeting my friends and go for coffee with them. And it sure changed in a hurry. All my friends have. They never come and see me here. But I don't know, sometimes I just want to be left alone now. I just want to be by myself. Sometimes it's a little hard and you just want to go hide somewhere and just, you know, make the world go away for awhile. (Pamela)

Family Support

Many of the participants spoke about the support they received from their family before, during, and after the move into a care facility. Though some verbalized frustration with their family relationships, the overall theme indicated positive and supportive family relationships, some of which had significant roles in advocating for the participant both prior to and after the move. This theme came up in every interview and many participants discussed about how their family members supported them during their hospitalization, decision making about the move to residential care and the actual transition to a care facility. Common themes included increased family support during the illness and transition phase and family advocating during both the hospitalization period and transition to residential care. Randy shared how his mom was his primary source of support during the initial days in the care home:

Yeah [my mom] helped me quite a bit. She doesn't, she doesn't help me as much now as she did at first. Because she makes me feel like I'm a lot more on my own, you know. But she used to help me lots. She used to come all the time, twice a day sometimes. But now she comes once a day, once every two days. Yeah. So that's, well, that's okay. She needs her time too. She was there for me in the beginning a lot so that was good, yeah. (Randy)

Kimberly's mom continues to support her daily by assisting with her care and bringing home-cooked meals:

Yeah if she [my mom] wasn't around I'd probably not be around now 'cuz, um, yeah when I was [in the hospital] and in really bad condition, she was a lot of support being there for me. And, like, she kept me alive [*laughs*]. She's been taking care of me ever since. She stays here with me all, like, every night she

sleeps on the couch there. It pulls out to a bed and she goes home during the day from lunchtime 'til dinner. To prepare food for me to eat and stuff 'cuz the food's not too great... it's your basic hospital food so...you can't expect too much from it [*laughs*]. So I'm really lucky that my mom, you know, brings me food, home-cooked meals every day. (Kimberly)

Pamela spoke about how her family was not as supportive as she had hoped they would be during her time in the hospital and after she moved into a care facility:

I have sisters, three sisters and three brothers. I was the oldest of ten. But the only two ones that I see are my two sisters once in awhile. Yeah, once every two or three weeks...for about fifteen minutes. They don't like to see me in a hospital environment they said. But I think that's just a cop-out. They came to the hospital but only when my husband died. Then they came. (Pamela)

Rebecca and Ken spoke about support from their spouse and the ways their spouse acted as an advocate during the process of transition to the residential care facility:

When I came into this facility I was told I could, could be placed in any facility from the other side of the Fraser like Burnaby to, out to Abbotsford. And my husband said, 'No absolutely not.' You know, I live here and my support group is here. So yes and the house that we're in right now, we've lived [there] for 22 years. You know, I've always worked in this community and our son went to school in this community so a lot of our friends are here. I wasn't going to leave. (Rebecca)

We've been together 38 years. Right from her graduation, and we moved in together. We got married in 1979. We've been together a long time. She's been there with me all the way through this craziness that's gone on. She knows a lot about MS. She knows a lot about everything because she's *had* to know. And that's been the way she's been ever since I've been diagnosed. She's a fighter and she won't give up. She gets things done that are...that people don't believe. (Ken)

Relationships with Older Residents

Each participant spoke about the experience of living in an environment with elderly residents, some of whom have cognitive impairments. Rebecca shared that for the most part, she enjoys the company of the elderly residents: "I know most of them by name and some of the older residents can be very, very humorous just from their point of view

and their age, you know? They can crack you up [*laughs*] when you least expect it.”

(Rebecca). Many participants spoke about the challenges of living with people who have memory impairments. “I like it here but the people here, I mean the patients...you can be talking to somebody and then they don’t remember you. That’s the sort of thing I’m running into.” (Jack). Randy shared that he often spends his time socializing with the care staff or maintenance staff more often than with the older residents:

I socialize with everybody – all the nurses and most of the patients. Which ones I can, I do. But not all of them you can socialize with, you know. Some of them are just too far gone that they don’t know, right? It’s like speaking through them, in one ear and out the other so, you know, I just don’t waste my time. I just find other things to do, you know? (Randy)

Other participants referred to time they attempted to befriend older residents and found it difficult to relate, as well as communicate with, residents who have significant memory loss. “Sometimes it’s sad, you know, seeing [other residents] so confused. It bothers me but what can you do really?” (David). “I have a lot of friends here. I talk to the older ones too that are, have dementia. Uh, and they’re not that bad once you get used to them.”

(Pamela). Ken finds it difficult to socialize with the other residents in the facility he lives in:

Do you want to know what it’s like for someone my age to be in here? It’s tough because people don’t have memories. I don’t have much in common with anybody. I mean and, uh, they’re nice people, but they don’t remember a lot of things. I smoke cigarettes and there’s about five of them that smoke cigarettes. And that’s who I associate with. We have a little gazebo outside where you’re allowed to smoke. So my conversation is with them. And my caregivers. That’s about it. (Ken)

Kimberly shared that she is close in age to most of the other residents' grandchildren and even though she sometimes has difficulty relating to others, she enjoys the company of the elderly residents:

I know it would probably be nice to have someone my age too but I, I love old people [laughs]. I like talking with them and I get along well with them so it's nice. You know, they're all so friendly here so... 'Cuz I grew up living with my grandma when I was little. And it's nice to be around other grandmas [laughs]. 'Cuz I've got really close friends, here you know, ever since I moved. Some of the residents here, we've been really close. And when I see them, I feel really comfortable and you know, it's really nice to see them when you're up, out and about. Mm, I guess it might be nice to live with people more my age, and you know, talk about more similar interests. More our time [laughs]. 'Cuz the residents here, when they talk about, like, when they go to... they're reminiscing time. Like we talk about, 'Oh you know, back in the days we did this and this.' And I'm just, like, 'Yeah that was way before my time.' [laughs] That's before I was born. But it's so fun listening to the stories. (Kimberly)

Ken also shared that it can be a challenge to share a room with other residents:

I've got a semi-private room with a fellow that's quite pleasant. I was with a different person but they moved him out. I think he has Parkinson's Disease and he has his moments. It was pretty rough living with him because when I moved into that room his roommate had passed away and he was quite torn up about it. And it was his room. Don't come over this side. Don't do this. Don't do that. It was, it was trying but he was moved to a private room and I was given a guy I knew from upstairs who was my roommate upstairs so...yeah. That was okay. (Ken)

Relationships with Facility Staff

Another emerging theme was relationships with the facility staff. Rebecca describes the skill of the recreation staff at her facility in dealing with potentially difficult situations:

We have a wonderful therapeutic recreation team on this floor that are just terrific. And every week there is a big bus outing that we go on out to a restaurant or we go gamble and have lunch. This week we had a backyard picnic. You know, they are just terrific. They are wonderful. I'm sure they are not paid enough but I know for a fact they don't have a big enough budget. But they are great. I'd go nuts with boredom if it wasn't for these ladies. Next week we are going to a park for another picnic and there will be a mixture of young and old and skill level for lack of a

better word like competency. You know like there's some people that are really on their own little planet. But they are always included in the recreation activities and these ladies are very, very good [at] diverting people's attention. You know, somebody that has real mental deficiency sometimes starts acting out or interfering with the other residents. They [the staff] can handle those situations with tact and firmness and nobody's feelings get hurt. (Rebecca)

Rebecca also shared how the care staff can become like family to the residents because they work so closely with the residents every day;

Most of the staff are residential care aids and the majority of them are gems. They really are. They just, you know...A couple of them actually give you, give you hugs and kisses which...you may think kind of sloppy but it's not. (Rebecca)

Others shared that the staff in the facility have a good relationship with the residents;

The staff here are so busy all the time. But I get along really well with the care staff that's always on for me. Like not the casuals but, you know, they're really friendly. And we, like, while they give me care, we talk a lot and they tell me about their kids. So there's lots of things to talk about. It's good to hear outside stories [*laughs*]. (Kimberly)

We have one team leader who is a registered nurse with a lot of experience. And you can, you know, take all of your issues to her about medication and so on. The staff, yeah they're good. They treat me well and they're all really good to me and stuff. If I need something usually they can help me get it or whatever. If they can't help me they can get somebody to help me. So that's good. That works out okay. (Randy)

Pamela shared her frustrations about feeling "mothered" by some of the care staff, though she has a close relationship with several of them:

I'm almost 60 years old and I don't think I want to be treated like a child again. But they're pretty good to me. I get along pretty well with the staff. They're just like my own kids, since I don't have kids. I love every one of them. They make me feel good. (Pamela)

Participants shared that their relationships with staff members were for the most part positive, but even so, certain situations were quite frustrating, particularly when dealing with a new staff member who may not be familiar with the care routine.

Kimberly shared her frustrations about staff that may not be familiar with the daily routines and how she has to help direct her care:

‘Cuz some of the staff, you know, you can tell they really care for the residents and do it ‘cuz they want to. But then there’s the few that you don’t want to mess with. They kind of seem like they’re here just to make money and not really care as much so...when there is a new staff, oh it’s so frustrating because you have to tell them one by one...[exasperated sigh] And, um, because I don’t know, it seems like some of them just don’t have a clue what they’re supposed to do [laughs] and they just stand there and you have to, um, run through everything step by step with them. And it kind of makes me wonder, you know, like if I have to do this with them, like what about the other residents who aren’t able to communicate as well, you know? (Kimberly)

Ken expressed how he feels that the facility staff do not understand what it is like to live in the facility:

What do [the staff] know? They’re not living in here. They go home. You’re here 24/7 and you know a lot more about this place than they know. I’m not saying that they’re not good people and everything else but they, they get to go home. They get to eat real food and they get to fight with their kids and their husbands [laughs] (Ken)

Others spoke about their frustrations with staff’s lack of time, sharing that the care staff work very hard, but appear to be limited by a lack of time to meet everyone’s needs:

I think they are grossly overworked. The demands on them are very, very high and I think their morale is low because of that. You know, the residential care aides work their butts off from the time they come on shift until the time they leave. You know, in the evening, for example, the care aide that works this side has about thirteen people to put to bed between the hours of six and nine. And that means toileting, washing up and getting them into bed. I’m not doing my own transfers yet and they all have to do some type of mechanical lift. Either the ceiling lift or the Sera or Sabina lifts. You know, so that’s a lot of, you know, back and forth, back and forth, back and forth. And plus the fact that anybody that she’s already put in bed feels free to ring a bell to ask for something else. (Rebecca)

The staff try to make things okay for me, but they don’t have enough time to do what they have to do. I’m lucky I have family that comes by every day to help with what I need. (Lisa)

That's what really frustrates me because there's one physiotherapist and she kind of expects my mom to do everything for me, like, do all the exercises in my room... although my mom and I can't seem to find enough time during the day to do that. 'Cuz she's already doing so many other things for me. I wish I could do everything on my own but having to depend on someone for things, it's hard. There's not enough staff for the amount of resident care they need to do. So, you know, a lot of times, you have to wait a lot. We kind of have to fit to the schedule but you know, like, it's something I guess we have to deal with being here. (Kimberly)

Adjustment and Coping

A common theme that arose in each interview was the process of accepting the current situation and adjusting to the care facility environment. Pamela spent nearly a year in the hospital before moving into a care facility and she shared that it was a difficult move, even though she knew it would happen eventually, "Yeah. Took me awhile [to adjust]. Probably six months... maybe more? I didn't want anything to do with anybody for awhile. I just didn't want to be bothered with anybody. Now it's okay I guess." Many of the participants agreed that it takes time to adjust to a new living environment, particularly an institutional setting. Several participants shared that the first few months were especially difficult:

Oh yeah. It took probably about six to eight months... maybe six months to a year. Yeah, it took quite awhile. I was in [the hospital] for four months and then [a rehabilitation facility] for four months before I moved here. There's a few young people but I'm the youngest one here. It was different to adjust at first but I've adjusted to it now. It's quite, well, I'm comfortable with it. There's a few people that I can interact with here, yeah. So that's good. (Randy)

David shared a room when he first moved into the care facility he lives in and it was a difficult transition:

No, they moved me in with one other person, uh, the second week I was here and I was in with him for a couple days and then they moved me back here. So I got my private room back. They had... somebody else was up for it and then we got it. So

then we kept it and we've had it ever since. Well I didn't mind it at first but he was snoring and that and I couldn't sleep and oh god, it would have been hard...to share with somebody else. I'm glad I got a private room. (David)

Kimberly's family made the arrangements for her to move into a care facility after she spent a long period of time in hospital:

Uh, it was, it was okay 'cuz my mom took a look at some of the care homes. She liked this place the best, because she said there are pretty gardens and everybody seems so friendly here. So, you know, I wasn't worried. So yeah, I was happy about coming here I guess. It was better for my condition to come here than go home. And hopefully I'll get better soon and get to go home. So far it's nice here. It took a long time to get used to it though. Like with meeting people, you know, getting your routine set up and getting to know everyone and stuff. (Kimberly)

Autonomy and Choice

Several participants spoke about frustrations over loss of their autonomy and control over their own life situation. Loss of autonomy and choice appeared to be a prevailing theme throughout the interviews. Pamela shared her anger over her doctor's decision to arrange her move to a residential care facility after her husband, who had been her primary caregiver, passed away:

Yeah. Funny how life just slaps you in the face. I'll just have to accept it. There's nothing else I can do about it. Oh, I was mad when [my doctor] told me I'd be here the rest of my life. I said a bad word but like I thought, I'm going to show him. It's kind of hard when your legs don't move and you just want to go do things. I'd like to see him live here in my position for awhile. Maybe [my doctor] will change his mind in another couple of years or something. I want out on my own so bad. (Pamela)

Rebecca points out that many of the elderly residents do not speak up for themselves for fear of upsetting the staff:

I think there's some fear, I would say especially among the elderly. You know, they're afraid to question anything because they don't want to be in trouble or cause upset or, you know, be at risk, being kicked out or asked to leave. (Rebecca)

Ken shared that the move into residential care was just one move in a series of many, from home to hospital, to a rehabilitation facility, back to hospital and then to a care facility, all in a period of less than two years. He reflected on the changes that occurred when he moved from the hospital, where he had spent a significant amount of time, to the care facility he now lives in:

My doctor came and moved me over here and I was here for six and a half months. And they put me through [physical] rehab so I was able to transfer and do all that stuff. So that was a big change in my life. But it, uh, made it so much better 'cuz I couldn't even sit at the side of the bed without falling off. The rehab place over there was just excellent for me and I ended up going home, but I'm back and I'm in the [care facility] now. (Ken)

Moving into a care facility involves a lot of planning and adjustment, but when asked if they would prefer to live in a facility designed specifically for younger residents, each participant stated they would prefer to live at home than move to another facility. Close proximity to family and medical supports was seen as being more important than being close to other residents of a similar age and situation. Most of the participants chose to live in a facility in their home community rather than move to an unfamiliar place:

No, because if I want to, 'cuz if I had to leave here, I'd rather go home and that's my goal. So if I had to go to another care facility I wouldn't want it. I'd rather stay here. I've adjusted to here, I'm close to my mom, and I'm comfortable with it. It took me a long time to get adjusted to here, right. So, like, I'm comfortable here. This is okay for now. (Randy)

Randy also spoke about the similarities between the hospital and a care facility:

Just the noise I guess when I first came - the noise from the call bells and that. Always going off and the people laughing down the halls and people yelling, talking and stuff. But I've adjusted to that because I was in [the hospital] for four months and then in [a physical rehabilitation facility] for four months. Same thing there so... I basically got adjusted to it when I was in [the hospital] for the, for the first part after my accident. And then I was sort of adjusted to it. But when I went to rehab, I was basically adjusted to it then, so I came here I was already adjusted to it basically. (Randy)

Rebecca spoke about feeling like she had lost her identity when she moved into a residential care facility:

I have been in residential care for six years now. I can't believe how quickly the time has gone. Overall I do not enjoy living here because I no longer make my own decisions. They're all made for me the minute I entered those front doors. And I lost my autonomy completely and in some ways I feel I have lost my identity. (Rebecca)

Jack shared that he felt discouraged after the move but decided to make the best of the situation:

I can deal with it. You know, I can, you know, this is how it's going to be and it's not going to change anything. So I might as well just get along. I watch a lot of TV and surf online. I have Shaw Cable and I have shows I like to watch. So I'm pretty content in my room. I'd rather that the other residents just leave me alone, actually. (Jack)

Perceived loss of autonomy and attempting to make the best of living in a residential care facility environment was a common theme throughout the interviews.

“Making the Best of It”

Many of the participants spoke about making the best of their living situation, even when the circumstances are less than ideal:

Yeah, so being here, it's alright. There's a few ups and downs but I usually go pretty smoothly through the day here except for the odd screaming and yelling you hear from patients or whatever. You know, there are noisy walkers going up and down the hallway. Everything else is pretty good. I've got the run of the place. I can go downstairs and go and watch the guys in the maintenance shop or watch them in the kitchen. There's day help down there. There's people and you can mingle with the people down there or whatever. (Randy)

Rebecca appreciates the space in the facility where she lives, stating she had looked at a group home that was “small and depressing”:

I do like the space in here especially now that I'm in a power chair. You know, I've got room to move around. You know and all outside. I can go to Tim Horton's whenever I want. Like a group home facility would probably not suit me at all. But

this is good because I do have a lot of space to wander. But you know, I'd rather not be here. I'd say, 'Kick me out!' if there was a way for me to be at home again. (Rebecca)

Jack passes the time by surfing the internet:

I have a computer and that passes the time along, you know. I just go on there for awhile. The internet is not working right now. It got disconnected a few weeks ago, but it's going to get hooked up again soon. I've just got to wait for my wife to do it. And then I'll be back online again on the internet surfing the web. (Jack)

Kimberly still hopes to return home but states she is happy living in the care facility for now:

Oh yeah I'd probably need a bunch of different equipment but, you know, realistically it's better for me to be here, um, 'cuz everything is here [*laughs*]. So I'm happy living here, you know. There probably wouldn't be much difference being at home other than I guess less noise. I feel safe, I guess, in here. (Kimberly)

Pamela shared that although she still hopes to return home, she tries to "make the best of it" while living in the care facility:

I couldn't ask for anything because there's nothing else I need. I've got everything I need. I've got my friends. It's okay, of course it is. I didn't want to be here at first, but now it's okay. Sometimes it's a little boring. (Pamela)

Coping with Grief and Loss

Experiences of grief and loss are common when changing one's living situation, especially in cases where one may feel a lack of control or choice in the situation. Many of the participants spoke about feelings of grief and loss for the lives they had once lived.

Rebecca spoke about loss related to living separately from her family:

You know, I thought just before my stroke that my life couldn't get any better other than becoming a grandmother, which hasn't happened yet. I lived in a community that I loved. I had a half acre piece of property, which I had transformed into woodland garden and I loved it as well. I would spend time out there every day. And on free days off, I would spend all day in there with my dog. When you are removed from your family home to residential care [*starts crying*]

one of the things you really miss...one of the things you miss is the sense of touch because you're no longer with your family members. If it wasn't for the care aides and of course visits from my husband, I would, I would forget what it's like. And I am still obviously grieving for my losses [*pauses to cry*]. (Rebecca)

Kimberly spoke about her expectations for the future and how her life drastically changed after her illness stopped her from finishing high school on time:

Well, like, before I was sick, um, when I was healthy and not in bed, I always loved going out and do sports and all that [*laughs*]. In the wintertime I liked to go snowboarding. Um, I love swimming, rollerblading and running around. And before I was sick I was in school. That year it was supposed to be my last year of high school. Finally graduate [*laughs*] and all I had to do was Math 11 and a few extra credits and stuff. But, um, starting in September I was hospitalized, and then for the whole year I couldn't go to school, so I didn't get to graduate which was probably one of the most upsetting things for me. I was really looking forward to finally getting out of high school and 'cuz I was already, um, behind a few years to my friends 'cuz ever since I got my disease I've been only able to do half of the course load a year. So I was, you know, held back so much and, yeah [*laughs*]. Before when I was healthy, you know, I always expected myself to finish high school on time, go to university and, you know, go on with life. And you just never expect something like this to happen. (Kimberly)

Ken shared that there are things he misses about his previous life that he did not expect:

I, um, I have my moments but, you know, you get over it. I mean I miss my wife and I miss my kids. I wish I was still living at home. I miss the dog that barks across the street. Even though I didn't like him, I still miss him [*laughs*]. (Ken)

Pamela still grieves for the life she shared with her husband of 28 years:

My husband helped me with the cooking and that at home. Like I chopped up and then he'd wash and put it on the stove and he'd cook. I miss that life. I met some very good friends here [in the care home]. I miss my husband though. We were married for 28 years. We used to do everything together. 24 hours a day we were together. I wish I could bring my husband back. But I can't. That's okay. I'll be with him again someday. (Pamela)

Several participants shared how they miss the normalcy of holidays and family gatherings, saying that they are not the same once you have moved out of the family home: "I miss things like being home for holidays, spending time with my family, having

friends over for dinner...social stuff like that.” (Lisa). Other participants spoke about loss related to their decreased mobility. Randy shared about his loss of mobility and independence, “I’m used to getting up and doing things and I can’t now. You just, just stop in your tracks, you know, without the wheelchair...” (Randy). David shared his frustrations with the changes in his ability to pursue leisure activities he once enjoyed:

I used to be able to do things, now all I can do is lay in bed. I used to be able to spend hours reading, going online [*long pause*] but now I don’t even want to bother with any of it. My wife has told me I should write a book or something but I just don’t see the point. It’s frustrating not being able to do things you did before. My eyes are bad and I’m afraid of falling if I get out of bed, so really what’s the point? (David)

Ken reflects on the loss he felt when he was diagnosed with Multiple Sclerosis:

When you find out you have MS, well, you know it’s going to change your life like you wouldn’t believe. I know I’ll never walk again. I mean that’s, that’s a given. That’s, um, just something I have to live with. (Ken)

Another topic that was raised by several participants was loss related to other residents and staff leaving the facility. Kimberly shared how it was difficult when older residents passed away:

And maybe...I guess if I was with people my own age, I’m not sure, maybe I would do more things with them? [*laughs*] Go out with them or something but here, um, like, uh, it’s upsetting sometimes ‘cuz there’s so many seniors here and you become close with someone. Then they pass away and that’s hard. I know I really like all them but I know it’s better for them than to be here suffering. So with younger people that might not happen so much. (Kimberly)

Ken spoke about the challenges of staff turnover, stating that often the residents are unaware a staff member is leaving until after they are no longer working for the facility:

My biggest worry is [the staff] that are here leave. And the staff have their own issues...or a better job comes up for someone. Like everybody that I’ve met upstairs in the hospital all started in [the care facility]. This is the starting ground, and then you move your way up to work in the hospital. You get enough seniority to apply for a position. There’s only one nurse that I know that was upstairs and

came down here; everybody else moved the other way. They like the hours up there...they like whatever, I don't know what it is. I don't question them. If you're leaving, you're leaving. And half the time they don't even tell you. Just all of a sudden, so and so is not here anymore. So that's the way it is. It's nice down here and the people are nice and if I could change anything, I'd stop people from leaving! (Ken)

Institutional Culture

Many of the participants shared what a typical day is like in the facility they live in, in order to provide context to the situations they were describing during the interviews.

The culture and institutional nature of the care facilities was also a prevailing theme:

Saturdays they have, like, 50/50 Bingo and they have with the Wii games through the week. You know, the Wii video games? They've got a big projection screen set up in the dining room for that. Then you can play it. So that's kind of neat. But some of the games I don't participate in. Like they've got crossword puzzles or mindbender games or whatever. It's just doing a crossword puzzle and that and I'm not really into that. Sometimes I go down to the mall down there or else up to the corner to the gas station. But I don't venture out too far usually. Oh and sometimes I go on the bus outings. They have bus outings and we go, like, we're allowed to go on one a month. So I get to go on them usually. So that's good. (Randy)

Randy shares that he would change the quality of the food in the facility where he lives:

Yeah the breakfast is on the schedule. Lunch and dinner is on a schedule, yeah. But I don't usually eat the, not very often do I eat the food here. Like at dinner time and that, like my mom brings me a lot of food or I'll get take out. I'll order take-out food or whatever because the food here is just, it's not that good. It's in these container things that keep the food hot and then they put them on carts and serve them on the trays. So it's kind of, like, eww...you know what I'm saying? If I could change something it would be the food. Yeah, change the food. (Randy)

Dissatisfaction with the food was a common theme that arose in every interview, often in response to the question "what would you change about your living situation?"

So I'm going to make sure when I move to another facility that I am not within an extended care unit attached to the hospital because it'll mean I get the same food, lousy food, that we get here. And I understand that the private care facilities, the food is quite different. And I know a lot about the food here because I am actually,

sit on the food services committee. To try and... but until we go back to cooking the food on the premises, I don't think it's going to change. And it was a budget cut by the provincial government that we went to the system. (Rebecca)

Rebecca also mentioned the lack of rehabilitation in residential care facilities:

They don't mention rehabilitation or physiotherapy – two things which I badly need and do not get in here. This place is not set up for rehab which is unfortunate because I can name two or three people on this floor alone that if they had had proper rehabilitation could probably be living at home with some type of home support right now. But they didn't get it and it was just not going to happen for them. They have deteriorated so far. I hope that isn't me yet. There is huge difficulty in securing a full time physiotherapist. They are just not available. They are in very high demand. The lack of physiotherapy and rehabilitation really gets me upset. Because I have seen a lot of people in here that could have been what I call 'saved' from permanent dependency. (Rebecca)

Lisa shares how she is frequently bored by the lack of activities she enjoys in the care facility:

I don't play bingo so it can get boring in here. The health system doesn't really have much for someone like me. Nursing homes are supposed to be for old people, not someone my age. (Lisa).

Other participants reflected on the numerous policies and rules that exist in care facilities and how they struggled to challenge them when they appeared to have little basis in logic:

Everything they do in here is what old people like – bingo, oldies music, stuff like that. The [staff] never ask me what I want to do. It was a big hassle to even get internet hooked up. The manager told my wife “they don't do that here” and so my wife just called and had it done. It was stupid, all these rules. What do they expect me to do all day in a place full of old people? (David)

When I moved in I told the social worker I wanted internet access for all of the residents. I couldn't understand why there was no computer or internet for the residents to use. The social worker helped me get internet in my room but staff were not very helpful. They kept telling me my laptop might get stolen or what if someone dropped it on the floor and it broke? They don't understand that going on the internet is all I can do anymore. Everyone uses computers, why can't I have one in my room? This is where I live now. They tell me to make it feel like home but then they don't want to help me do that. (Jack)

Several participants mentioned they often felt ignored by the management staff and those who make the policy and decisions that influence the daily routines in each facility:

I never see the managers. It feels like I'm being ignored. You know, they never come in and say, 'Well how are things going?' Which you know, they should. That is their job. Whether we have a complaint about a room, our roommate or the food or a staff member, that is their job. But [the social worker] is pretty high profile here. She's in the dining room often lending a helping hand. She's very accessible, I mean, her office is just out in the lobby there. (David)

Lisa and Kimberly spoke about conflicts with the care staff and how they dealt with challenging situations:

I don't think anyone really *wants* to move into a nursing home but sometimes you have no choice really. I couldn't look after myself and there was no one else to help. The staff are pretty good but they have some weird ideas sometimes. They have their routine and expect you to fit into it, so if you challenge them, well, they don't like that. One staff told me to stop being so difficult. (Lisa)

So, you know, a lot of time you have to wait a lot. I'm lucky 'cuz I have my mom, you know, she gives me showers every night and all that so I feel fresh. But other residents, I know they only get a shower once a week. And I know that probably isn't the nicest thing. And when I first came here, I had a bit of problem with the nighttime staff. Um, getting changed in the middle of the night and stuff and there was a lot of argument over it, I don't really know why. So I just, ever since I told them not to bother with my change over night, my life's been a lot easier [*laughs*]. Not having to deal with them. (Kimberly)

Paternalistic Attitudes of Staff

A common theme in several of the interviews was the paternalistic attitudes of medical and facility staff member. Several of the participants referred to situations when they felt their opinion was ignored or devalued. Ken shared that he feels demeaned when staff speak to him as if he is a child:

Um, my brain is fine. It's my body that's give up on me and I find it frustrating. People that are trying to treat me like somebody I'm not. And [they say] things like 'did you have a pooh-pooh?' Um, you know, I'm not a child. Pee-pee and things like that. I mean I'm not that far gone yet so...(Ken)

Pamela shared that she feels extremely confined by the rule and regulations of the facility and wishes the staff would “mother” her less:

And that, I’m, I just get impatient sometimes. I just want to go do things. Oh I get to go to my friends who is just down the road. But they [the staff] got so worried every time I want to go out. But it’s like having a bunch of mothers at my age. It makes me feel like a big kid. Sometimes it’s hard because I didn’t have my mother growing up. I went to live with my grandparents. I never had a mother growing up so now it’s kind of late for me to start listening to a mother. (Pamela)

Others spoke about facility staff and medical professionals, such as their physician, speaking about them as if they are not in the room or speaking to their family or other staff instead of asking them directly how they are feeling:

Sometimes the staff, they forget to ask me what I think. It’s the same with my doctor when he comes in to visit. He goes to the nurses and asks, ‘How is she?’ You know, I know my body and I know my own health. I know what the concerns are and I can see whether they’re getting better or not. (Rebecca)

Fitting into the Facility Environment

Jack shared his perspective on how he feels like he does not fit in:

When I moved in, my roommate was 92 years old. It was like sharing a room with my father, he was so much older [than me], so now I have a room by myself. He liked to play poker and chat with everyone, but I’m not social like that. I feel like I just don’t quite fit in. So I just want to be left alone. (Jack)

Kimberly shared that she struggles with being dependent on others and is fortunate to have the support of her mother, because it is a challenge to fit her routine into the daily schedule established in the facility:

Not having my independence, you know. I wish I could do everything on my own but having to depend on someone for things, it’s hard, ‘cuz there’s not enough staff for the amount of resident care they need to do. So, you know, a lot of times you have to wait a lot. We kind of have to fit to the schedule but you know, like, it’s something I guess we have to deal with being here. (Kimberly)

Hope

Hope for the future was an emerging theme particularly when discussing future plans. Several participants spoke about their hopes to move back into the community. As Kimberly states, “I would love to get out and go home. As long as, like, I could walk or if I could see again. You know, I’d go home. That’s what I want more than anything.”

Rebecca has plans to move to another care facility so she can retire with her husband: We are getting ready to move. We bought a new house three years ago, so I have to look for another residential care facility closer to our new house.” Other participants spoke about feeling discouraged by their family and staff.

Pamela shares her frustrations about staff limiting her independence and how she remains hopeful in spite of the opinions of the staff and her family:

I want to keep going and do a few more things. I’m still hoping that I can get my own place but they won’t let me so... Yeah. The [staff] worry ‘cuz apparently there’s a lot of bad people out there. But my goal is to move out of here. They won’t let me but I’m not going to give up. (Pamela)

Others shared plans to move in with family members. Randy spoke about his plan to eventually move into his mom’s apartment:

Yeah I plan to go home and live with my mom within the next couple years. Probably in about a year and a half. She wants to build a condo and then have me come home there for awhile. So I’ll probably go there part time and then still stay living here but get to go home there and have a home there too as well then, right? So there’s a few people here that do that to go home on the, through the week and on the weekends and that. So that’ll be alright. (Randy)

Several participants discussed being frustrated by the lack of support to move into independent or supportive living, stating that it seemed like medical and care staff viewed them as being “at the end of the road” as Lisa stated. She said, “This was never meant to be a long-term thing you know, and I really, I still hope to get outta here and go back

home. This isn't my home, not really." Rebecca and Kimberly agreed that they feel like they are seen in the same light as the older residents, even though they do not feel like they fit into the same ability and future as the others.

Yeah. Like, um, the physiotherapist, whenever I used to, like, say, yeah I tried doing the bicycle and all that. For like a year I had to beg her, 'Let me do it, let me do it' to get me started on it. And just those kind of things. They, she, I feel like she looks at me equally as other residents. When I feel like 'cuz I'm younger I can do more [*laughs*]. But so that's a bit frustrating. 'Cuz I can do it but she thinks not so...it's frustrating. (Kimberly)

Rebecca remains positive about her life and looks toward her future goals, stating that even though she shares space with elderly residents, she does not feel like she is in the same stage of life as the others:

I do not feel that I am any different than I was the day before I had my first stroke. I, you know, I still feel 'me' inside me and today I'm young and I've still got a lot of living left to do. And I think compared to a lot of the other seniors in here or all of the seniors in here, a lot of them know that they will probably die in here. And I don't see that for me. (Rebecca)

The theme of hope is particularly noteworthy, as a significant portion of the existing literature on nursing homes discusses the challenges of living in an institutionalized setting and it is apparent that several of the participants in this study maintain hope for the future as a coping mechanism. As Rebecca states above, working-age residents are at a different stage in their life cycle than elderly residents, so they should not be viewed in the same manner or be expected to fit into the same environment as the elderly.

DISCUSSION

The findings of this study encompass many aspects of how working-age adults experience residing in a care facility designed for a geriatric population. The first theme, the stories of how each participant came to be living in a residential care facility and how they make sense of this process, gives insight in the decision-making process that occurs when one's support system starts to break down. This support system can include formal supports such as paid home support caregivers, and informal supports such as family caregivers. One participant, Pamela, moved into a care facility after her husband passed away. She relayed a story about not having time to grieve for her loss and feeling as though she was forced to move into a residential care facility. A common thread in these stories was externalization of the decision process. Many of the participants spoke about the decision to move in a passive way, as though they had limited participation in the decision. These stories helped to provide context to each participants' situation and to understand how they came to be living in a care facility.

It appears that the externalization of the decision-making process of moving into a residential care facility is related to paternalism and removing power from the client. As Bishop (2002), points out in her theory of anti-oppressive practice, systems where power is given to an outside force, in this case a physician or health professional, it is difficult for clients to feel empowered to make their own decisions and instead passively accept what is recommended. It may appear that moving into a residential care facility is the best option from the perspective of a health professional, but it is rare that one takes a step back and tries to relate to what it would be like to be in that position and trying to make such a decision oneself. This also became apparent during discussions with other health

care professionals about the focus of this study, and many were surprised that there are no services specifically designed for working-age adults. Due to the small size of the demographic of clients who reside in a geriatric residential care, it is imperative that power imbalances be addressed during decision-making about care, particularly because these clients are typically part of an oppressed group.

The second theme, relationships, addresses the many relationships and social supports that each participant has in their life. Family relationships were a significant topic of discussion, and many of the participants spoke about the ways their relationship with their family members had shifted or changed since their illness and subsequent move into a care facility. Duvall's (1977) theory of roles and the family lifecycle is helpful in understanding the shift in expectations one may experience when their life course is disrupted by an unexpected event. Serious illness or disability and living separately from one's family are unexpected events that can change the dynamics within a family, and the developmental goals of individual family members can be interrupted when a serious illness occurs, since the family as a whole can be disrupted (Rolland, 1999).

Participants also spoke about how living in an institutional setting shifted how they related to their spouse and children. There appeared to be a sense of trying to "protect" family members from the realities of living in a care facility. A few of the participants made reference to only visiting their family outside of the care facility, or refraining from sharing stories about difficulties with staff or other residents, because they did not want to upset their family members. Some participants also shared that they felt others did not understand the reality of their situation, including the staff members who work in the facility.

Another emerging subtheme was the relationships with staff and older residents in the facility. Several participants spoke about feeling a sense of family and relayed how they created a support system within the facility. Others shared that they tended to be more withdrawn from the other residents and spent most of their leisure time alone or with family and friends who did not reside in the facility. Residing in a setting where one feels different from others, in this case being part of a younger generation, can also contribute to issues of relocation stress and depression. Every participant in the study shared how it was extremely difficult to adjust to living in a residential care setting, but all stated they had made the best of the situation.

The third theme, coping and adjustment, addresses related to grief and loss, autonomy and choice, and making the best of the situation. I had expected that the residents who had been living in a care facility for a shorter period of time would be less adjusted to the setting than residents who had lived there for a longer period of time, but proved to be incorrect. Each participant spoke about feeling they adjusted to the hospital setting as an institutional setting prior to moving into a care facility, so it was easier to adjust to the care facility once they made the transition. Several participants cited that having familiar staff and a strong support system helped them to adjust to the setting. It is also important to note that each participant shared that it took a minimum of several months to adjust to the residential care setting, which is reflected in the literature (Brook, 1989; Silin, 2001)

Another common theme throughout the interviews was the concept of choice. Several participants spoke about having a choice about where they would live, but the choice was often between several long-term care facilities. Some spoke about feeling they

did not have a choice about where they would live and one participant spoke about feeling as though he had to move into a care facility due to the caregiver stress his wife was experiencing.

The fourth theme, institutional culture and environment, looks at the culture within the residential care facilities and how this environment can limit autonomy and independence. Many of the participants spoke about trying to fit into the setting, rather than the facility meeting their needs. Wendell (1996) explains that the social model of disability indicates that systemic barriers, negative attitudes and exclusion by society are measurements of disability in society, so the argument can be made that the very environment of a nursing home is “disabling” since the culture discourages independence and autonomy. As Rebecca so aptly stated, “Overall I do not enjoy living here because I no longer make my own decisions. They’re all made for me the minute I entered those front doors. And I lost my autonomy completely and in some ways I feel I have lost my identity.” The very environment of a nursing home limits autonomy and choice in a way that is not replicated outside the facility, as Goffman (1961) details in his classic work, *Asylums*.

Additionally, human rights law details that society must preserve the dignity of each individual, the concept of autonomy or self-determination, equality for all regardless of difference in ability; and solidarity, which requires society to promote and support the freedom of individuals with disabilities by providing appropriate social supports (Birnbaum & Mosher, 2008). One can certainly argue that the environment of a residential care facility does not do so, particularly for working-age residents. Throughout the

interviews, participants alluded to “making the best of it” while also mentioning goals that indicated they would rather live in a more independent setting.

The final key theme in this study was hope. Each participant spoke about having hope for the future and many referred to plans and goals such as moving back into a community setting or improved mobility. Hope is an important factor in looking at aspects of the environment that can be improved as well. It appeared that many of the participants had a difficult time articulating what they would change about the facility, but when prompted, all mentioned issues such as more appealing food, more care staff and increased freedom and choice. However, upon further reflection I realized that this seemed to be a difficult question to answer because most of the participants seemed to prefer to live in an alternative setting.

In discussing policy implications, it is important to note that specialized residential services are a resource that is certainly appealing to some residents, and going into to this project I had expected more of the participants to say they would prefer to living with people their own age. Several of the participants made a valid point about wanting to be close to family and remain near their support network which is obviously preferable to moving further away in order to access specialized services. Despite this, the Fraser Health Authority is moving towards centralized services in many areas due to cost effectiveness. An example of this in practice is that while I was working as a social worker in residential care, there was a plan in place to move all of the ventilator-dependant residents to one facility in Surrey. My understanding is that this project did not come to fruition as many clients and their families expressed great concern about moving from the facility where they had become comfortable and many refused to move. I find this

concerning that even though literature (Lander et al., 1997; Tickle, 1993) demonstrates that moving residents creates significant stress on both the resident and their caregivers, in practice this continues to occur, frequently with little consideration for the well-being of the clients. Clients should be given the opportunity to move if there is another setting that would meet their care needs more effectively, but should not be forced to move due to poor planning or lack of funding for residential care beds.

Another example of this would be the creation of temporary residential care beds. Often when there is a shortage of residential care beds, Fraser Health will fund “temporary beds” in a private care facility in order to admit clients who are unable to remain at home and would instead have to wait in a hospital for a vacant bed. Clients move from hospital or their home into these “temporary” beds and then after they settle in, they are moved again to another facility. There are not enough funded beds and if there were a sufficient number of residential care beds, this would not be an issue. The costs of keeping someone in a hospital bed is significantly higher than paying for a residential care bed. It is also likely that paying for a residential care bed costs less than paying for daily home supports. A government-funded residential care bed costs between \$930 and \$2100 per month and every resident of British Columbia is eligible for a government funded residential care bed. The “per diem” or day charge is set based on a client’s monthly income.

I am curious about the implications of increased funding and encouragement to utilize alternative services in place of residential care. Each participant alluded to or stated outright that they would prefer to live at home with their family or in a community-based setting instead of a nursing home. Many of the positive statements about the residential setting appeared to be the participant attempting to make the best of a less than ideal

situation, and the two participants who reviewed the preliminary themes of this study confirmed the accuracy of this idea. Therefore, it is an important policy implication to look at both improving the existing services in residential care to suit a variety of clients, as well as allocate funding to alternative services in the community. It would also be helpful to have staff in place who could facilitate discharges from residential facilities and assist clients who wish to move back into the community to find alternative living and care arrangements.

Summary of Discussion

The findings of this study highlight that working-age adults face unique challenges when living in a residential care facility. Themes related to relationships, autonomy and choice, making the best of the situation, not fitting in were explored in depth. Policy implications include increased consideration of this demographic of clients as well as increased community services to attempt to prevent further admissions of young clients to geriatric care facilities. The regionalization of policy and resources can also force clients to be removed from their medical and social support systems and this will have a negative effect on their quality of life. Implications for social work practice and further research will be discussed in the implications section.

Limitations of Study

As participation in the study was limited to participants between the ages of 19 and 60, I have been unable to capture the experiences of all of the younger residents within the long-term care system. Participation in the study was limited to residents who live in facilities run by the Fraser Health Authority, mainly because I am an employee of Fraser Health and was able to access research participants as an employee of the organization

once my study has been approved by the Fraser Health Research Ethics Board. The outcomes of this study are not representative of all nursing home residents under age 60 who reside in Fraser Health owned and operated residential care facilities, but I expect that the study findings capture a “flavour” of the experience that may lead to future research studies on program delivery and funding allocation within residential care. Additionally, the study did not include the experiences of residents who do not communicate in English and would likely share significant cultural considerations. I also did not interview residents who live in a care facility owned by a private company and these residents would likely have unique experiences, particularly with regards to financial considerations.

Implications for Practice

The health care system is structured in a way that gives most power to those in a professional role and little power to the client. Social workers can assist the interdisciplinary professional team to view clients as an expert in their own lives, and advocate for the client to have input and a voice in their own situation. It is vitally important to give voice to clients and involve them in the care planning process whenever possible in order respect autonomy and allow for utilization of the most appropriate services available. It may also be possible to advocate for creation of services to fill a need that is currently unmet. Specialized residential services designed for working age adults with disabilities are nearly non-existent in the Fraser Health Authority. Additionally, in a health region covering such a vast geographical area, it is difficult for families to access many required services if they reside in outlying communities. The result of this is either the resident’s isolation from family or placement in an potentially inappropriate setting. Clients and families who challenge these circumstances and request more appropriate

services are often labeled as “difficult” or “uncooperative” by the health care professionals who work within the system, and often families are told they need to find private pay services to meet their needs.

Policy implications for these issues include a need to consider revising the Fraser Health FAAB policy, or create a different policy for younger residents. All of the residents who participated in this study shared how difficult it is to adjust to a care facility and that given the choice, they would not move to another facility even if it is designed specifically for younger clients. This indicates that it is vital to ensure clients are placed in an appropriate setting right away, rather than placing them in one facility and then asking them to move to another. Additionally, the social worker in both the hospital and the care facility can act as an advocate to ensure the clients can access the most appropriate services possible. Social workers can also provide adjustment counselling to the new residents and their families. This is a skill that needs to be taught in schools of social work and would be useful in all areas of health care social work practice. Social work students also need to be educated about the possibility for improving the environment in residential care facilities and how social workers can be an integral part of this.

A Fraser Health working group should be established to consider the admission process in residential care settings and this would include some younger residents in order to give them a voice in changing the current process. There is no better source of information for what needs to be changed than the client themselves, and this group could also consider alternatives to residential care facility admission such as increase home support services in the community or a group home environment. The current policy for access to home support services may need to be revised in order to increase the level of

home support services available for clients with a limited income. Further education for all health professionals about this issue and other issues related to the challenges experienced by clients who have a disability is vital. Course such as the courses run by the UBC College of Health Disciplines would be an ideal venue for such education. Medical students also need to be educated about long-term care issues so physicians can offer alternative services to clients whenever possible.

As the number of residents under age 60 in residential care facilities continues to grow, the lack of appropriate placements certainly need to be addressed. This research topic is important to the field of social work, as the experience of residents in nursing home care is usually studied in the context of gerontological practice, which does not account for the experiences of residents under age 60. Taking into consideration the changing demographics of the population of Canada and the extensive health needs of people of all ages, this is an important topic worthy of further investigation.

Reflections

I have struggled with how to articulate what I learned during the course of this research. I began my data collection phase with some fairly strong ideas of what I expected to find and was quite surprised by the data I collected in the interviews. I expected more anger from the participants about their situation, and I recognized I am frustrated by the notion that people are living in less than ideal conditions simply because it appears to be easier than it is to question what is happening. Many of the participants mentioned that their physician was the one to suggest they move into residential care and this strikes me as being significant in light of the power differential at play in this situation. I know from my own work experience that many doctors suggest residential care

to a client who cannot return home stating it is “the best place for them.” It appears that this is the frequent solution to this issue when the problem actually lies with an external force (the health authority) when the actual issue is a lack of alternatives. I find it difficult to justify that facilitating the placement of young people in a geriatric nursing home is in fact best practice, especially in light of the fact that when questioned many of these clients state that would rather be at home. This leaves me wondering who is really making the decisions but in many cases, it appears that the voice of the client is lost completely.

Many of the participants in this study spoke about making the best of the facility they live in yet none of them described it as feeling like their home. Several times a participant mentioned feeling like they “didn’t quite fit” into the setting, yet they had decided to make the best of it. When exploring this situation from a human rights perspective, it seems quite apparent that there should be alternatives in place for clients if they so choose.

During my initial data analysis, I found myself analyzing the experience of having a disability alongside the analysis of the experience of living in a geriatric residential care facility. After consultation with my thesis advisory committee, I attempted to reconnect my analysis to my original research question while keeping in mind that being an adult who has a disability is directly connected to the experience of living in a residential care facility. However this does not speak directly to the research question. I found myself needing to readjust my focus several times during the data analysis in order to ensure I was addressing my research question.

Over the course of conducting this research, I was continually amazed by the willingness of the participants to share their experiences with me and by the diversity of

the group of people I spoke with. It has been a privilege to work with the participants and I have enjoyed the research process immensely. The interest in this topic from both clients in residential care and other health professionals indicates that it is a topic worthy of further study.

CONCLUSION

This thesis has contributed to the literature on the experiences of clients with a disability and highlights implications for social work practice in various areas of health. The findings suggest that working-age adults with a physical disability face multiple challenges when navigating through the health care system and residing in a residential care facility designed for geriatric clients. Social workers in various areas of health care practice would benefit from further awareness of these experiences. As the number of working-age adults with physical disabilities living in all types of residential care facilities continues to grow, the lack of appropriate services and client disempowerment certainly need to be addressed.

REFERENCES

- Auerbach, C. F. & Silverstein, L. B. (2003). *Qualitative data: An introduction to coding and analysis*. New York, NY: New York University Press.
- Bartlett, M.C. & Baum, B.H. (1995). What happens to patients after nursing home placement? *Social Work in Health Care*. 22(1), 69-79.
- Birnbaum, R. & Mosher, J. (2008). *Law for social workers*. 4th Ed. Toronto, ON: Thomson Carswell.
- Bishop, A. (2002). *Becoming an ally: Breaking the cycle of oppression in people*. London, UK: Zed Books.
- Cohen, C.B. & Napolitano, D. (2007). Adjustment to disability. *Journal of Social Work and Disability in Rehabilitation*. 6(1/2), 135-155.
- Creswell, J.W. (2007). *Qualitative inquiry and research design: Choosing among five approaches*. (2nd ed.) Thousand Oaks, CA: Sage Publications Inc.
- Creswell, J.W. (2003). *Qualitative, quantitative, and mixed methods approaches*. (2nd Ed.) Thousand Oaks, CA: Sage Publications Inc.
- Dominelli, L. (2002). *Anti-oppressive social work: Theory and practice*. Hampshire, UK: Palgrave Books.
- Duvall, E.M. (1977). *Marriage and family development*. 5th Ed. Philadelphia, PA: J.B. Lippencott Company.
- Eckhardt, E. & Anastas, J. (2007). Research methods with disabled populations. *Journal of Social Work and Rehabilitation*. 6(1/2) 233-249.
- Franks, J.S. (2004). Comparing perceived quality of life in nursing homes and assisted living facilities. *Journal of Gerontological Social Work*. 43(1). 119-130.
- Fraser Health Authority. (2009). *First Appropriate Available Bed Policy*.
- Gass, K.A., Guastad, G., Oberst, M.T. & Hughes, S. (1992). Relocation appraisal, functional independence, morale and health of nursing home residents. *Issues in Mental Health Nursing*. 13(3), 239-253.
- Goffman, E. (1961). *Asylums: Essays on the social situation of mental patients and other inmates*. Garden City, NY: Anchor Books.

- Harlan, S. L. & Robert, P.M. (1998). The social construction of disability in organizations: Why employers resist reasonable accommodations. *Work and Occupations*, 25(4), 397-435.
- Harris, Y. & Cooper, J.K. (2006). Depressive symptoms in older people predict nursing home admission. *Journal of the American Geriatrics Society*. 54(4). 593-597.
- Hayashi, R. (2007). MiCASA – My home. *Disability & Social Work Education: Practice & Policy*. 6(1/2). 35-52.
- Jackson, B., Swanson, C., Hicks, L.E., Prokop, L. & Laughlin, J. (2000). Bridge of continuity from hospital to nursing home – Part I. *Continuum (Society for Social Work Leadership in Health Care)*, 20(1), 3-8.
- Koren, C. & Doron, T., (2005). Being a social worker in homes for the aged: The real, the ideal and the gaps in between. *Journal of Gerontological Social Work*. 44(3/4), 95-114.
- Krogh, K. & Johnson, J. (2006). A life without living: Challenging medical and economic reductionism in home support policy for people with disabilities. In D. Pothier and R. Devlin (Eds.). *Critical disability theory: Essays in philosophy, politics and law*. Vancouver, BC: UBC Press. 151-176.
- Krout, J. & Wethington, E. (2002). *Residential choices and experience of older adults: Pathways to life quality*. New York, NY: Springer Publishing Company.
- Lander, S.M., Brazill, A.L. & Ladriagan, P.M. (1997). Intra-institutional relocation: Effects on residents' behaviour and psychosocial functioning. *Journal of Gerontological Nursing*, 23(4), 35-41.
- Linzer, N. (2002). An ethical dilemma in home care. *Journal of Gerontological Social Work*. 37(2). 23-34.
- Mason, J. (2002). Sampling and selection in qualitative research. In J. Mason, *Qualitative Researching (2nd Ed.)*. London, UK: Sage Publications, Inc.
- Maxwell, J. A. (1996). *Qualitative research design: An interactive approach*. Thousand Oaks, CA: Sage Publications, Inc.
- Melrose, S. (2006). Practical approaches in treating depression. *Canadian Nursing Home*. 17(2). 11-15.
- Meyers, S. (2006). Role of the social worker in old versus new culture in nursing homes. *Social Work*. 51(3). 273-277.

- Miller, N. (2007). Participation and knowledge related to a nursing home admission decision among a working age population. *Social Science & Medicine*. 64(2). 303-313.
- Mullaly, B. (1997). *Structural social work: Ideology, theory and practice*. Don Mills: Oxford University Press.
- Neugarten, B.L. (1979). Time, age and the life cycle. *The American Journal of Psychiatry*, 136(7), 887-893.
- Nolan, M., Walker, G., Nolan, J., Poland, R., Curran, M., Kent, B. & Williams, S. (1996). Entry to care: Positive choice or fait accompli? Developing a more proactive nursing response to the needs of older people and their carers. *Journal of Advanced Nursing*, 24(2), 265-274.
- Olkin, R. (1999). *What psychotherapists should know about disability*. New York, NY: Guilford Publications.
- Parker-Oliver., D. & Kurzejeski, L. (2003). Nursing home social services: Policy and practice. *Journal of Gerontological Social Work*. 42(2). 37-50.
- Payne, M. (1997). *Modern social work theory*. 2nd Ed. Chicago, IL: Lyceum.
- Rioux, M.H. & Valentine, F. (2006). Does theory really matter? Exploring the nexus between disability, human rights and public policy. In D. Pothier and R. Devlin (Eds.). *Critical disability theory: Essays in philosophy, politics and law*. Vancouver, BC: UBC Press. 47-69.
- Rolland, J.S. (1999). Parental illness and disability: a family systems framework. *Journal of Family Therapy*, 21(1), 242-266.
- Ronch, J.L. (2004). Changing institutional culture: Can we re-value the nursing home? *Journal of Gerontological Social Work*. 43(1). 61-82.
- Roth, D. (2005). Culture change in long-term care: Educating the next generation. *Journal of Gerontological Social Work*. 45(1/2). 233-248.
- Ryff, C.D. & Heidrich, S.M. (1997). Experience and well-being: Explorations on domains of life and how they matter. *International Journal of Behavioural Development*. 20(2). 193-206.
- Sacco-Peterson, M. & Borell, L. (2004). Struggles for autonomy in self-care: The impact of the physical and socio-cultural environment in a long-term care setting. *Scandinavian Journal of Caring Sciences*. 18(4). 376-386.

- Sigelman, C. & Rider, E.A. (2003) *Life-span human development. 4th Ed.* Belmont, CA: Thomson Wadsworth.
- Silin, P. (2001). *Nursing homes.* Baltimore, MD: John Hopkins University Press.
- Statistics Canada. (2001). *A profile of disability in Canada.* Ottawa, ON.
- Statistics Canada. (2004). *Innovative methods for surveying difficult to reach populations.* Ottawa, ON.
- Thun, B. (2007). Disability rights frameworks in Canada. *Journal of Individual Employment Rights. 12(4).* 351-371.
- Tickle, E. (1993). The relationship of health care experience to satisfactory relocation in long term care. *Nursing Connections, 6(4),* 13-24.
- Vandewater, E.A. & Stewart, A.J. (2006). Paths to late midlife well-being for women and men: The importance to identity development and social role quality. *Journal of Adult Development. 13(2).* 76-83.
- Vourlekis, B.S., Bakke-Friedland, K. & Zlotnik, J.L. (1995). Clinical indicators to assess the quality of social work services in nursing homes. *Social Work in Health. 22(1).* 81-93.
- Watt & Konnert. (2007). Quality of life in the nursing home: Perspectives of younger and older residents. *Canadian Journal on Aging. 26(4).* 403-41.
- Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability.* New York, NY: Routledge.

Appendix A: Interview Guide

1. Tell me about yourself.
2. Tell me about your life prior to moving into residential care.
3. Tell me about your family and support system.
4. What was it like for you when the decision was made for you to move into residential care?
5. What do you wish you had known prior to moving into residential care?
6. What is the hardest part of dealing with this transition?
7. What has helped you deal with this?
8. What is unique about being your age and dealing with your situation?
9. Is there anything else you would like to tell me?

THE UNIVERSITY OF BRITISH COLUMBIA



November 20, 2008

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Tel: 604-822-2255
Fax: 604-822-8656
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Re: The Experience of Working-Age Adults in Residential Care

To Whom it May Concern:

I am a Master of Social Work student at the University of British Columbia's *School of Social Work*. My research study for my thesis **The Experience of Working-Age Adults in Residential Care** is on working-age adults' experiences of living in a residential nursing home facility designed for a geriatric population. I am looking for adults between the ages of 19 and 60 who live in a Fraser Health owned and operated residential care facility to participate in one, or possibly two in person interviews. All names and identifying information will be kept confidential and the information provided used within my thesis and may possibly be published in the future.

The interviews will be a maximum of one hour each in length and they will be conducted in person at a location of the participant's choice. The questions can be provided to participants in advance, and at anytime throughout the interview participants may choose to stop the interview or not answer a question. Each interview question will be regarding the participants' experience of living in a residential care facility within the Fraser Health Authority.

This study is being supervised by Dr. Paule McNicoll, Associate Professor in UBC's School of Social Work, 604-822-xxxx. Should you have any questions, please feel free to contact me by telephone at 604-xxx-xxxx or via email at xxxx@interchange.ubc.ca.

Thank you very much for your time and consideration. I look forward to hearing from you.

Sincerely,
Sarah Chapple
MSW Student

Version 1: November 20, 2008

THE UNIVERSITY OF BRITISH COLUMBIA



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Title: Are you a working-age adult living in a residential care facility?

I am a Master of Social Work student at the University of British Columbia. My research study for my thesis, **The Experience of Working-Age Adults in Residential Care**, is exploring the experience of working-age adults who live in residential care facilities designed for a geriatric population.

You are eligible to participate in the study if:

- You are an adult between the ages of 19 and 60;
- You have lived in a Fraser Health owned and operated residential care facility for a minimum of six months;
- You communicate in fluent English;
- You have a physical disability; and
- You are willing to participate in one or two one-hour interviews (maximum total time commitment is two hours).

This study is being supervised by Dr. Paule McNicoll, Associate Professor in UBC's School of Social Work, 604-822-xxxx.

Interested? Please contact:
Sarah Chapple
MSW Student
Phone: 604-xxx-xxxx
Email: xxxx@interchange.ubc.ca

Version 1: November 20, 2008

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Consent Form

The Experience of Working-Age Adults in Residential Care

Principal Investigator: Dr. Paule McNicoll, School of Social Work, 604-822-xxxx
Co-Investigator: Sarah Chapple, MSW Student, University of British Columbia,
604-xxx-xxxx, xxxx@interchange.ubc.ca

This research is being conducted as a requirement for a master's thesis, a public document. You will be informed regarding the use of and access to the information being provided. All identifying information will be removed from the information collected during interviews.

Purpose

The purpose of this study is to explore the experience of working-age adults who live in a residential care facility owned and operated by the Fraser Health Authority. Specifically, this study asks "How do working age adults with a physical disability experience living in a care facility designed for a geriatric population?"

Study Procedures

You will be asked to participate in a semi-structured interview, which will be audio recorded or video recorded. Maximum total time commitment is 2 hours.

Confidentiality

Your identity will be kept confidential. Any identifying information will be removed from interview transcripts. Audiotapes or videotapes and written transcripts of the interviews will be kept in a locked filing cabinet. Any study documents stored on the computer will be password-protected. Participants will not be identified by name in any reports of the completed study.

Risks

This research study deals with a sensitive topic and while no risks are anticipated, I, Sarah Chapple, will attempt to minimize any potential risks of emotional distress by ensuring you may stop the interview at any point during the process if you become too distressed to continue.

Remuneration/ Compensation

No remuneration or compensation is offered for any participation in this study.

Contact for information about this study

For further information about this study, you may contact the investigators named above.

Contact for concerns about the rights of research participants

Any concerns about your rights or treatment as a participant may be directed to the Research Subject Information Line in the UBC Office of Research Services at the University of British Columbia at 604-822-xxxx.

Consent

Your participation in the study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without consequence.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

If you are unable to sign the consent form due to the nature of your disability, verbal consent may be used as a substitute for a written consent. The interviewer, Sarah Chapple, will ensure that you have had the opportunity to read the consent form prior to agreeing to participate in this study. The interviewer, Sarah Chapple, will go over the consent form with you prior to obtaining your verbal consent and commencing the interview.

Signature: _____

Printed Name: _____

Date: _____



CERTIFICATE OF APPROVAL - FULL BOARD

PRINCIPAL INVESTIGATOR: Paule McNicoll	INSTITUTION / DEPARTMENT: UBC/Arts/Social Work	UBC BREB NUMBER: H08-02825
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:		
Institution	Site	
N/A		
Other locations where the research will be conducted: Interviews will be conducted in a private setting of the participants' choosing. This will likely be in a private office or conference room within the residential care facility the participant lives in. Interviews will not take place in a public setting.		
CO-INVESTIGATOR(S): Sarah Chapple		
SPONSORING AGENCIES: N/A		
PROJECT TITLE: The Experience of Middle-Age Adults in Residential Care		
REB MEETING DATE: December 11, 2008	CERTIFICATE EXPIRY DATE: December 11, 2009	
DOCUMENTS INCLUDED IN THIS APPROVAL:		DATE APPROVED: January 23, 2009
Document Name	Version	Date
Protocol:		
Research Proposal	2	November 20, 2008
Consent Forms:		
Consent Form	2	January 12, 2009
Advertisements:		
Recruitment Poster	1	November 20, 2008
Letter to Participants	1	November 20, 2008
The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.		
<p>Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:</p> <p style="margin-left: 100px;"> Dr. M. Judith Lynam, Chair Dr. Ken Craig, Chair Dr. Jim Rupert, Associate Chair Dr. Laurie Ford, Associate Chair Dr. Daniel Salhani, Associate Chair Dr. Anita Ho, Associate Chair </p>		



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LETTER OF AUTHORIZATION TO CONDUCT RESEARCH

Date: February 26, 2009

PI Name: Ms. Sarah Chapple

Address: [REDACTED]

City/Province: [REDACTED] British Columbia

Postal Code: [REDACTED]

FHREB File #: 2009-008

Study Protocol #:

Study Title: The Experience of Working Age Adults in Residential Care

The following required applicable approvals have been received and are in order:

FH REB Certificate of Initial Approval
Dated: 2009 February 17

Consent not required
Reason:

Consent Waived
Reason:

Consent Required and approved
Dated: 2009 February 13

The signed signature page of the consent form for a specific study must be submitted to Health Records/Decision Support for the release of any personal information for that subject for that study. Ensure that the study title is included on the signature page of the consent form

Department Agreement for Providing Research-related Services Authorization
 Not Applicable

Health Canada Letter of No Objection
 Not Applicable

Clinical Trial Registration No.

Registered at:

www.ClinicalTrials.gov

www.Controlled-trials.com

Not Applicable

Funding:

Unfunded

Industry

Grant-in-aid

Grant awarded to Fraser Health

Grant awarded to external Institution

Agreements:

Executed Clinical Trial Agreement for Industry Sponsored Trials

Affiliated Researchers: Executed "Research Collaboration Agreement" dated:

Executed "Sub-Agreement" dated:

Grant Contribution Agreement dated:

Name of Granting Agency:

This letter authorizes the principal investigator to begin research-related procedures.

Please note that the ethical approval for this study must be renewed before the one year expiry date of the certificate of initial approval if the study will be ongoing at that time.

Authorized by:

Susan Chunick

Director, FH Research Administration & Development



Cc: [REDACTED]

<p>Fraser Health Authority People, Organization and Academic Development Research Administration & Development http://www.fraserhealth.ca/professionals/research/</p>	<p>300 – 10334 152A Street Surrey, BC V3R 7P8</p>	<p>Tel (604) 587-4436 Fax (604) 587-4665</p>
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