

EXPLORING THE QUALITY OF LIFE OF YOUNGER RESIDENTS LIVING IN RESIDENTIAL CARE FACILITIES

by

Kara Hay

Bachelor of Arts - Sociology, University of Victoria (2005)

THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF ARTS

In the
Department of Gerontology

© Kara Hay 2010

SIMON FRASER UNIVERSITY

Spring 2010

All rights reserved. However, in accordance with the *Copyright Act of Canada*, this work may be reproduced, without authorization, under the conditions for *Fair Dealing*. Therefore, limited reproduction of this work for the purposes of private study, research, criticism, review and news reporting is likely to be in accordance with the law, particularly if cited appropriately.

APPROVAL

Name: Kara Hay
Degree: Master of Arts (Gerontology)
Title of Thesis: EXPLORING THE QUALITY OF LIFE OF YOUNGER RESIDENTS LIVING IN RESIDENTIAL CARE FACILITIES

Examining Committee:

Chair: **Dr. Atiya Mahmood**
Assistant Professor, Gerontology, SFU

Dr. Habib Chaudhury
Senior Supervisor
Associate Professor, Gerontology, SFU

Dr. Barbara Mitchell
Supervisor
Associate Professor, Gerontology, SFU

Dr. Martha Donnelly
Supervisor
Director, Division of Community Geriatrics, Department of Family Practice, UBC

Dr. Denise Cloutier-Fisher
External Examiner
Associate Professor, Centre on Aging, UVic

Date Defended:

APRIL 22ND, 2010



SIMON FRASER UNIVERSITY
LIBRARY

Declaration of Partial Copyright Licence

The author, whose copyright is declared on the title page of this work, has granted to Simon Fraser University the right to lend this thesis, project or extended essay to users of the Simon Fraser University Library, and to make partial or single copies only for such users or in response to a request from the library of any other university, or other educational institution, on its own behalf or for one of its users.

The author has further granted permission to Simon Fraser University to keep or make a digital copy for use in its circulating collection (currently available to the public at the "Institutional Repository" link of the SFU Library website <www.lib.sfu.ca> at: <<http://ir.lib.sfu.ca/handle/1892/112>>) and, without changing the content, to translate the thesis/project or extended essays, if technically possible, to any medium or format for the purpose of preservation of the digital work.

The author has further agreed that permission for multiple copying of this work for scholarly purposes may be granted by either the author or the Dean of Graduate Studies.

It is understood that copying or publication of this work for financial gain shall not be allowed without the author's written permission.

Permission for public performance, or limited permission for private scholarly use, of any multimedia materials forming part of this work, may have been granted by the author. This information may be found on the separately catalogued multimedia material and in the signed Partial Copyright Licence.

While licensing SFU to permit the above uses, the author retains copyright in the thesis, project or extended essays, including the right to change the work for subsequent purposes, including editing and publishing the work in whole or in part, and licensing other parties, as the author may desire.

The original Partial Copyright Licence attesting to these terms, and signed by this author, may be found in the original bound copy of this work, retained in the Simon Fraser University Archive.

Simon Fraser University Library
Burnaby, BC, Canada

STATEMENT OF ETHICS APPROVAL

The author, whose name appears on the title page of this work, has obtained, for the research described in this work, either:

(a) Human research ethics approval from the Simon Fraser University Office of Research Ethics,

or

(b) Advance approval of the animal care protocol from the University Animal Care Committee of Simon Fraser University;

or has conducted the research

(c) as a co-investigator, collaborator or research assistant in a research project approved in advance,

or

(d) as a member of a course approved in advance for minimal risk human research, by the Office of Research Ethics.

A copy of the approval letter has been filed at the Theses Office of the University Library at the time of submission of this thesis or project.

The original application for approval and letter of approval are filed with the relevant offices. Inquiries may be directed to those authorities.

Simon Fraser University Library
Simon Fraser University
Burnaby, BC, Canada

ABSTRACT

The purpose of this qualitative study is to explore the characteristics of the quality of life of younger residents in residential care facilities, and to gain an understanding of the important factors that contribute to their quality of life. Multiple methods were employed to collect data, including younger resident in-depth interviews, focus groups with staff members, and interviews with a member from the management team at two residential care facilities in British Columbia, Canada. The data analysis revealed four main themes, each containing a number of specific codes: (1) A New Chapter in life; (2) Experiencing Quality of Life; (3) Staying Engaged and (4) Social Life. These themes outline the characteristics of the younger residents' quality of life and the important factors that contribute to it. The results are beneficial for understanding younger resident quality of life needs and providing person centred care that is appropriate for this population.

Keywords: Residential Care Facilities; Nursing Home; Long-Term Care; Quality of Life; Younger Residents; Younger Adults; Young-old.

DEDICATION

*To all younger residents living in residential care
facilities*

ACKNOWLEDGEMENTS

I would like to express my appreciation and gratitude to those who provided me with guidance, encouragement, support and motivation through this research project. I would first like thank my senior supervisor, Habib Chaudhury, for his constant support, careful revisions and constructive feedback. Thank you for the continued guidance and encouragement throughout this process. To my supervisors, Barbara Mitchell and Martha Donnelly, thank you for your constructive feedback, encouragement and kind words. I would also like to thank Denise Cloutier-Fisher, my external examiner for her thoughtful review and critique of my research.

This accomplishment would not have been possible without the love and support from all my friends and family. You supported me in my research when needed and more importantly distracted me from my research when needed! To my parents, thank you for all the love and support you have shown me throughout all my endeavours. To my siblings, thank you for being my central support system, life wouldn't be as much fun without each of you to enjoy it with. To Will, I couldn't have done this without your support. Thank you for listening and discussing younger residents with me for the past year, encouraging me to keep going and for the countless hours you spent editing my every word! Most importantly thank you for your unconditional love and support.

TABLE OF CONTENTS

Approval	ii
Abstract	iii
Dedication	iv
Acknowledgements	v
Table of Contents	vi
List of Tables	viii
1: Introduction	1
1.1 Significance of this Study	5
1.2 Purpose of this Study	6
2: Literature Review	8
2.1 Quality of Life in Residential Care.....	9
2.2 Diagnoses and demographics	14
2.3 Violation of age norms.....	16
2.4 Lack of Privacy	18
2.5 Financial Difficulty	18
2.6 Activity Programming.....	19
2.7 Community and Social Belonging.....	20
2.8 Unmet Needs	21
2.9 Staff Training.....	22
2.10 An Imperfect Refuge	23
2.11 Research Limitations and Future Research.....	24
3: Methods	27
3.1 Research Design.....	27
3.2 Study Sites.....	31
3.3 In-depth interviews	39
3.4 Focus groups	43
3.5 Data Analysis	47
3.6 Trustworthiness.....	49
4: Findings and Discussion	52
4.1 A New Chapter in Life.....	55
4.1.1 The Big Picture on Quality of Life.....	56
4.1.2 Adapting to a New Life.....	60
4.2 Experiencing Quality of Life.....	64
4.2.1 Frustrations.....	65
4.2.2 Quality of Care.....	68

4.2.3	Environment	72
4.2.4	Unmet needs	77
4.2.5	Money Matters	80
4.3	Staying Engaged	82
4.3.1	Misfit in Activities	83
4.3.2	Alternative Activities	86
4.4	Social Life.....	90
4.4.1	Community Connections	90
4.4.2	Interaction with Other Residents	96
4.4.3	“Staff are good”	98
4.5	Focus Group Findings	100
4.6	Management Interviews	112
4.7	Discussion.....	115
5:	Implications and Conclusion.....	130
5.1	Implications for Practice	130
5.1.1	Organizational Policy	132
5.1.2	Housing Content	135
5.1.3	Considerations for Provincial / Regional Health Authority	137
5.2	Limitations and Further Research.....	138
5.3	Conclusion	140
REFERENCES	142
Appendix A	147
Appendix B	149
Appendix C	150
Appendix D	151
Appendix D	153
Appendix E	154
Appendix F	155

LIST OF TABLES

Table 1: Quality of Life Domains.....	12
Table 2: Resident Background Information.....	37
Table 3: Resident's Conditions and Limitations	39
Table 4: Emergent Themes and Codes from Resident Interviews	55

1: INTRODUCTION

It is well known that older adult residents comprise the majority of the population of residential care facilities. However, it is rarely recognized that there is a small but significant segment of younger residents aged 65 or younger who are cared for in long term care settings due to their similar levels of care needs. According to recent literature, younger adults are estimated to account for approximately 10% of residential care facilities (Fries et al. 2005; Jervis, 2002 & Watt & Konnert, 2007). These younger residents' distinctive needs are often not taken into consideration within the care facilities, since the care services and activity programs are typically geared towards the needs of the older adult population. Thus the quality of care and planned activities may not be responsive to the needs and preferences of the younger age groups.

Institutional living can be difficult for older adults; however residential care may pose unique challenges to the younger residents' quality of life. Residing in residential care may be more difficult for the younger residents as it is a non-normative residential milieu for them. Living in residential care at a young age goes against the idea of age norms and may be psychologically difficult for the residents, their family or the staff. Age norms dictate that individuals who have reached a certain chronological age should be engaged in particular activities and should avoid others (Hagestad, 1996). Living in a residential care facility at a young age disrupts the socially acceptable timing of this circumstance of life. The characteristics and key factors that contribute to the quality of life for the

younger adults may be unique and beneficial to understand in order to provide person centered care that is appropriate for this population. To date, there has been little research that specifically investigates the quality of life of younger residents living in residential care facilities. Research on quality of life in residential care facilities has focused solely on older residents (Gerritsen et al., 2004; Kane et al., 2003; Lassy & Lassey, 2001; Mozley et al., 2004; Stewart & King, 1994). Eight common domains for measuring the quality of life of residential care residents can be identified in the literature. These are: autonomy, independence and control; meaningful activities or stimulation; social relationships; safety and environment; privacy; perceived physical and mental well-being; financial security; spiritual well-being.

To date, little research focusing on younger resident's quality of life in residential care facilities has been conducted; however the research that has been conducted has provided a few insights into the issues. Nine major substantive themes could be identified in the literature in this domain. The first theme concerns the similar diagnoses and demographics found within the younger resident population. The studies found an equal sex distribution and the mean age of the younger residents to be between 40-50 years old (Fries et al, 2005; Gutman, 1989; Gutman et al., 1995; Jervis, 2002; Watt & Konnert, 2007). Of the younger residents, 30-40% of them were married (Gutman et al., 1995). Regarding the common reasons for living in care facilities, studies documented multiple co-morbid conditions. The most prevalent conditions were multiple sclerosis, cerebrovascular accidents, chronic mental health problems,

Alzheimer's, Diabetes and Parkinson's disease (Fries et al, 2005; Gutman, 1989; Gutman et al., 1995; Jervis, 2002). Compared to the older population, younger residents were more likely to be cognitively intact, but likely to have high care needs (Fries et al, 2005; Gutman et al., 1995).

The violation of age norms is the second identified theme. Many younger residents view living in residential care at a young age as a non-normative experience, which violates their perceived age norms and creates an untimely life course timetable (Jervis, 2002; Watt & Konnert, 2007). Younger residents may struggle to make sense of their residence in a care facility and may not feel a sense of belonging to their home. Issues of privacy, personal space and private rooms were identified as an issue within the literature (Jervis, 2002). This issue is particularly salient for younger residents who are married, are still sexually active or need privacy with a loved one. The fourth theme centered on the resident's financial situation. Many younger residents are seen to be dependent on social assistance or have a limited income. If disability occurred at an early stage of life, the younger resident may never have worked or have a limited work history affecting their financial situation (Allen & Mor, 1997). Being on a tight budget and not being able to afford to participate in leisure activities or have spending money may impact their quality of life.

Activity programming was highlighted in the literature as most programs are geared towards the older adult population and can be unsuited for the younger population. The younger residents tend to avoid the formal activities in the home and prefer to be taken out into the community; however this is not

always an option due to budget and staffing issues (Jervis, 2002). The sixth theme includes issues of community and social belonging. It is suggested that many younger residents are disconnected from the community and may have little contact with friends and family (Watt & Konnert, 2007). Younger residents reported feeling detached from resources, places, and events in the community outside of the care facility (Watt & Konnert, 2007).

The issue of unmet needs was also raised within the literature. The unmet needs which were highlighted are physiotherapy, counselling, and recreation/leisure services (Gutman, 1989, Gutman et al., 1995; Jervis, 2002). The need for physiotherapy was expressed in order to maintain the residents functioning and ability to perform their ADLs. A variety of counselling, including marital, family and disease management counselling was recommended for both the residents and their families (Gutman et al., 1995). The eighth theme questions the adequacy of staff training to deal with the physical and mental needs of this population. Most residential care staff is trained to deal with the older adult population and may not understand or be adequately prepared to care for the younger resident population (Gutman et al., 1995). These younger residents are being cared for in a geriatric based system. The last theme is centered on a study that found that for many younger residents, the residential care facility was an 'imperfect refuge' seen as both a place of comfort and unease. Some residents felt depressed or imprisoned within the home, while others felt it was a refuge from the responsibilities and realities of the outside world (Jervis, 2002).

The issues raised in the literature require in depth exploration to understand their true relevance, variations and nuances. Previous research has only begun to uncover and understand the characteristics and key concepts that contribute to the quality of life of younger residents living in residential care. Nine substantive themes from the literature have been identified as briefly discussed here; however each theme needs to be elaborated and explored further. An in-depth research study would provide a deeper understanding and acknowledgment of the issues and would add to the growing body of literature in this area. It is also important to look beyond what has already been discovered and aim to uncover new concepts, interrelationship of issues or applied topics in the area that have not yet been recognized.

1.1 Significance of this Study

Younger residents are a relatively small proportion of the residential care facility population; however it is still a significant and important percentage of the residential care residents. This segment of residents has also been estimated to rise in the future with the increased incidence of chronic disease in middle- aged adults and the increasing expansion of technology that increases the life span of people with disabilities (Fries et al, 2005; Watt & Konnert, 2007). Little research has been conducted concerning the appropriateness of the care and programs offered and their potentially unique physical, psychological and spiritual needs. This study will address the research gap by exploring the key quality of life issues salient to this population. In addition, the younger resident population has been

largely overlooked by media, institutional policies and resource and funding allocation. Younger adults living in residential care facilities need a voice in these areas in order to have their issues acknowledged and addressed. Findings from this study will raise awareness of the issues important for this population in residential care. Identified issues and concerns will allow institutional policy makers, administrators and program planners to better understand the unique needs of this population and undertake policy and planning decisions that would better respond to those needs and increase the quality of life in residential care.

1.2 Purpose of this Study

The purpose of this study is to explore the characteristics of quality of life of younger residents in residential care facilities, and to gain an understanding of the important factors that contribute to their quality of life. This is a relatively small, however significant proportion of the residential care population who are vulnerable within the system and often overlooked. It is important that this topic is explored in more depth and that the facility staff, managers, educators, decision makers and policy makers have an understanding and insight into the issues surrounding young adults living in residential care. To address this purpose, qualitative research methods were employed to explore the issues faced by the younger resident population. The two main research questions are: a) What are the characteristics of quality of life of younger residents living in an age-integrated residential care facility, and b) What are the key factors that contribute to their quality of life? As the topic is relatively understudied, the

research questions will remain broad in an effort to explore both the issues mentioned in the literature and to identify new constructs through open questions and probes. The research methods include in-depth interviews with younger residents and focus groups with care providers. These strategies were utilized to provide an in-depth understanding of the lived experiences of the younger residents.

2: LITERATURE REVIEW

According to recent literature, younger residents account for approximately 10% of the residential care population (Fries et al. 2005; Jervis, 2002 & Watt & Konnert, 2007). Some theorize that this number is going to increase, as chronic diseases typical of older adult residential care residents are becoming increasingly more common in middle-aged adults and as medical advances enable the lives of people with chronic physical disabilities to be prolonged (Fries et al, 2005; Watt & Konnert, 2007). Research on this relatively small, however significant population is scant. Few studies have been found that explore the issues surrounding this population. Younger residents living in long term care have been largely overlooked by academics and media, resulting in an unknown, poorly understood experience of their life in a residential care home. One of the major challenges to understanding this population is the insufficient sample sizes that limit researchers in describing or characterizing this population in any detail (Fries et al, 2005). However, it is important that the physical and social environments, care practices, services, and activity programs are appropriately responsive to the younger residents.

2.1 Quality of Life in Residential Care

Substantial research has been devoted to the definition and measurement of quality of life in residential care settings. These studies range from broad comprehensive measurement packages to face-to-face qualitative interview methods conducted to understand the quality of life characteristics from the resident and staff perspectives. Quality of life has been defined and measured in a number of ways, as it is a multidimensional concept, however most studies use a quantitative approach (Dunne et al., 2007) There is a consensus that quality of life and the factors that contribute to it represent objective factors, subjective factors or a combination of the two (Mozley et al., 2004; Thapa & Rowland, 1989). Objective indicators include factors such as: adequate food, shelter, income and access to medical care (Hulsman & Chubon, 1989). Subjective factors are based on the individuals perceived needs regarding health, leisure, social relations, satisfaction with living conditions, etc. (Hulsman & Chubon, 1989; Thapa & Rowland, 1989). There is a strong belief within the literature that quality of life is essentially multi-dimensional and concerns well-being in a broad sense consisting of various dimensions (Gerritsen et al., 2004; Mozley et al., 2004).

Many believe the concept of quality of life is inherently subjective, therefore it is argued that residents themselves are the best reporters of their quality of life (Kane et al., 2003). A research study by Oleson et al. (1994) looking at residential care facility residents' quality of life compared nurse and resident responses. Most of the responses were similar, the most frequent

response being individuality. However it was found that nurses and residents place different emphasis on quality of life variables. The residents placed less emphasis on their physical functioning alone, implying that physical function was less important if their philosophical, emotional and spiritual needs were adequately met (Mozley et al., 2004). The World Health Organization Quality of Life Group defined quality of life as “individuals’ perceptions of the positions in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (Chan & Pang, 2006). It is important to recognize that quality of life can be affected by social class, past experience, gender and age group (Gerritsen et al., 2004). Researchers need to be sensitive to different values, social groups and changes in priorities that occur with increasing age (Mozley et al., 2004).

There are multiple conceptual bases for assessing the quality of life of residential care residents. Each conceptual basis recommends a comprehensive look at quality of life through a collection of specific important domains. By comparing six different conceptual bases and research results, eight common domains for studying the quality of life of residential care home residents were identified (Donnelly et al., 2007; Gerritsen et al., 2004; Kane et al., 2003; Lassy & Lassey, 2001; Mozley et al., 2004; Stewart & King, 1994). The first domain includes aspects of autonomy, independence, individuality, empowerment and control. This refers to the residents’ ability to remain in control of their everyday environment, choice of options and maintaining a sense of continuity and identity. The second domain identified as a key component of quality of life is

being able to participate in meaningful activities or stimulation. The definition of meaningful activities may vary between individual residents and can include physical activities, intellectual activities or activities of daily living. The importance of social relationships or social integration was another common domain. This encompasses any relationships that the residents find meaningful, including family, friends, staff or other residents.

The fourth quality of life domain includes sense of security, safety, comfort and environmental quality. Having an overall sense of security, safety and order affects the quality of life for an older adult. Aspects of the environment such as brightness, cleanliness and nice grounds are seen as positive aspects of the environment, while little personal space, and noisy wards are negative aspects of the environment (Donnelly et al., 2007). Attaining privacy, private space and personal possessions is the fifth quality of life domain for residents living in a residential care facility. The sixth domain includes one's perceived physical and mental well-being, which is an importance building block for a resident's perception of their quality of life. This domain includes functional ability, dependency, pain, and discomfort. The seventh domain of financial security was seen as a quality of life indicator in many studies. Financial security ties into lifestyle opportunities, as it allows the resident to engage in other quality of life options. The final domain deemed important is spiritual well-being. These eight domains summarize what has been identified in the literature as the key quality of life measures for residents living in a residential care facility.

Table 1: Quality of Life Domains

Quality of Life Domains
1. Autonomy, Independence, Individuality, Empowerment & Control
2. Meaningful Activities or Stimulation
3. Social Relationships or Social Integration
4. Security, Safety, Comfort & Environmental Quality
5. Privacy, Private Space & Personal Possessions
6. Perceived Physical and Mental Well-being
7. Financial Security
8. Spiritual Well-being.

A qualitative study by Donnelly et al. (2007) exploring the quality of life of ventilator-dependent residents living in long-term care described four additional quality of life domains to the key domains described above. These domains were formed through semistructured interviews with 14 residents living in long-term care. This study's findings are particularly salient to the present study as the sample population had a mean age of 57 years old, comparable to the age group being explored in this study. Additionally, the domains were formed from the residents' responses, as they all had the mental capacity and ability to articulate their quality of life needs (Donnelly et al., 2007). In conjunction with the key domains, Donnelly et al. (2007) included sense of self, personal qualities, care and feeling on the ward. Sense of self included such concepts as feeling needed or useful, contributing to the community, having a sense of purpose, personal growth and learning (Donnelly et al. 2007). Personal qualities or characteristics needed to obtain a positive quality of life were described by the residents as being adaptable, having a positive attitude, being flexible, accepting fate and determination. Care, the third domain, included the importance of having good, competent and available care with input from multiple disciplines.

Having good care added positively towards their quality of life, while a lack of care was reported as being a threat to their quality of life (Donnelly et al. 2007). Lastly the feeling on the ward domain included the importance of individualized and flexible care (Donnelly et al. 2007). It was described by one resident as “receiving good personal care, in a respectful manner from competent, caring, flexible, organized, friendly, same-gender staff where they leave you feeling clean, all your needs met, and unstressed and looking forward to the day” (Donnelly et al., 2007 p.70). Donnelly et al.’s (2007) study looked at a unique population living in residential care and through a qualitative study greatly added to the quality of life literature. The findings are important to consider while exploring the quality of life of younger residents due to the similarity in the sample populations age group, high cognition and uniqueness. In the proposed study, the described domains of quality of life reported in the literature will be used to identify the younger resident’s perception of their quality of life.

Literature focused on younger residents living in residential care is minimal. Very few studies have been conducted that acknowledge or discuss any issues that specifically concern younger residents. The existing research has touched on many topics, however more in-depth exploratory research is needed to fully capture and understand the many complex issues. The following is a summary and review of the research that has been found to date regarding younger residents living in residential care. Gutman et al. (1995) conducted a study that interviewed younger adults with severe disabilities and their families

within the Capital Regional district of British Columbia, including those living in long term care facilities (Gutman et al., 1995). With the deinstitutionalization of psychiatric hospitals, residential care facilities began seeing an increase in younger patients with psychiatric problems. In 2002, Jervis conducted a field study in a care facility that housed a large population of psychiatrically disabled clientele, and explored some of the issues within the younger resident population (Jervis, 2002). In another study, Fries et al. (2005) sought to describe the younger adult population by their diagnoses in nine states using the mandated computerized data program, the minimum data set (MDS). Most recently Watt and Konnert (2007) conducted a study looking at the quality of life of younger adults and compared them to the older residents. These studies identified several themes concerning this resident population.

2.2 Diagnoses and demographics

Disabilities within the younger adult population vary, and often multiple co-morbid conditions are present (Fries et al. 2005). In 2005, Fries et al. conducted a national study in the United States to understand the common diagnoses in residential care homes by age groups. The research used MDS information from care facilities in nine states from 1994 to 1996. They found that approximately 8.4% were under the age of 65 and of that half were aged 55-64. Adults aged 25-44 were most likely to have an explicit terminal prognosis and have complex levels of care. Adults aged 45-64 had increased chronic disorders such as

cerebrovascular accident(CVA), chronic mental health problems, Alzheimer's, Parkinson's disease, cancer, other cardiac diseases and diabetes.

Gutman et al (1995) conducted a study looking at younger adults with severe physical disabilities in the Capital Regional District of British Columbia. It is important to note that this study only included physical disabilities, excluding any mental disabilities. Gutman's review found that that degenerative neurological disorder was the most common diagnostic category for the younger population. Head injury, spinal injury and cerebral palsy were the next three common diagnostic categories. Others included: cancer, cerebrovascular accident (CVA), arthritis, metabolic conditions, epilepsy and Gardner's syndrome. A common theme in the literature is the high prevalence of multiple sclerosis in this population. Many studies looking at this population have found that the single most common diagnosis for disabled younger adults in the community or in a care facility is multiple sclerosis (Gutman, 1989; Gutman et al., 1995; Watt & Konnert, 2007). Compared to residents over 65, the younger residents were more cognitively intact and more capable of performing ADLs, however they have high average care needs (Fries et al, 2005; Gutman et al, 1995).

Chronic mental health problems are relatively uncommon in residents under 25, but they are seen to increase in prevalence to about 10% in younger adults; these problems were rarely seen in residents over 65 (Jervis, 2002). Jervis's (2002) study at a residential care home with a high percentage of psychiatrically disabled clientele found the most common diagnoses to be: schizophrenia, dementia, mood disorders, substance-related disorders or some

form of mental retardation. These residents were not high functioning enough to live in the community, and due to the deinstitutionalization of many state mental hospitals they had no other place to go. Common physical illness for this population was diabetes, hypothyroidism and hypertension.

All the available past and current studies which were reviewed documented consistent demographics of the younger resident population (Fries et al, 2005; Gutman, 1989; Gutman et al., 1995; Jervis, 2002; Watt & Konnert, 2007). An equal sex distribution was found in all studies. The mean age for younger adults living in a facility was middle aged, between 40-50 years old. For younger adults living in a facility, studies documented that between 30-40 percent were married. Studies spanning a 20 year period all documented similar findings on the population's demographics, indicating relative little change regarding this population.

2.3 Violation of age norms

Institutional living is recognized to be difficult at all ages. Residents become physically separated from loved ones and the outside community, which may cause a decline in social support and a perceived loss of control. A reduction in normal activities and a stronger dependence on others may lead to a decline in the resident's quality of life. For both the younger and older populations, the goal is to provide care in the least restrictive setting, which in most cases is considered the individual's home. However, due to many reasons, such as lack of services, support, or finances, this is not always feasible and

people need to be placed in a residential care facility. For the younger resident, however, it is recognized that common problems faced with living in a care facility may be even more difficult than for the older adult resident. Needing high levels of care and having to move into residential care violates the culturally shared expectations regarding the timing of entering long-term care and creates an untimely life course timetable.

Studies by Jervis (2002) and Watt & Konnert (2007) both identified one of the main issues faced by younger adults living in residential care as the non-normative experience, which violates their perceived age norms. Age norms dictate that individuals who have reached a certain chronological age should be engaged in certain activities, an important way in which people measure themselves against others (Jervis, 2002). Younger residents, especially those with no cognitive impairment, living in “old folk’s homes” may struggle to make sense of their residence in such a facility, and struggle to feel a sense of belonging. Residents arriving from more active, possibly work-filled lives can “languish without age appropriate social stimulation, growing depressed, losing motivation for rehab therapies and weakening physically” (Parsons, 1997, p. 3). Younger residents must also deal with the psychological challenge of living almost exclusively with people in their frailest, oldest years, often with dementia (Parsons, 1997). The oddity of younger residents in a care facility can also be disconcerting for staff (Jervis, 2002). Staff may not be properly trained to deal with the unique needs of younger residents, especially if any mental issues are involved.

2.4 Lack of Privacy

Lack of privacy is often a complaint of residential care facilities, and plays a major role for the younger resident population (Jervis, 2002). The need for sexual relations is an issue for both the younger and older population. However, younger residents are more likely to be married, still be sexually active, and need privacy with a loved one. Residential care facilities often do not provide a private space for couples to be alone. Private rooms are available; however they cost more and often have a very lengthy wait list. Private rooms or areas for visiting, larger personal space and better access to public areas within the home, such as outdoor space and elevators, are all environmental design issues that have been outlined by interviews with young adults living in care facilities and their families (Gutman, 1995; Jervis, 2002).

2.5 Financial Difficulty

Financial difficulty may also be an issue for many of the young residents living in care facilities. Disability for many older adult people usually comes later in life after homes are paid for and retirement funds and pensions are secured. In contrast many people who have been disabled at a younger age or diagnosed with a disease at a younger age either have never worked or have limited work histories, consequently acquiring fewer assets and savings (Allen & Mor, 1997). Many younger adults with disabilities are dependent on social assistance, which

can be very limiting and challenging. Being on a tight budget can confine the younger resident to the care facility if they do not have extra funds to participate in outings to the community or to participate in extra activities not provided by the home.

2.6 Activity Programming

Activity programs are often planned and provided based on the physical abilities and preferences of the older adult, offering limited activities that interest the younger generations. The same services and programs that work for the geriatric population do not necessarily work for the younger resident population who are living in residential care (Weyrich, 1994). Younger residents tend to avoid formal activities in the home, and prefer activities that take them into the community - to movies, coffee shops etc. (Jervis, 2002). Activities such as these require greater resources in budget and staffing than most facilities have, and therefore are rarely done. The activity staff accustomed to meeting the older adult needs may not have the time or ability to create alternative programs for the younger residents (Parsons, 1997). A recent study looking at the quality of life of ventilator-dependent residents living in long term care found that the barriers to activities were reported as poor weather, lack of family or friends to take them out, and budget restrictions (Donnelly et al., 2007). Recreation and leisure activities that are geared towards the younger residents need to be provided. In

order for the younger resident to be connected to the larger community, activities both inside and outside of the care facility should be provided and encouraged.

2.7 Community and Social Belonging

Social belonging and community belonging for younger residents were rated low in Watt and Konnert's (2007) study. This suggests that this group feels somewhat disconnected from friends, relatives, other residents and social events. In addition, the residents reported feeling detached from resources, places, and events in the community outside the care facility. This study found that 37.2% of the younger residents reported leaving the care facility less than once a month. It is also important to have family participation in leisure activities in order to maintain strong ties, support and involvement from family. Social support and family involvement is another important dimension of quality of life in a residential care facility. Watt and Konnert's (2007) study found that the majority of younger residents were visited once or twice a week or more, and 26% of the people in the sample were visited less than that. Sixty-five percent of the sample reported having a confidant relationship, which is seen as an indicator of higher life satisfaction. In a study by Dunne et al., (2007) exploring the quality of life of ventilator-dependent residents living in long-term care reported through the Medical Outcomes Study Social Support Survey (MOS-SSS) high levels of self reported social support. This study consisted of many younger residents as the mean age of the sample was 57 years old, with a range from 20-82 years old. In regards to receiving emotional and informational social

support, 77% of the respondents felt they were supported all or most of the time (Dunne et al., 2007). The availability of positive social interaction was rated equally as 77% reported availability to positive social support all or most of the time (Dunne et al., 2007). Lastly, 85% of the respondents reported that they received love and affection from the people around them all or most of the time (Dunne et al., 2007). Jervis (2002) explains one reason for the institutionalization of younger adults, especially for residents with mental problems, may be due to their lack of familial resources. It was found that many of the younger residents had little contact with their families. It was thought that residents with behavioral problems may have alienated their family members. In addition, the stigma associated with psychiatric disorders and hospitalization can induce avoidance behaviour on the part of the families.

2.8 Unmet Needs

The most significant unmet needs for this population mentioned in the literature are physiotherapy, counselling, and recreation/leisure activities (Gutman et al., 1995; Gutman, 1989; Jervis, 2002). Gutman (1989) expressed that the main goals and objectives within this population should be rehabilitation, recovery and return to the community if possible. All the interviewed clients in Gutman's study expressed the need for more physiotherapy to maintain their function. Counselling was identified as an important need for this population. Gutman (1989 & 1995) recommends that a number of different types of counselling be made available to younger residents living in long-term care.

These include occupational, educational, sexual, marital and family, and disease management counselling. A diagnosis of a disability or a move to a care facility may significantly alter life plans and family relationships. Counselling should be offered to both the adult in care and their family. Parents who were caregivers prior to institutionalization may feel guilt about putting their child into an institution. Spouses and children may require help coming to terms with their loved one's differences in their physical appearance and mental status.

Counselling for the spouse is needed as they may find themselves looking after young children alone and may be having a difficult time coping. Support groups should also be offered as a way to deal with the resident's depression, anger and frustration around their illness or situation (Weyrich, 1994). Younger residents often have complex medical, emotional and psychological needs, that are different from the older population, and many residential care facilities don't have the staff or equipment needed to meet them (Parsons, 1997).

2.9 Staff Training

Some research has looked at the adequacy of staff training in order to appropriately deal with the needs of younger resident population. Most residential care staff has been trained to work with the older adult and may not be adequately prepared to care for the younger population (Gutman, 1995). Younger residents have differing needs from the older adults, and yet they are being cared for within a geriatric based system. One example given is the need for younger residents to have more frequent bathing and hair washing than what

is typically given in a residential care facility (Gutman, 1995). In the case of psychiatrically disabled residents, more training is needed for the staff to be able to understand and appropriately deal with issues common with mental disorders (Jervis, 2002).

With an increase in younger residents, the nature of the residential care home residents changes dramatically. Many younger residents have histories of substance abuse, mental illness or complex medical problems (Healy, 2003). These patients can bring with them problems that are complex and potentially dangerous to handle, as they can be more prone to lash out violently posing a threat to other residents and staff members, who are often not trained to deal with such patients (Healy, 2003). Inadequate training to deal with these residents can lead to misdiagnoses of the problems, or insufficient attention, and if the problem erupts, the patients are often strong enough to overpower the staff member (Healy, 2003).

2.10 An Imperfect Refuge

Jervis's (2002) study found that for many younger residents, the residential care facility was both a place of comfort and unease. Many felt unhappy, depressed or imprisoned in the care home. Some compared living in the home to being in prison or in hell, however others felt the facility was refuge from the responsibilities and realities of the outside world. Many of these residents had spent most of their lives in an institutional setting (psychiatric hospital or jail) and knew how to adapt to the situation and make a home for

themselves. For them this place was safe and secure with plenty of food and care. For some residents, it was a better option than living on the streets, and therefore they were satisfied with the facility. To some the facility was seen as place to regain their mental and physical health, with staff always available to help. Many residents were cognizant of the benefits that the facility had to offer such as a home, safety, rehabilitation and good care, even if they would rather be living in their own apartment. Jervis (2002) concluded that for the residents in the home she studied, the care facility was seen as both a place of comfort and unease. Some residents acknowledged both these aspects simultaneously, while others' assessments fluctuated with their personal circumstances.

2.11 Research Limitations and Future Research

Due to the relatively small percentage of younger residents in residential care facilities, a major limitation in this area of research is the small sample sizes. In past research relatively small sample sizes have likely created a selection bias. Many of the studies conducted only included participants from one care facility. This research design gives a very limited perspective on the issues at that specific care facility. A larger and more comprehensive study would benefit this body of literature. Another limitation is the lack of ethnically diverse sample populations. Persons with diverse ethnicity are often excluded from these research projects. However those from different ethnic backgrounds are likely to be at an even greater risk, especially if English is not their first language or if they do not speak the language at all.

To date, the research on this topic is limited and more attention needs to be given to this population's issues and needs. The literature touches on the non-normative experiences of being young with high care needs, lack of privacy, lack of finances, appropriate activity programming, community and social belonging, unmet service needs and appropriately trained staff. These are central issues that face younger adults and call for some significant implications for policy and practice. There is still a significant need for future research on this topic area. First, the research has only briefly touched the topics mentioned, an in-depth qualitative study would strengthen the literature and allow for a deeper understanding of the issues presented. Second, there may be concepts, interrelationship of issues and applied topics in this area that have not been recognized. An in-depth exploratory study would allow for a more comprehensive review of the issues faced by younger residents living in residential care.

Watt and Konnert (2007) express the need for research in this area that encompasses a multidimensional approach to the younger residents needs. Rather than simply focusing on the physical needs of the population, all aspects of their quality of life should be recognized. Watt and Konnert (2007), after conducting research with an age segregated facility, suggest that future research should address whether there are differences in the quality of life between younger residents living in age-integrated units and those who reside in age-segregated units.

Literature regarding quality of life for people living in residential care is often unclear concerning what are the constituting factors or components of ones quality of life and what are the determining factors to ones quality of life. This is a limitation within the quality of life literature that this research hoped to identify. This research has recognized this limitation and therefore constructed the research questions in two parts in an effort to separate the two. The first question is concerned with the characteristics or components of one's quality of life, and the second question focuses on the key factors that contribute to one's quality of life.

3: METHODS

3.1 Research Design

The proposed study aims to explore the quality of life of younger residents living in an age-integrated residential care facility. In order to understand the relevant issues from the grounded perspective, a qualitative, exploratory research design will be used. Qualitative research is especially useful for the exploration and discovery of topic areas (Morgan, 1998). Exploratory studies seek to explore certain areas of research in depth and are especially useful when not a great deal is known about the topic area (Gray, 2004). Qualitative methods permit researchers to study selected issues in depth and detail. One particular strength of qualitative methods is its ability to collect data “without being constrained by predetermined categories of analysis, which contributes to the depth, openness and detail of qualitative inquiry” (Patton, 2002 pg.13). Typically qualitative methods produce a wealth of detailed information about a much smaller number of people. This method aims to increase the understanding of the people and situations studied (Patton, 2002). Due to the limited research on this topic and the small sample sizes, a qualitative research design is best suited to conduct this study.

A qualitative inquiry strategy emphasizes and builds on several interconnected themes (Patton, 2002). The strategy of inductive designs is used to “allow the important analysis dimensions to emerge from patterns found in the cases under study” (Patton, 2002, p. 44). An inductive analysis is used through in-depth interviews and focus groups, which allows the respondents to describe what is meaningful and salient without being confined to a standardized questionnaire (Patton, 2002). The depth and detail found in many qualitative methods typically comes from a small number of case studies, a theme known as unique case orientation. Study findings based on small numbers of case studies are often not generalizable. However they are useful to understand purposefully selected groups, particular problems or unique situations in great depth with rich information (Patton, 2002). In order to obtain credible research, the researcher will adopt the stance of empathic neutrality. The investigator must “commit to understand the world as it is, to be true to complexities and multiple perspectives as they emerge, and to be balanced in reporting both confirming and disconcerting evidence” (Patton, 2002, p.55). It is the researcher’s responsibility to reflect on, deal with and report any potential bias. In conjunction with being neutral, it is also important that the researcher be empathetic as well. Empathy must be used while working directly with the respondents through interviews, being able to take and understand the stance position, feelings, experiences and worldview of others (Patton, 2002). Empathy is needed while encountering the respondents and gathering the data, while neutrality refers to being nonjudgmental during the data collection and findings. The last key theme of qualitative inquiry is the

importance of design flexibility. Qualitative designs will have initial focuses, plans for interviews and primary questions to explore, however the inductive nature of the inquiry makes it inappropriate to have specific designs in advance (Patton, 2002). The research strives to do what makes sense, report on what was done, why it was done and what the implications are. Employing a qualitative inquiry design is well suited for the proposed study as it will provide rich data and a strong base for understanding the issues faced by younger residents in care facilities.

For this study, the data collection methods consists of in-depth interviews with the younger residents, focus groups with a selection of the facilities staff, and a face to face interviews with the executive director and/or the director of care. The purpose of the in-depth interview is to understand their quality of life as experienced by the respondents. Open ended responses enable the researcher to capture the points of view of other people without predetermining those points of view by asking to select their answers out of questionnaire categories (Patton, 2002). Since this area of research is relatively understudied, in-depth interviews will provide an understanding of the nature of the lived experiences of the younger residents and identify the key issues that are grounded in their lives. This method generates rich data from the younger residents' personal experiences living in the home as well as from the staff that interact with the participants on a daily basis. The research has been approved by the Simon Fraser University Office of Research Ethics. Participation in this

study is voluntary for all participants and they do not have to answer any questions that they do not feel comfortable with and are free to withdraw at any point of the study. All of the answers will be kept strictly confidential; names will not be revealed at any point of the study, pseudonyms will be used and answers will be coded to preserve privacy.

In order to gather staff perspectives on the issue emergent from residents' experiences, a focus group with staff members was conducted in each facility after the resident interviews were completed. Focus groups are small group interviews where the participants discuss in a group setting topics that are raised by a moderator. The moderator guides the group discussion through the main issues by asking questions to the group and allowing everyone a chance to speak (Morgan, 1998). The group dynamics in a focus group generates valuable data through the group's interaction and discussion of similarities and differences within the topic area (Belle Brown, 2000). In order to facilitate group discussion the focus group members were seated around a small table where all members were able to see each other and everyone was perceived as equal contributors (Stewart et al., 2007). In order to capture the group participation and nonverbal communication, which can provide further insight to the data, the focus group was video recorded. The main goal of the focus group is to get a closer understanding of the participant's perspectives of the research questions. Focus groups' open response format provides a good opportunity to obtain rich data in the respondents own words. The staff were interviewed in the focus groups in

order to gain another perspective regarding the characteristics of younger resident's quality of life as well as the key factors that contribute to their quality of life. The face to face interview with the executive director and/or the director of care was approximately 20 minutes and focused on the facility's organizational care practices, policies and procedures with regard to younger residents. The executive director and director of care did not participate in the focus groups since the staff may not feel free to express any concerns or opinions regarding the organization or care practice with the higher management present. By separating the care staff from the upper management, it is felt that the care staff will feel more secure and open to discuss any organizational issues that may be of concern. The focus groups and face to face interview took place after the all the in-depth interviews were completed and a preliminary analysis was done. This allowed the major themes from the resident interviews to be highlighted in the focus group interview guide in order for the discussion to be contextualized by the residents' perceptions.

3.2 Study Sites

For the purpose of this study, two residential care facilities in the lower mainland, both privately run under the Vancouver Coastal Health Authority, were chosen. The facilities were purposely chosen based on the high percentage of younger residents residing in these care facilities, the age of the facilities and the physical environment of the facilities. This was done in order to compare and report on any implications for younger residents' quality of life regarding the

physical environment. Facility A is a larger facility built in the 1970s under the medical model of care, creating a hospital like layout and design. In contrast, Facility B is a smaller facility built in the year 2000 under a person centered model of care, creating a more modern, home like layout and design.

Facility A, built in the 1970s, is a 205-bed complex care residential care facility. The facility has four floors including an extended care unit and a special care unit. Within the last five years, Facility A has seen an increase in younger residents coming into care and has developed a reputation as a good care facility for younger residents living on Vancouver's North Shore. Due to the majority of Facility A's population being older geriatric residents who tend to be more frail, the care facility does not accept younger residents with behavioural problems that could jeopardize the safety of the older residents. This facility currently houses 22 younger residents, comprising 11% of their total population. Within the younger residents there is an equal sex ratio, 11 younger men and 11 younger females. Of the 22 younger residents, 18 residents were eligible for this study under the selection criteria. Eligible residents were chosen based on the social workers' discretion, availability and willingness to participate. The researcher asked the residents if they would like to participate and then scheduled a time for the hour long interview. Of the 18 eligible residents in Facility A, ten younger residents were interviewed, including background questions.

Facility B, built in the year 2000, is a 72-bed multi-level residential care facility. The facility consists of four self contained areas, including a special care

unit. Facility B was built as a replacement care facility for one that stands next door to it. This other facility ran as a senior residence from 1913 until the 1960s when it became a 58 bed licensed care facility for seniors operated by the city. This care facility was not a typical care facility; it was run down and known to house low-income residents from the community, many with behavioural problems. In 2000, Facility B opened and many of the residents from the facility next door were asked if they would like to move in. This started Facility B's reputation as a care facility that welcomes people from the community that many other care facilities would reject -- mainly younger residents with difficult behaviours or psychological issues. Since opening, Facility B has become a care home that houses this unique population of residents, as well as many older adults from the community. This history has created a mix of lower income younger residents with unique needs compared with the more typical geriatric resident from the community that is found in most care facilities. Many younger adults residing in Vancouver who are in the care system will be referred to Facility B by case managers as it is known to be a good place for them. Younger residents living in other care facilities will also put their name on the wait list to be transferred to Facility B, which has an average wait list time of 4 years. Due to their willingness to house this more difficult population, Facility B is also unique in the sense that 70% of the care facility is male.

Although most residential care facilities are predominately older females, Facility B is predominately male, half of whom are younger males. Facility B has 72 residents, 51 of which are male. Of the 72 residents, 30 are under the age of

70, and of the 30 younger residents, 26 are male. Facility B's younger residents comprises 42% of the population, and of the younger residents 87% are male. Under the study's eligibility criteria, 23 of the younger residents living in Facility B were eligible. The social worker at Facility B asked the younger residents if they would like to be a part of the research study and if they accepted set up a time for the hour long interview. As in the other facility, residents were chosen based on the social worker's discretion, availability and willingness to participate. Of the 23 eligible residents in Facility B, 9 younger residents were interviewed, including background questions.

At the beginning of each interview, background questions were asked.

Table 2 below provides a summary of the background questions and answers on their socio-demographics such as age, sex and marital status. Table 3 summarizes the younger resident's conditions, daily limitations and care needs.

In facility A, five of the respondents were male, and five were female, with an average age of 60 ranging from 40-68 years old. The length of time spent living in residential care ranged from five months to ten years. Eight of the respondents were divorced or separated, one was widowed and one had never married. Of the ten respondents, seven of them had children, all of which are close to them; however, one respondent's child had since passed away. The community affiliation varied, four reported North Vancouver, two Vancouver, one West Vancouver, one Pender Harbour, one Gibsons, and one Vernon. In terms of education, two had completed high school, five had some college or university, one had some specialized non-degree training and two had completed a

university degree. Most of the respondents were born in Canada; three were born outside of Canada, in England, Scotland and Germany. Spiritual or religious importance was rated low for seven of the respondents, while three reported a high importance. The respondents' overall physical health was self-reported, one reported excellent health, three reported good health, four reported fair health and two reported poor health. The respondent's health conditions and limitations varied in each case (Table 3). Of the ten respondents, six did not have any limitations to their daily care.

In Facility B, all the residents were male, with an average age of 55, ranging from 40 – 68 years old. The length of time spent living in residential care ranged from one and a half to ten years. The marital status varied as one was married, 3 were divorced, one was widowed and four were never married. Only two of the men had any children, one reporting he was close with them and the other reporting he hadn't seen them in years. Seven respondents reported Vancouver as the community they affiliated with, one reported Burnaby and one reported no community affiliation. In terms of education, 3 had graduated from high school, 5 had a college diploma or some specialized training and one respondent had a university degree. Seven of the respondents were born in Canada, while two emigrated from Scotland. Spiritual or religious importance was rated low for three of the men, while six reported a high importance. The respondents overall physical health was self-reported, one reported excellent health, four reported good health, two reported fair health and two reported poor health. The respondent's health conditions and limitations varied in each case

(Table 3). From the nine respondents, five did not have any limitations to their daily care.

Table 2: Resident Background Information

<u>Demographics</u>	<u>Facility A</u>	<u>Facility B</u>
Males	5	9
Females	5	0
Ages	40 55 (F) 59 (F) 60 (F) 62 (F) 63 64 67 67 (F) 68	40 46 53 55 57 58 60 62 68
Years in facility	5 months 6 months 7 months 9 months 1 yr 3yrs 5 yrs 2 yrs (6 years in LTC) 7 years 10 years	1.5 yrs 1.5 yrs 2 yrs 9 months 3 yrs 4 yrs 5 yrs 3 months (5.3 in LTC) 3 yrs (10 in LTC) 10 yrs
Marital status		
Married	0	1
Divorced/separated	8	3
Widowed	1	1
Never married	1	4
Children?		
YES	7	2
NO	2	7
Close?		
Yes	6	1
No	0	1
Passed away	1	0

Community affiliation	North Vancouver 4 Vancouver 2 West Vancouver 1 Pender Harbour/ Deep Cove 1 Gibsons 1 Vernon 1	Vancouver 7 Nowhere 1 Burnaby 1
Education		
Less than High school	2	3
High school grad	5	0
Some college/ univ	0	5
College diploma/ sp. Degree	1	0
University degree	2	1
Born in Canada?		
YES	7	7
NO	3 (England, Scotland, Germany)	2 (Scotland)
Spiritual/Religious needs		
1-5 (not important)	7	3
6-10 (Important)	3	6
Overall Health		
Excellent	1	1
Good	3	4
Fair	4	2
Poor	2	2

Table 3: Resident's Conditions and Limitations

	<u>Facility A</u>	<u>Facility B</u>
Conditions	<ol style="list-style-type: none"> 1. MS 2. MS 3. MS / Exema 4. Lung Emphazema / Asthma / trouble with legs 5. Stroke / onset Dementia 6. Diabetes / Thyroid Condition 7. Epilepsy / Diabetes 8. Brain Cancer 9. Substance related disorders / balance 10. Substance related disorders / gout / diabetes 	<ol style="list-style-type: none"> 1. Right Leg Parthesis/Alcohol Abuse /Diabetes 2. Primary Lateral sclerosis 3. Huntington's 4. Head injury/mild dementia/ substance related disorders 5. Poor self management / Diabetes 6. High blood pressure / legally blind / poli-stigmia 7. Schizophrenia / Diabetes 8. HIV positive / Anxiety 9. Substance related disorders
Limitations	<ol style="list-style-type: none"> 1. Wheelchair, Toileting, bathing, need assistance with everything 2. Wheelchair, no use of legs, toileting, bathing 3. Wheelchair, Bathing, Toileting, no use of right hand, need help with everything 4. Wheelchair-can't walk, Bathing 5. No 6. No 7. No 8. No 9. In Wheelchair, does all own self care 10. No 	<ol style="list-style-type: none"> 1. Wheelchair, bathing 2. Wheelchair, bathing, toileting 3. Chewing, problems sleeping, bathing 4. In Wheelchair 5. No 6. Eye Sight 7. Problems with leg 8. No 9. Uses a walker – no self care help

3.3 In-depth interviews

In-depth interviews with younger residents were used to uncover the challenges and advantages that they face in their daily lives that shape their quality of life in residential care. Qualitative interviewing allows the researcher to

enter into the other person's perspective and understanding. An in-depth interview involves one to one, face to face interaction and seeks in-depth information and knowledge from the participants (Johnson, 2002). The interviews provide a framework where people are free to respond in a way that represents accurately and thoroughly their points of view about the world in which is inquired about (Patton, 2002). The purpose of in-depth interviewing is to find out from people those things that cannot be directly observed and to find out what is in and on someone else's mind (Patton, 2002). In-depth interviewing is used to explore what is on someone's mind and begins with the assumption that the perspective of others is meaningful (Patton, 2002). The purpose of this study is to understand the life, feelings, experiences and thoughts of younger residents living in residential care. Since the topic is underdeveloped, in-depth interviews provided the means to explore the topic more openly in order to allow the interviewees to express their opinions and ideas in their own words (Esterberg, 2002). The goal of the interview was to have the participant reconstruct their experience within the topic under study and build upon and explore the participant's responses (Seidman, 2006). From each study site, 8-10 younger residents will be interviewed with a total sample size of 16-20.

The literature on the topic has generated a few substantive themes which helped to structure the interview guide. The quality of life literature has also generated several domains that correspond with the literature on younger residents in residential care. The interview was loosely structured around an interview guide containing key questions based on the literature review and

quality of life domains (see appendix A). Using an interview guide provides a more systematic approach to data collection and helped organize the analysis (Rubin & Rubin, 1995). Allowing the participant to elaborate and discuss further ideas or thoughts, helped facilitate discovery of aspects of the younger residents' quality of life that have not been identified in previous studies. The in-depth interviews were scheduled simultaneously between the two facilities. This was done in order to have consistency within the two facilities as new questions or probes may have arisen as the interviews were conducted that might inform the subsequent interviews. The interview was expected to last approximately 45-60 minutes. In reality, the interviews times ranged from 20 minutes to 85 minutes in length, with an average length of 47 minutes, depending on the participants willingness to discuss and elaborate on the questions. Each interview was scheduled at a time best suited for the participant, and the participant was required to sign a consent form before the interview commenced. With the permission of the participants, the interviews were tape recorded and transcribed verbatim for the purpose of analysis.

In addition to the in-depth interviews, a brief structured questionnaire was used to obtain standard information about the respondents (see table 2 and 3). This included demographic and background information such as date of birth, sex, marital status, education level, nationality, and self-perceived health. The structured questionnaire was asked prior to the interview in order to gain some insight into the background of the resident and to 'break the ice' and get the conversation rolling.

Studies examining the younger adult population in residential facilities define their population as under the age of 65. Sixty-five is the socially constructed age in our society where one becomes a senior. Most literature on older adults defines the older adult population to be over the age of 65. Stemming from experience in a residential care facility with a large proportion of younger residents, it is believed that young adults living in residential facilities should be defined as people under the age of 70. It can be generally assumed that adults who are aged 65-70, who meet the study's criterion, will relate better to the younger population than the older. Since the average age of a care facility resident is around 85 years, being in one's late 60s is a relatively young age in a residential care home. In our society we attribute being in a care facility to being old and frail. Seventy years old, although defined as a senior citizen, is generally considered a younger age to be living in a care facility, especially if they meet the other sample criteria. This study will include residents who are under the age of 70.

Within the two care facilities, purposive sampling techniques guided the selection of younger resident participants. Purposive sampling selects information-rich cases to study in-depth in order to learn a great deal about the issues of central importance to the study (Patton, 2002). In order to select the younger residents, the logic of criterion sampling was applied. Criteria sampling is a purposive strategy that studies all cases that meet a predetermined criteria of importance (Patton, 2002). To be eligible for this study, the participant must be under the age of 70, have been living in the residential care facility for three

months or more, be cognitively intact or have low cognitive impairment indicated by the mini-mental status examination score over 16 or by consultation with the social worker to be deemed able, be able to verbally communicate in English, be physically well enough to participate in the study, and agree to participate in the study and sign a consent form. Eligible participants were identified through discussion and partnership with the two facilities' social workers.

3.4 Focus groups

The study used focus groups with selected staff in the care facility in order to acquire their perspectives on the issues faced by younger residents as well as the organizations care practices, policies and philosophies. A focus group is a guided group discussion to generate a rich understanding of the participant's experiences and beliefs on a specific topic (Morgan, 1998). Focus groups are often used in qualitative research to explore topics that are poorly understood or where little is known about the topic of interest (Morgan, 1998; Stewart & Shamdasani, 1990). Focus groups are useful when conducting exploratory research designs as they have the ability to explore and discover new ideas and concepts through an interactive group discussion. Through the group dynamics, focus groups allow respondents to react and build off each other's responses as they share and compare their thoughts and ideas. This synergistic effect created by the group setting may have resulted in the production of a wider range of information, insight and ideas that may not have been uncovered in individual interviews (Stewart & Shamdasani, 1990). In a group discussion, participants

are encouraged to investigate and listen to the ways people are both similar and different from each other in their responses. Observing how the participants react to each other gives an in-depth view of the range of the groups experiences and opinions (Morgan, 1995). Focus groups allow the researcher to interact directly with the respondents, providing opportunity for clarification, follow-up questions or probing. In addition to the spoken word, focus groups allow the researcher to observe non-verbal responses, in expression or gestures, which may carry useful information that supplements or even contradicts the verbal response (Stewart & Shamdasani, 1990).

The goal in using focus groups is to get closer to the participants understandings of the research topic, using the open response format of focus groups provides a good opportunity to obtain large amounts of rich data in the respondents own words. Focus groups are created for a well-defined purpose, focused on the researcher's interests and therefore are run by a moderator who has written guide covering the discussion outline (Greenbaum, 1998). A moderator guide was developed for the studies focus group which contains the researcher's main goals of the discussion (see Appendix B). The focus group was moderated and run by the researcher with the help of an assistant who operated the video camera. Data collection from the focus groups is used to enhance the individual interview data and add to the larger program of research. Additionally, this provides follow up data to the interviews, which allowed the researcher to explore the responses or issues that came up during the individual interviews. Once all the interviews were completed, an initial analysis of the data

guided the focus group questions. Questions were formulated to discuss any themes or topics that were highlighted in the individual interviews.

Within each facility one focus group interview with a group of staff members was conducted. The focus groups was a “minigroup” (Greenbaum, 1998), consisting of approximately 5-7 staff members. Both sessions were 60 minutes long, allowing for the typical 10 minutes of talk time per person (Morgan, 1998 & Greenbaum, 1998). The focus groups took place in the boardroom of each facility. In order to work around the staff’s busy schedules the focus group took place during their lunch hour, and food was provided. Each focus group was digitally audio-recorded, videotaped and transcribed for analysis. The focus groups were videotaped in order to capture the nonverbal responses, in expression or gestures which add to the spoken word. Each focus group participant was required to sign a consent form before participating in the focus group.

In order to obtain focus group participants who met the needs of the project and would generate the most productive discussions, a purposive sampling method was used. Staff within the facility was chosen based on their involvement with the younger residents on a daily basis and their job positions. Staff members were chosen from the recreation department, nursing department (nurse, care aide) and management (social worker). The social worker manager was chosen due to their high knowledge and interaction with the residents within their job. The nurses and care aides were chosen based on their high level of

interaction on a daily basis with the younger residents regarding medications, assistance with daily living and daily interactions. A recreation therapist was also invited as she/he interacts with the younger residents on a regular daily basis and they are in charge of the facilities' daily activity programs.

Compatibility is a key concern when deciding on the focus group composition. A compatible group is preferable for focus groups so they can spend less time explaining themselves and more time discussing the issues, in a comfortable, safe, trustworthy atmosphere (Morgan, 1998). Within this group, each individual works in the service sector of health care, are co-workers, and understands each other's roles within the facility, however as individuals with different roles within the facility, had different perspectives regarding the quality of life issues of younger residents. The discussion was contextualized within the particular organizational philosophy and policies about care practices, activity programming and work culture.

In each facility, one face to face interview was also conducted with the executive director or the director of care in order to understand the facility's organizational care practices, policies and procedures about younger residents' needs. The interview was approximately 20 minutes long and was scheduled after the younger resident interviews and the focus groups were completed and the analysis had been done in order to integrate the major themes from the data into the discussion. The interview with the higher management was conducted separately from the staff focus group in order to have the focus groups be a

secure environment where the staff felt uninhibited to discuss issues and concerns in the organization.

3.5 Data Analysis

The in-depth interviews were typed into verbatim transcripts and inductively analyzed throughout data collection and analysis. This process allowed the findings to emerge from the data by discovering new and existing patterns, themes and categories in the data (Patton, 2002). Content analysis, which involves identifying, coding, categorizing, classifying, and labeling the primary patterns in the data was used to determine what was significant and to analyze the core content of the interviews (Patton, 2002). Content analyses of the interviews began with line by line open coding in order to reveal the potential insights meanings and themes without rigidly applying pre-established codes to the data (Esterberg, 2002). This early examination of the data using detailed open coding provided preliminary suggestions of recurring themes for the detailed focused coding based on concepts emergent from the earlier open coding method and existing literature. Focused coding further refined and labeled the data by identifying and linking the data into general categories and themes identified during the open coding (Esterberg, 2002). The interview data was also analyzed by comparing cases, which compared individual interviews to discover concepts and themes and generate an understanding of these emergent themes (Rubin & Rubin, 2005). The two facilities were also compared concerning their environment, organizations care practices, policies and

philosophies. Throughout data collection and analysis memos were written. Analytic memos were used during data collection to note observations, personal feelings or emerging categories or themes (Esterberg, 2002; Rubin & Rubin, 2005). These memos documented substantive themes, feelings and ideas that could get lost with time, and helped in the analysis and write up of findings, especially the reflective process. Procedural memos were also used in the data analysis section in order to keep track of how the categories and codes were created, what they included, and what codes were rejected in order to keep track of the analysis procedures (Esterberg, 2005).

The focus groups were also tape recorded and transcribed verbatim for analysis. Analysis began by going back to the intent of the study and pulling out the main ideas, themes and content using content analysis coding. Focus group analysis is unique as it uses many strategies and approaches as data is gathered through observations, conversations and background information (Krueger, 1998). Analysis examined the words as well as the actions and behaviors of the participants through video recording the focus group. Data is produced through a group process in a focused manner, resulting in participants influencing each other, changing opinions, and new emergent insights (Krueger, 1998). The focus groups provided an insight into the younger residents' lives through the perspective of the staff. The main themes and concepts from the younger resident interviews were discussed in the focus groups, in order to acquire a different perspective and enrich the findings.

3.6 Trustworthiness

In qualitative research, trustworthiness brings rigor into the research process, as validity and reliability are used in quantitative research (Lincoln & Guba, 1985). Lincoln and Guba (1985) defined the basic issue of trustworthiness as the inquirer's ability to "persuade his or her audiences (including self) that the findings of an inquiry are worth paying attention to" (p. 290). The researcher must seek to establish credibility, transferability, dependability and confirmability in order to establish trustworthiness in the research study. Drawing from Lincoln and Guba (1985), several suggested measures will be used to ensure the trustworthiness of this study.

1. **Credibility** techniques are used to make it more likely that credible findings and interpretations will be produced from the study (Lincoln & Guba, 1985). Lincoln and Guba (1985) suggest a few ways to achieve credibility. First, the technique of methods triangulation is employed through in-depth interviews with multiple interview respondents combined with focus groups with staff members. The combination of these data collection methods will illustrate the perspective of a variety of people regarding the same issues, thereby enabling greater confidence in the findings. Second, peer debriefing will be used to enhance the credibility by keeping the inquirer "honest", by means of probing the biases, exploring the meanings, clarifying and defending the interpretations (Lincoln & Guba, 1985). Third, negative case analysis will be used, which is the "process of revising a hypothesis with hindsight . . . [by] refining a hypothesis until it accounts for all known cases without exception" (Lincoln & Guba, 1985, p. 309). This

technique will be employed during the revision and definition of the hypothesis in order for it to account for all cases. Lastly, a reflexive journal, which records information about self and method will be kept in order to record any biases, personal reflections, and methodological decisions. The reflexive journal will increase the credibility by allowing for the examination of the researchers biases and how they may affect the outcomes.

2. **Transferability** refers to whether or not the findings will be useful to others in similar situations. The transferability of this study will be strengthened by providing the necessary information of the study's progress. Descriptions of what decisions were made and why regarding the process, setting, people, sampling rationale, data collection and analysis will be made available. Readers and future researchers will be able to use this information when applying it to their own setting and study.

3. **Dependability** concerns the study's reliability in yielding similar results with similar measurements. In order to address the issue of dependability, an audit trail will be made available for examination. The raw data, memos, progress notes, reflexive journal and analysis information will be accessible in order to see how decisions were made, reasons for the decisions, and how biases were accounted for. An audit trail can allow others to understand how the conclusions were grounded in the data and accuracy can be verified (Lincoln & Guba, 1985).

4. **Confirmability** concerns whether or not the data confirms the findings. The audit trail will also address the issue of confirmability. The audit trail documents the work, decisions and process conducted throughout the study documenting

how the conclusions are grounded in the data. By consulting the audit trail the accuracy of the data may be verified.

4: FINDINGS AND DISCUSSION

This chapter presents the findings based on qualitative analysis of the younger residents' in-depth interviews, the staff focus groups as well as the management interviews. The staff focus groups and management interviews will be discussed separately at the end of the chapter. The resident interviews were loosely structured around an interview guide containing key questions based on the literature review and quality of life domains (See Appendix A). The focus group questions were based on the interview guide and were also supplemented with questions added due to the interview responses (See Appendix B). The focus groups were conducted after all the younger resident interviews were completed and a preliminary analysis was done, outlining some of the major themes from the interviews. Issues from these themes were then brought up in the staff focus groups. The management interviews were completed last, focusing on the facility's organizational care practices, policy's and challenges with regards to the younger residents. Using an inductive approach, the interview transcripts were analyzed to identify several substantive codes. Similar codes were then clustered together under larger thematic issues. Four main themes developed from the interview data: a) A new chapter in life; b) Experiencing quality of life; c) Staying engaged; and d) Social life (Table 4). The first theme, *a new chapter in life*, is based on two codes: "the big picture on quality of life" and "adapting to a new life." "The big picture on quality of life",

addresses how the residents themselves define quality of life, more specifically, how they describe their quality of life, and how they feel that their quality of life has changed since moving into residential care. “Adapting to a new life”, contains accounts of residents adapting and accepting both their illness and their new life in residential care, and those who have not. The second theme, *experiencing quality of life*, contains five codes: “frustrations”; “reporting on quality of care”; “environment”; “unmet needs” and “money matters.” “Frustrations” talks about frustrating and difficult aspects of the care home described by the younger residents. “Reporting on quality of care” looks at how the younger residents perceive the quality of care given by the staff. The “environment” code discusses aspects of the structural and organizational environment in each facility. “Unmet needs” include such things as physical, sexual and nutritional needs which were expressed by the respondents. “Money matters” examines the financial situation of the younger residents as described by the respondents. The third theme, *staying engaged*, takes a look at the activities from the younger residents’ perspective containing two codes: “misfit in activities” and “alternative activities” “Misfit in activities”, describes what the younger residents reported about the planned activities and what they enjoy doing, while “alternative activities” looks at how helping out in and out of the home brings meaning to the residents. The last theme, *social life*, encompasses the residents social life outside of the care home as well as within the care home containing three codes: “community connections;” “interaction with other residents;” and “the staff are good”. “Community connections” describes the

connection to the larger community as well as to the resident's friends and family outside of the home. The code "interaction with other residents" describes the social interactions with the other residents within the facility, while "The staff are good" describes the social interactions with the staff in the facility. This collection of thematic issues encompasses the various aspects of the younger residents' quality of life as discovered from the interviews.

The interview data was collected from two residential care facilities. Yet, there was no significant difference between the two groups regarding the majority of their answers. For the most part, the four themes were relevant to both groups. Thus, the findings are represented by the common themes and include all participants' responses. The only major differences between the two facilities were seen regarding the environment and the activity programming. Within the discussion of the themes, significant differences that have emerged between the facility participants will be highlighted.

Table 4: Emergent Themes and Codes from Resident Interviews

A NEW CHAPTER IN LIFE
The Big Picture on Quality of Life
Adapting to a New Life
EXPERIENCING QUALITY OF LIFE
Frustrations
Reporting on Quality of Care
Environment
Unmet Needs
Money Matters
STAYING ENGAGED
Misfit in Activities
Alternative Activities
SOCIAL LIFE
Community Connections
Interactions with Other Residents
“The Staff are Good”

4.1 A New Chapter in Life

This theme, a *new chapter in life*, is comprised of two larger codes: “the big picture on quality of life” and “adapting to a new way of life.” “Quality of life” can be measured on either an objective or subjective basis (Thapa & Rowland, 1989). This study aims to examine the subjective factors of quality of life based on the individuals’ own perceptions of their lived experiences in the care facility. This section allows us to gain an understanding of how the respondents define and understand quality of life, as well as how they define their own quality of life and any changes therein since moving into the care home. Beginning a new chapter in life also encompasses the role of their adaption to life in a facility. The second code that ties into this thematic concept discusses how the respondents

described adapting to their new chapter in life. Several main codes were found within the interviews as adoption tools such as: acceptance, positive attitude, personal techniques or turning to religion. Overall, this theme is about a new beginning in life and how quality in life is understood within this new phase of life.

4.1.1 The Big Picture on Quality of Life

Quality of life in this study is a subjective perception reported from the younger residents based on face-to-face interviews which discussed topics focused on a selection of quality of life domains from the literature. To get a sense of how the participants themselves thought about the term *quality of life*, they were asked “what does the term quality of life mean to you?” The respondents mostly answered with short, broad answers, having a hard time elaborating on the term. The majority of participants talked broadly about having the independence and freedom to do what they enjoy doing in their daily lives, describing it in terms of what they enjoy doing. A common response defined quality of life as “doing the things that you want to do”. Most participants defined the term by talking about what was important or meaningful within their own lives, as one respondent, Jack stated: “well quality of life means being able to be with your friends,” which was an important aspect in his life. Responses varied depending on the individual’s values, health condition or life situation. Denis described quality of life in terms of what was important to him in his daily life:

Being able to function normally, meaning that if you need to go to the bathroom. You don’t need nobody to help you if you want to go out, you don’t have to wait for

nobody but if you're able to be helpful and that's quality of life and you know, if you make a few dollar makes you feel human. You'd be able to go out and enjoy yourself once in a while. That's quality of life and you start taking some of that. And that's when.... that's the most scary part for me.

Another respondent who is more dependent on the nursing staff due to being in a wheelchair and living with Huntington's disease described his quality of life more in terms of the help he receives in his daily functioning, stating "Quality of life is ...being able to count on them for regular things like cutting your nails and stuff like that, make sure you have a shave."

The respondents were also asked to describe what their quality of life is like *living in the care facility*. Responses varied in a wide range from "The quality of my life is terrible! It's terrible!" to "In a few words... I would say good."

Interestingly, among the respondents that answered the question, half reported a more negative quality of life, while the other half reported a more positive quality of life. Residents reporting a more negative quality of life used words such as "dismal," "poor," "low," "not happy," "terrible" or "it's fine . . .but" to define their quality of life. One common explanation for the low quality of life mentioned by a few respondents was the idea of not being able to do what they want to do. For example, Roger explains why his quality of life has declined:

...it's fine here, you know, but you miss so much when you're here... you can't go to the pub. You can't go to the ballgame. You can't do this. You can't do that, you know, normal stuff that I used to do. You can't do it, but as far as sleeping and eating and sitting outside and everything. It's okay, so I just can't do what I used to do.

Respondents who reported a more positive quality of life used words such as “good,” “great,” “fun,” “lucky,” and “can’t complain.” A few who are more dependent on care mentioned how the care staff takes good care of them, which is an important aspect to their quality of life. Others had a “can’t complain” attitude due to their condition or saying that there are more positive than negative aspects to living in care.

While describing their quality of life, many respondents compared their life to dramatic circumstances. Some compared it to an extreme example in order to make their situation not as bad. James puts it, “Now I’m not bad I suppose, it’s not great but it’s far from living under a bridge.” Many thought that the situation they are in now, although not ideal, was better than the alternative. A number of respondents compared it to their life before coming into care, or where they would be living now if they hadn’t moved into care, feeling that compared to that they were better off. Connie mentioned, “[my doctor] said I could have died out there (on the street). He thought it would be better for me to live in here. And I’ve been really good here.” Moving into a residential care facility was a big change for all of the respondents; however, the change for some was very different than for others.

Many of the respondents reported a negative lifestyle change when moving into care, with a strong theme of loss. Issues such as the loss of friends and family, the loss of freedom, the loss of space, privacy and belongings, and the loss of sexual relations were all mentioned. Anthony describes the negative change he experienced when moving into residential care:

Then I end up in [name of facility], an old folks home with a bunch of weirdo's! Ha. So this is very different for me, from what I would want to live... I could go anywhere and do what I wanted. I had a little sports car, and I had a truck.... And now, instead of a sports car, I have a walker! (Haha) Quite the difference. Yeah...

On the other hand, there was a group of respondents who reported the opposite - a positive change in their life since moving into residential care. Two respondents reported an improvement in their lives due to coming into care and 'straightening out their lives.' Before coming into care, both Connie and Martin had lived hard lives struggling with substance abuse, spending some time in shelters and became immensely overweight. Since coming into care they both talked about the journey they have taken in order to improve their lives by losing weight and getting into a more healthy lifestyle, both attributing it to the help they received when coming into the care home. Connie talked about straightening out estranged family relations and forming better relations since being in care, having everything "come together." Ryan, another respondent, said that "[the] services they give and going (sic) support, the regular programs of showers..." improved his quality of life, as this is something he could not do for himself at home. The idea of coming into care to 'straighten out' one's life either concerning a physical need, emotional need or psychological need was clear within the respondent's answers who reported a positive change in their life since coming into care.

4.1.2 Adapting to a New Life

At the time of the interview, the majority of participants had lived in a residential care facility for more than a year, with the average length of stay being approximately four years. Seven of the respondents had lived in a different residential care facility before residing in their current facility. The idea of adaptation became a prominent theme within the interviews. Almost all of the respondents reported having to adapt in various ways since moving into residential care. The respondents have to adapt to living in residential care, as well as the parallel struggle of adapting to their illness or condition. They talked about the difficulties of getting used to a wheelchair, living with an illness that “gets you down” or dealing with the feeling of personality and identity loss due to their condition. Not only are the residents trying to make sense of and adapt to their illness, they are also trying to adapt to their new living situation. Every time anybody finds themselves in a new position there is a natural period of adaptation. Adapting strategies are different for each individual and dependent on many factors, such as their values, situation, or personality. When asked how they have adapted to living in residential care, the answers varied, however four issues arose from the responses: acceptance, positive attitude, personal technique, and religion.

From the respondents' answers, it is seen that an accepting outlook of one's new life in residential care is an important aspect in being able to adapt. Within the participants there was a continuum of acceptance, from little or no acceptance to full acceptance. Those who accepted their situation seemed to

adapt better and, in turn, are likely to be happier in their daily life. Martin, who has been in care for ten years, and has accepted this way of life, explains:

They said I would stay in here indefinitely. So yeah, that's quite a while. When I think about here, I think you might as well make yourself as comfortable as you can . . . I've been in the system so long . . . I have yeah, but now I'm just satisfied with the way things are going. I can't complain that much . . . [facility name]...I can accept it, yeah.

The respondents seemed to accept it because they do not have anywhere else to go, they believe it is for the best, or they feel that there is not much they can do about it and they have to live with it. Many respondents used the word 'stuck' to describe their current situation and stated that "there's not much I can do about it," so they "have to live with it" or "make the best of it"

Having a positive attitude was also a strong determinant of accepting and adapting to life in residential care. Many respondents talked about how their positive attitude and personality have helped them adapt to living in this situation. One respondent attributed being able to adapt to his "deep strength," others attributed it to being "positive" or "happy" people. One respondent, Denis, describes how he has adapted to life in residential care by trying to stay positive:

There is a lot more good than there is bad. You cannot always have everything perfect . . . and try to think about the good things. Everybody has disappointed its part of life. So if you let it destroy you. You know, that's why I try to be positive . . . yeah I'm doing okay, because I try not to let the little things bother me and as long as it continues this way.

Having a positive attitude helps people to accept the situation, and in turn, adapt to it.

Respondents also had individual techniques which they used to adapt, depending on what was personally important for them and what made them happy. For some people, the food was a hard thing to adapt to; respondents shared ways that they adapted to the food by making their own breakfast in their room, going out and buying food they enjoyed, or buying their own condiments such as salad dressing and ketchup to add to the meals. Other people concentrated on their hobbies or passions such as playing the guitar or doing art work. Some described how they chose to help out within the facility by making the bed or helping the staff as a way of feeling good about themselves and making it feel more like 'home.' Matt, a 40 year old resident, said that he has "slowed right down" as a way to adapt since not much goes on and the pace of the older adults is a lot slower than his abilities.

The fourth predominant way that a few of the residents expressed how they adapted to living in residential care, as well as living with their illness was their religious beliefs. Five of the respondents put high importance on religion in helping them adapt to both their illness and their lives in residential care. The respondents reported that when they got diagnosed with their illness or when they moved into care, they turned to their religion or went searching for a religion. Two individuals described how they "found Buddha" and are now passionate about Buddhism, describing how it has helped them deal with their illness as well as living in care. One of these individuals, who suffered from schizophrenia, described the importance Buddhism has in his life and how it has helped him adapt to his illness and living in care:

Buddha, I found Buddha . . . So I started meditating. Now when I meditate, I Meditate, oh it's good. Not a nerve in my body when I sit up! Oh there is never a time I feel alone in my room. I have Buddha and that sort of thing. I know maybe you won't believe that but... meditation . . .But I have Buddha. So I'm happy! It's a spiritual thing that mattered to me.

Richard expressed becoming more spiritual when he got diagnosed with cancer, joining his mother's church, praying often and joining the facility's spiritual group on Sundays. The other two residents, having a religious past, talked about how religion is an important aspect of their being; however, as they age it has become more prominent in their daily lives. As these respondents show, for some, religion and spirituality represent a key aspect in their lives which helps them to accept and adapt to life and the challenges it brings.

The process of adapting to this new life in residential care was also reported as taking time. A handful of respondents recalled that it was not easy at first and that it took some getting used to. Another common thought was that at first they did not think that they would ever get used to it, but over time through various ways they have become happy and "used to this way of living." This excerpt describes how Connie found it difficult at first:

Interviewer: *So when you first came in you didn't like it?*
Respondent: No. I was 49 years old when I first came in here.... There was a lot of things happening, I didn't really get along with anybody. So... I was by myself a lot . . . Oh yeah. It was hard. There was hard to get to know people.

This respondent has since adapted to living in care, gets along well with other residents and enjoys living in residential care. One respondent who has lived in the care facility for ten years said that he would not move into another care facility now because he “would start on the bottom rung again so it wouldn’t be worth it.” He believes that things get better the longer one lives at a place, finding a huge difference in his circumstances from the time he first moved in and now, ten years later. Perhaps the longer one lives at a place the better they get to know the staff and the privileges one receives. It can take time to adapt to a place, get to know the staff, accept the circumstances and have the place feel as close as possible to a home. According to the respondents, accepting and adapting to this new life can take time. Adapting to a new way of life was a significant code that came out of the respondent’s interviews. Each individual described how they adapted differently; however, it was a common thread within each interview.

4.2 Experiencing Quality of Life

The respondent’s quality of life is being explored through their own thoughts, perceptions and feelings on several of the quality of life domains. These subjective factors are based on the individuals’ perceived needs and satisfaction with their living condition (Hulsman & Chubon, 1989). Throughout the interviews several quality of life factors were seen as important and often referenced by the individuals. In this thematic cluster the broad quality of life codes that will be reported on are: “frustrations,” “quality of care,” “environment,”

“unmet needs,” and “money matters.” The code “frustrations” was formed from residents indicating frustrating or difficult aspects with the care home or towards other residents. Reporting on quality of care takes a closer look at the younger residents’ quality of care descriptions. The environment code includes the organizational and physical environment of the facilities, where a few differences between the two facilities are distinguished. The fourth code describes the unmet needs reported by the younger residents. Lastly, “money matters” takes a look at the younger residents reported money situations and how it affects them in their daily life. These five codes make up the theme *Experiencing quality of life* as they touch on many of the important quality of life domains within the literature.

4.2.1 Frustrations

Throughout the interviews, a common code that arose was *frustration* or difficult things to deal with while living in a residential care facility. Numerous residents stated frustrations or difficulties that fell within three subcategories: “frustrations with the facility,” “frustrations with other residents,” and “difficult to live with the ill and dying.” Respondents reported numerous things that frustrated them about the facility, depending on the individual’s experiences. One frustrating aspect mentioned was personal belongings not being labeled properly by the staff and going missing in the laundry. Another frustrating aspect reported was not getting the help needed in terms of extra care or assistance, for example, finding somebody to help plug in their telephone, to pick up some

dropped jewelry, or assist with daily exercises. One resident mentioned that she did not want to ring her bell because she did not want to bother the care staff. Another resident mentioned that she gets frustrated with her nurse telling her roommate “all sorts of things that are not right” like that she has to get ready for dinner at 3:30pm, when she doesn’t eat till 6:00pm.

The respondents also expressed some frustration with the other residents in the facility, mainly the residents who are “confused” or have dementia. Richard describes: “in the dining area there is screaming, and I think of one flew over the cookoo’s nest! It’s a bit wild some days.” For the younger residents with high mini mental (MMSE) scores, it can be difficult to live twenty-four hours a day next to someone with advanced dementia. James explained how he feels the facility should be more “segregated” finding it difficult to live with people with dementia on a daily basis, “you have people scattered here there and yon, and sometimes you got the crazy ones living right beside you.” Most deal with it fine on a daily basis, but it can be frustrating and challenging at times, as one respondent puts it in a humorous manner, “Don't worry - I've felt like strangling a bunch around here and that's about the only thing that stops you sometimes - 20 to life! (haha).” Humour seems to be a way some residents deal with and adapt to the situation. As another resident puts it “I’m much better than I was when I first arrived here. At the beginning I didn’t find it funny at all.”

A few respondents expressed how it was difficult to live with so many people that are so ill. It is depressing for the younger more able bodied residents to “see everybody in the situation that they are in” as Rose puts it. One man who

had recently transferred to Facility B from a different residential care facility with few younger residents describes why he chose to move:

everyone's got something wrong with them and that people that were in this place. I didn't care for them and being old... and wacky.. it was... so I came here . . . I just don't like living with people, especially weird people that have something wrong with them. I find that horrible and ugly . . . It's kind of awful when everybody's old or they've got white hair, they are in a wheelchair. It's really awful.

Betty, who lives in the extended care unit constantly hears other residents yelling, moaning or shouting out, and she described how "it makes her sick" to hear the other residents calling out when she cannot go out and help them. Seeing other residents in such frail stages in their life and being fed or wearing a diaper cause anxiety in the younger more active residents. For them, it is like getting an unwelcome preview of what *their lives* might be like in the future, as one resident expressed, "I feel like I'm going to be like that. I'm going to be one of those patients." In the interviews, the discussion of death from the respondents in Facility B was prominent as a fellow resident had recently passed away in the smoking room. Many of the respondents in Facility B alluded to this event, expressing their anxiety and their concern that next time it could be them. The majority of the respondents knew him from the smoke room or were friends of his, so his passing hit the younger residents hard and caused them to face their vulnerability. One resident expressed that dealing with all the death "is pretty hard to live with all the time" as six people that he knew from his floor had died since he moved in.

4.2.2 Quality of Care

During the in-depth interviews, the participants were asked the question, “how would you characterize the quality of care given by the staff in the facility?” The vast majority of respondents had very positive things to say about the staff within each facility. Words such as “good,” “great,” “well treated,” “fabulous,” and “excellent” were used to describe the care given by the staff. A few residents specifically expressed how they liked a particular care aide because he/she knew their routine. For instance, one woman with MS who needs to be helped in and out of bed stated, “[care aides name] knows how to do it, knows how it works. We know each other. She knows which parts work better than others. She knows to roll me that way and put this hand up.” Within the interviewed younger resident population, the level of care ranged from residents who needed no assistance in their daily care to others who required full assistance on a daily basis. What seems to be unique within this resident population, compared to the older population, is the number of residents who do not require any daily physical care. Many residents described being independent in their physical care, as Roger puts it:

You know if I needed something it usually happens. Very seldom I need anything. I don't know, but they don't have to dress me they don't have to bath me. They don't have to do nothing. You know, leave me be. Let me go around and have my cigarette or whatever. So I guess I'm not very high maintenance.

Other respondents also reported not being 'high maintenance' regarding physical care, one respondent receiving no physical care mentioned how he likes that there is medical help available 24 hours a day, having somebody in charge of his medication and having his meals prepared. The majority of the respondents reporting on the quality of care given by the staff do not require much daily assistance, other than medications. Overall, the responses given by the respondents regarding the quality of care given by the staff were positive; however, some residents expressed a few issues. A few residents mentioned how some staff can be bossy, harsh, or treat them like children. One resident, James, mentioned how on occasion the staff will infantilize him and other residents by the language they use or the by the way they treat them, he describes one scenario:

One of my favourite ones that drives me up the wall...when something is going not to their satisfaction or whatever the first thing out of their mouth is "go to your room, go to your room, go to your room" ... well that stopped when I was five years old and I sure as hell don't need it from somebody here! You know somebody who is younger than me is telling me to go to my room? Yeah right.

This poor use of language or direction was seen as an issue, as well as a lack of communication when interacting with the staff. One respondent talked about language barriers with staff members who do not speak English very well. He discussed how at times it is very difficult to get them to understand what he is saying. Another communication issue expressed by a respondent was how sometimes the staff will treat him as if he had dementia, not realizing that he is

“basically normal” and is capable of pouring himself his own cup of coffee.

Another point made by two respondents regarding the quality of care is the problem of “staff helping too much.” The respondents mentioned that they do not like it when the staff members try to help them when it is not necessary. This act takes away their independence and freedom, things that they strongly value. It was also mentioned that they hate seeing staff helping other residents too much because it is more convenient to them, for example putting residents in wheelchairs to push them to the dining room because it is faster than having them walk there. When the staff members appear to be providing too much help, it is perceived by the residents as taking away their independence instead of promoting it. Jack had a concern about the staff’s knowledge regarding how to deal with his severe anxiety, he explains:

Things running through my head like they don’t know the first thing about anxiety, that’s for one, right. It’s like well, just a little Ativan. It should be not a problem, right . . . No. Pills, knives and needles, are they only thing they have.

Jack felt that his psychological needs were not understood by the staff in the facility, needing care and support that was better suited to his needs.

A common code found within many of the interviews regarding the quality of care given by the staff is a feeling of compassion and sympathy regarding the sometimes difficult situation the staff were in and what they have to work with, recognizing that “they do the best work that they can do.” This compassion was seen within the nursing department, dietary department and the activities department. Even if there was an issue with the care given by the staff, many of

the respondents understood the demanding work load put on the staff and therefore did not complain, as Denis explained, “there are a lot of people that are very difficult . . . you cannot complain, they do as much as they can.” Respondents talked about the dietary department in the same way. A handful of respondents, who did not have very good things to say about the food, were still understanding of the department itself. Respondents were considerate to how many people they have to feed and how much money they have to accomplish it with, stating that it is “pretty good for facility food.” Regarding the activity department, there was a difference between Facilities A and B. Compared to Facility B, Facility A has fewer activity programs geared towards the younger residents interests. A few residents from Facility A expressed their understanding as to why there are very few activities geared towards the younger population, James explained:

being geared to that we've only got half a dozen younger generation here, so you can't very well gear for them to you know for six people or whatever the case may be but then how do you handle that you know? Because you have six and then you have 196 on the other hand . . . where does the bulk of your money go it has to go to the older generation instead of the younger generation because there's so many more older ones.

Instead of being angry that there is little to do within the facility, James was understanding towards the activity department's situation. Many of the respondents had the view that of course more could be done to make the living situation better, however, they are aware of what is available and feel that the

staff do a great job within the constraints. Two respondents even discussed the recent government cuts and how it is affecting the facility:

They've been cutting a lot now with all the cuts that the government has been doing. It shows the cuts on the hours that the nurse and the nurses aide can do and no overtime. So it's affecting the quality of life and things like that. Not that much yet, but it's going to get worse.

Many of the respondents are knowledgeable and understand the politics and economics of the situation within the government as well as within the facility.

4.2.3 Environment

From the interview section discussing the environment of the facility, three of the quality of life domains from the literature arose. One common code that arose from the findings was regarding the organizational structure of the facilities schedule and the residents desire to maintain a certain aspect of control in their lives. This finding touches on the quality of life domain which includes aspects of autonomy, independence, individuality and control as important quality of life characteristics. The second code recognized from the findings was the physical factors including the perceived quality of the facility's environment. This finding corresponds with the quality of life domain that includes safety, comfort and environmental quality. The last codes, discussing issues regarding the bedroom, personal space and possessions going missing are affiliated with the quality of life domain that includes attaining privacy, private space and personal possessions.

The description that daily life in the facility is too “structured”, not allowing the residents do what they want to do when and where was seen as a reoccurring code from the respondents. A few residents talked about how they like to stay up late in the evening and wake up late in the morning, however the care staff would always wake them up early in the morning for breakfast, following the daily routine of the facility. Due to the daily routine of the facility, residents have less control or independence in their daily lives. One resident living with MS explains how the staff makes her get out of bed for meals every day because they have rules that they must follow, however she describes the pain to vary daily and on some days, she does not want to get out of bed. The facility, in order to take care of so many residents, has to run under certain schedules and rules, which in turn takes away some of the resident’s freedom, autonomy and control over their daily lives. Roger talks about how his freedom to be able to take a shower when he feels like it is restricted:

but you can't do it when you want to. That's... you might want to get up in the morning and have your shower but you can't.... You know, you're used to getting up in the morning and having a shower or just going out the door or showering at night. Now they say Tuesday at 10 o'clock you be there I'm going to bath you!

The younger residents’ needs or preferences sometimes do not align with the schedule or rules within the facility, a system created with the older adult needs in mind. Graham, who is only forty years old, expressed his frustration that the doors to the facility are locked at 8pm and residents are not allowed to go out or have any visitors after that time. Another respondent discussed how the facility

wanted to control his finances when he moved into the facility; however, he fought to remain in control explaining “As long as I’m able to still able to take care of myself. I want to keep a certain control of my life.” Remaining in control over the aspects for which they are still capable is important to many people’s quality of life. The structure and control within the facility affects the residents’ individuality, independence and control domain that is important in one’s quality of life.

In order to get a broad overall sense of how the respondents felt about the physical environment of the facility the question was asked: “What do you think about the facility’s physical environment?” The respondents were then probed with the specifics regarding the quality of space in your room, activity area, dining area, other common spaces. Overall the respondents had very little to reflect on the physical environment, answering with phrases such as “it’s fine I guess.” It seemed that many respondents had never given too much thought to their physical surroundings or did not see it as something that affected them or that they could change. Many of the responses focused on their bedroom or personal space, instead of the common areas in the home. The responses regarding the overall physical environment of the facility were different between the respondents living in the two facilities, and will therefore be discussed separately. The respondents living in Facility B, the newer facility, regarded the physical environment in a more positive way. Respondents from this facility, when asked about the physical environment, replied by describing positive aspects of the facility, such as “good services,” “beautiful place,” “always clean,” “feels safe,” “a

nice building.” One respondent said, “this place is fantastic, on a scale of 1 to 10, it’s a 10.” One reason that the respondents in this facility may have talked more about and appreciated their building more might be due to the fact that they know they are living in a new facility. Many of the residents in Facility B acknowledged that they knew this facility was new and much better than others, either by word of mouth, from visiting other facilities, or from a comparative perspective of previously living in another facility. Comparing their facility to another facility was common for those that had seen others. One resident from Facility A, the older facility, had visited a newer facility and therefore knew that the physical environment was much nicer in the newer facilities. Another resident from Facility A explained it well, “That’s kind of a hard question, because you don’t know what some of the other ones are like. Maybe this may be Heaven, or it may be Hell, I don’t know!” Both facilities were acknowledged to have a good outside environment, one having a close proximity to a river and good walking trails and the other bordering a park. The majority of respondents in Facility A did not have as much to say about the physical environment of the facility, many said it was “fine.” Alice from Facility A regarded the environment as “old” and said it “need[s] help,” describing aspects of the environment that are not suited to wheelchair users such as out of reach buttons and door codes that allow her to get in and out of the facility.

The quality of life domain including privacy, private space and personal possessions were seen as issues through the respondent interviews. Many of the respondents brought up the importance of having their own bedroom and

bathroom in order to be able to close their door, “get away,” and attain some privacy. Regarding bedrooms, there was a difference between Facilities A and B. All the respondents in Facility B had their own private room and bathroom, as almost all of the rooms there are single occupancy. In Facility A, only two of the respondents had a private room and bathroom. Those who lived in a private room expressed how much they enjoyed it, “Oh I love it. It's my Castle! Haha. I love my room!” For many others that did not have a private room or bathroom expressed the desire to have one. As Ryan plainly states, “a private washroom is a very important quality of life detail.” The major reason for not having a single room for these residents was that they could not afford it, as a private room is more expensive. The biggest problem with having a shared room reported by the respondents was having a roommate. Many different roommate issues arose in the interviews. Betty, living in a three bed ward room, talked about the difficulties of living in a room with two other seniors who are unable to communicate and constantly make noise throughout the night. She describes how she “would like someone I could talk to. I would really like someone I could talk to . . . Or someone my own age..” as a roommate. Roger described how his roommate yells throughout the night, talks to himself and falls out of bed which “drives you nuts.” Richard was sharing a room with a resident with dementia, who was very confused and often went into his personal belongings and took his stuff describing, “I would have to watch him like a hawk, and I just didn't feel comfortable at night too, when I was sleeping there. I feel that things are going missing. My coin from my drawer and stuff out of my fridge.” Throughout the

interviews, having a private room and private bathroom was an important aspect of the younger resident's personal environment. Sharing a room can create issues regarding the resident's ability to attain privacy, retain personal possessions, and safety, which will affect their quality of life.

4.2.4 Unmet needs

The current literature regarding younger residents in residential care describes the three most significant unmet needs for this population as physiotherapy, counselling and recreation activities (Gutman et al., 1995; Gutman, 1989; Jervis, 2002). Many unmet needs were discussed throughout the interviews in this study on a wealth of topics, such as activity programming and finances, and will be discussed in the corresponding codes. However, in order to explore any unmet needs that the interview had not specifically asked, the question "do you have any other unmet needs that you feel are not being met?" was asked to give the respondent an opportunity to express these needs. Many respondents felt that they had touched on all of the important unmet needs through the interview and could not think of any other things to add. Other respondents, primarily the more independent younger residents felt that they had the ability to go out and take care of their needs. Of the residents who spoke on the subject, four main codes regarding unmet needs arose: physical needs, sexual needs, social needs and nutritional needs.

Physical needs were expressed by two of the more disabled younger residents who were both confined to a wheelchair. They both discussed the

need to get more exercise, as they are unable to do it on their own. Both residents acknowledged the fact that due to their illnesses they may never walk again, however, they still wanted to have the opportunity to use their body again and restore some strength. Alice was frustrated she wasn't getting any exercises to restore her strength because she needed one to one assistance to move her arms and legs, "I need [an] exercise period and like I said I get none." Howard, who wanted to walk again, expressed his desire for rehab in order to be able to practice walking, even if he would never do it independently again. The younger residents who are not as physically able, and are living with more daily limitations, need more assistance with their physical activity. Many of the ambulatory and more independent younger residents are able to get some sort of exercise through their own daily activities, however, little equipment or guidance is there for any strength or mobility training. If these younger residents have no opportunity to maintain their physical abilities when they enter residential care, they may quickly decline and lose their independence. One respondent who described exercise as important to his quality of life created his own exercise regime with some nearby steps and his own weights. The younger residents who are not as physically able, living with more daily limitations need more assistance with their physical activity.

Sexual needs were brought up by five of the respondents without any probing by the interviewer. Four men and one woman discussed their sexual needs or their desire to have a partner. The main problem discussed was being able to meet someone while living in residential care, especially for those who

are not involved in the community. Living in residential care with the majority of people being older adults means that finding someone in their own age range can be a barrier. A few of the respondents talked strictly about the absence of sex in their lives, however most respondents talked about wanting companionship or somebody to talk to. Being in an intimate relationship, having a companion or having a confidant was something that these respondents felt they were missing.

A few respondents touched on their unmet social needs living in residential care. Living in a small community with few people in the same age group is “a little something to get used to” as Matt puts it. Two respondents discussed missing the companionship and social aspect of their friends and acquaintances that they used to see more regularly. One respondent describes living in residential care as “sometimes it lonely, I have a hard time, certain times are harder, after dinner until bedtime seems to be a long time.” Although many of the respondents are social within the facility, they still felt they were missing out on a social aspect of their lives.

Most of the respondents did not complain about the food within the care facility, however there were a few significant comments made. A handful of the respondents who disliked the food went as far as to say the food is “atrocious, horrible or awful.” One suggestion made by a few of the respondents was that the menu is missing any fresh fruit. Two of the respondents admitted that they never eat at the facility, one going out to buy his meals on a daily basis and the other getting his sons to bring him take-out dinner every night. One forty year old

respondent mentioned that the “quality of food has been good, I could just put back more of it”.

4.2.5 Money Matters

Financial security is often seen as a quality of life indicator for residents living in residential care as it ties into lifestyle opportunities and allows the resident to engage in other quality of life options (Stewart & King, 1994). Many of the younger residents reported being on some social assistance, others reported having a pension, getting help from family, doing work for cash or did not elaborate on their source of income. For some, their money situation is “a disaster!” exclaiming that “those needs are not being met!” After paying the rent, many reported being left with very little spending money at the end of the month for anything else. Clothes, dentist, eyeglasses, physiotherapy, and any personal expenses such as cigarettes or food must come out of this small monthly amount. For some, it is embarrassing how little money they receive. As one respondent describes it, he would like to be able to make some money again so “I could get my self-esteem back, my confidence back.” Few of the younger residents stated that they would like to get back into the workforce, even if it was only part time. Most respondents stated that their finances limit them on a daily basis. Respondents reported their finances controlled their life, not being able to buy personal items, go out and participate in the community or join the outings in the facility going out into the community. Not being able to go on the facility outings was specific to Facility A. Facility B does not charge extra for its

community bus trips, however Facility A charges extra for bus outings.

Residents with limited finances cannot usually afford to participate in the community outings. As one respondent in Facility A explains:

You guys have a lot of nice programs, which I do enjoy, like going out to the dam that one time we went and different places...I loved going on them. So all the trips and everything that you put on have gone by the wayside now (as his rent increased and he no longer has enough money). So basically what it works out to is the only people that can go on the trips are people that have money from before. You know they sold their house and have put their money away somewhere or whatever.

In Facility A, transportation is a limitation, as many cannot afford to go on the facility bus outings or get out on their own. Some residents seem to have adapted to the situation and do what they can to improve it or accept it. Martin, has been in the system for ten years, collecting money from the government, he explained how he was excited that his 60th birthday was coming up which meant that he would be receiving an extra \$16 dollars a month, "progress" he called it. After years of being in the system, Martin has adapted to living with very limited finances by "staying out of the stores" because "they are a real money loser." Other residents have adapted to their limited finances by finding ways to make extra money to supplement their income. Connie, since living in residential care, started to paint with the encouragement of the staff. She now paints on card stock and sells her cards to the staff and residents, giving her the means to buy all the art supplies. Connie also described how she massages staff member's shoulders for \$2 on their breaks; she likes the work as it exercises her fingers

and is “a bit of money in your pocket.” Another respondent, Trevor, who is often out in the community, explained that he makes a few extra dollars a week by helping out his friend who works at the lotto booth, “she gets me to clean up around the booth, you know the three little bumps red, green and blue. I cleaned those up with wax, and she gives me some bucks, it’s pretty good!” Denis, who used to landscape for a living, continues to do landscaping work for people in the community and staff members who get him to do work in their yard. He describes how being able to go out and do something he loves is very important to him, however he also does it for the money explaining that “if it wasn’t for the job outside, it would be pretty hard [financially].” These three respondents have all supplemented their limited income by finding ways to make a little extra cash either outside or inside the facility. Working for extra money allows them to engage in other activities that are important to them and increases their quality of life as well as gives them independence and pride, being able to do it for themselves. Another six of the respondents reported that their financial situation was “fine” and that they did not have any problems. These respondents reported having enough money, being on a good pension or having family members helping out.

4.3 Staying Engaged

Satisfaction with recreational activity has been found to play an important role in enhancing the quality of life of older adults residing in residential care homes or in the community (Haberkost et al., 1996). Under this theme, the

information gathered from the interviews with the younger residents contained two main codes: “misfit in activities” and “alternative activities” The first code discusses how they feel about the facilities’ activities, what they enjoy participating in and what they do in order to stay engaged. The second code, “alternative activities,” discusses the way respondents expressed how volunteering, helping out, and using their skills brings meaning to activities and makes them feel “good”.

4.3.1 Misfit in Activities

A few of the younger residents responded that they liked to participate in the facilities’ planned activities, however the vast majority reported that they do not participate in the programs, as they are generally “not interested” or they “stay clear of that kind of stuff.” One issue that arose was that the activities were generally seen as geared toward the older adult population. Jervis’ (2002) study looking at younger residents in residential care reported that the activity programming was often geared toward the old and dying, offering limited activities that interest the younger generations. When asked if they participated in any activities, many respondents talked about how they were not interested in the types of activities offered, as an example James explains:

It's that they are geared to the older generation, older than myself I'm talking 80s, 90s, 70s or people that have disabilities, strokes or whatever I just cannot sit there and lift one arm up, you know . . . so I don't have much to do with the programs... 20 years down the line I might be

right in the middle of them you never know but right now
no.

Others talked about “not being a huge fan” of the type of music that is played for entertainment, saying it would be better if it was rock ‘n roll playing instead of the old war time tunes. The majority of the programs are seen to be geared towards the older adult needs and abilities, and as Matt puts it “I’m geared differently!” The programs are described by the respondents as “not what I am used to” or “doesn’t interest me.” Often, the planned activities are seen as not geared to the interests of the younger generations, nor towards the younger resident’s social group. Another aspect of the activities that was raised was that some of the younger residents did not want to join activities with the older residents, or were sensitive to which residents were joining. Richard, a 64 year old man, did not want to join any community bus outings with the facility because he was terrified and embarrassed that someone he knew in the community might see him on an ‘old folks’ bus. Having been a swimmer, the staff members were trying to convince him to go on the weekly swimming trip, but he refused answering “who wants to go out with a bunch of old fogies.” Other residents were particular in knowing who else was participating in the activity before accepting, as they indicated that “some people are no fun to be around.” When planning activities the social group is an important aspect to consider.

Facility B was seen to offer more activities geared towards the younger population’s interests compared to facility A. When asked what, if any, programs they like to participate in, the majority of respondents from both facilities

referenced community bus outings; however, most of the respondents who reported enjoying the bus outings were from Facility B. Facility B offers many more bus outings which are included in the residents' rent, compared to facility A's outings which cost extra to join. Residents from Facility B mentioned bus outings they went on to the movie theatre, out to lunch, and to various spots around Vancouver such as Granville Island or Stanley Park. Getting out of the facility and going on bus outings into the community was favoured by the younger resident respondents. Programs within the facility that some respondents mentioned participating in include musical performances, the weekly social/happy hours and artwork. Each respondent was asked if they could think of any programs or activities that they wish were offered within the facility and surprisingly only two respondents had suggestions. Betty wanted to start a cribbage game for fun, and Matt suggested a hiking group, in order to be able to get out more and keep the boredom away. The majority of respondents did not have any suggestions, responding mainly with answers such as "I can't think of anything right now."

Many of the respondents mentioned how they prefer doing their own independent activities instead of joining the facilities' daily programs. Independent activities that were mentioned included such things as: reading, watching TV, exercise, playing the guitar, being on the computer, smoking, shopping or doing artwork. Having their own activities and not relying on others recognizes their independence, their freedom, and their ability to do things on their own. One respondent who watches TV in his room most of the day explains

it as, “Well, I just... like it better doing my own thing, taking care of myself, right here.” Being able to care for himself, and being able to plan his own leisure time gives him independence and freedom in his life.

From some of the responses regarding the activities, the daily planned activities seem to be perceived by some of the younger residents as ‘for the elderly’, and they do not want to join because of that. Anthony explained why he doesn’t join any programs, “I don’t go and do all these stupid things that the old people do.” Planned activities may be seen by some of the younger residents as meaningless activities that the ‘old’ people do and feel they are pointless or stupid. Interestingly, Anthony also talked about how he did enjoy baking with a staff member, because she came to him saying she needed help making some treats for an event later that day. In his mind this activity was not a “stupid” planned activity, as he felt that he was helping this staff member do an important and meaningful job.

4.3.2 Alternative Activities

A common code for many of the respondents was the importance of volunteering, helping out, or engaging in meaningful activities within the care facility. For some respondents helping out in the home was something that they enjoyed doing. This was especially seen in the younger residents who are more physically able, active and able to lend a hand where needed, with the thought that “I can get around so I help them.” This help was seen towards the staff as well as fellow residents. A number of respondents reported that helping others

out in the facility “makes me feel good,” giving them a sense of pride, appreciation and purpose. A few respondents reported a conscious effort to help the staff members in ways they can such as making the bed or taking their dirty dishes to the kitchen. One respondent volunteers every morning to help serve breakfast, he explains, “I help a lot okay in the morning I do, the cereal, I do the bibs. I bring people to their table. I know all the juice they take, because the nurses are very busy in the morning...and that has helped me in a way to, you know.” The residents report feeling useful and appreciated when they help out within the home. Many of the younger residents who are ambulatory and able to go out on their own will make trips to the store for other residents who cannot get out on their own. Richard described how he likes to help out other residents and how it makes him feel:

I feel good helping, in fact, I have this one resident, in particular, and he's got Huntington's disease and he is deteriorating. And he's in a wheelchair. So I take him over to Park Royal, take him out into the sun and push him over to the Starbucks over at Park Royal. So he really and so I bring him back and he just loves it. He has a big smile on his face. It makes me really feel good.

Richard has found a positive way to spend his day helping a friend that makes both of them feel really good and appreciated. Many of the younger residents will be seen helping other residents, by doing such things as pushing their wheelchair or showing them the right way when they are lost. For some these acts of helping out in the facility give them a sense of purpose and they really enjoy doing it. One resident mentioned that helping out gives him privileges in the facility that he enjoys, such as special orders to the kitchen. A few of the

residents described helping out in the facility as a key aspect to what “keeps [them] going” living in a residential care facility. James volunteers every morning to deliver the daily newspapers to the residents who subscribe, a job that he enjoys doing and helps to assist the staff. People appreciate getting help and it also makes these residents “really feel good.” Connie, who is passionate about art has teamed up with a recreation staff to put on a weekly art class where she shows her artwork and encourages others to do their own. This is a successful program which uses the skills of this resident, includes the interaction with the other residents, and benefits all those who enjoy art. Some other respondents who were not involved in volunteering or helping out in the facility expressed an interest in doing so. Betty, who has experience as a cosmetologist, expressed interest in helping other residents by using her life skills:

I wanted to get a sewing machine and I would fix clothing because I know how to work a machine, I had two of them I don't know where they are. But I thought gee you see people with dresses with their hems coming down, I would really like to do something. And I do hair and I see girls with rollers and I would like to go over and say “Hey can I give you a comb out” but I don't. I don't interfere, but I should.

This respondent does not participate in planned activities, however she actively expressed interest in getting involved when she talked about things that she likes to do or that she is good at, and wanting to be involved in something more purposeful. Alice, a passionate gardener, spoke about wanting to pass on her skills and knowledge about re-planting as a way to spend money on plants.

Being able to continue to use the skills and knowledge from their life is important

for many of these residents. Often what they have to offer would be beneficial to themselves and the other residents if the facility had the resources to pursue and follow up on each resident's needs. Some residents even have skills that are valuable to the larger community, but are often not seen or utilized due to their situation. One resident from Quebec, who is fluent in French and very independent, mentioned how the city is short on French speakers for the Olympics and expressed how he would like to become a translator. With the right support, this resident would be capable to volunteer with the Olympics, which would be an amazing opportunity for all parties. A few of the respondents, especially the younger ones, voiced wanting to get back into the work force. Others, as mentioned in the *money matters* section, are doing work in and out of the facility which use their skills and supplement their income. Throughout the respondent interviews the importance of volunteering, helping out, engaging in meaningful activities, or having the opportunity to work was strong for many residents. Many of the younger respondents did not like to participate in the 'older' persons planned activities, opting for something independent or to get out into the community. For residents who are eager to help out or volunteer within the facility, it would be beneficial to the facility if they had the resources to facilitate their needs. This partnership would be beneficial to the facility as well as positively contribute to the younger residents' quality of life.

4.4 Social Life

The importance of social relationships or social integration was another common quality of life domain within the literature for residents living in residential care. This includes any relationships that the residents find meaningful such as family, friends, staff or other residents. Within this theme, three main codes emerged from the respondent interviews: “community connections,” “interaction with other residents” and “staff are good.” “Community connections” encompasses all the social interactions outside of the facility, including how the respondents discussed their connection to the larger community as well as their relationships with friends and family. “Other residents” discuss the socialization that takes place with the other residents with the care facility. Lastly, “staff are good” describes the social interactions between the respondents and the staff within the care facility. Social interaction with family, friends, other residents and connections with other people have been reported by resident interviews to be very important to resident’s lives (Donnelly et al., 2007). These three codes describe what the younger residents reported in their interviews regarding their social life.

4.4.1 Community Connections

The vast majority of respondents described the importance of being able to get out into the community and “get away”. Many respondents who have the freedom and opportunity to leave the facility unsupervised discussed how getting out into the community was something that was very important to them, and

made living in the facility easier. “I go out the door and go somewhere” says Trevor talking about his day. He goes out into the community everyday, has made friends with the neighbours and recently received the “customer of the week” award at Starbucks. Alice, an avid shopper, joins the community by going to the mall every day after breakfast until dinner time explaining, “I have met people in the mall that don’t know me, but we have become friends because we see each other at the mall all the time.” Having the freedom and means to do what she loves all day, and not being confined to the care facility is an important aspect to her quality of life. Graham, who is only forty years old, takes the bus to his mom’s house for dinner three or four times a week, and goes to the bingo hall with his brother. Most of the respondents liked to go out into the community to participate in activities they enjoy such as going for a walk, going shopping, or going for a drink at the pub. The respondents were not seen to be connected or involved within the community in terms of resources, or events available within the community. However, one respondent, Connie, with some extra assistance from a recreation staff, has recently obtained a discounted pass for the local community center in order to go swimming and perhaps to take a few art classes. Being able to get out into the community was strongly regarded as very important for most of the respondents. This was true for most of the respondents who are able to get out into the community on their own and did so, as well as for a number of respondents who were unable to go out but communicated the desire to get out more. There were three main barriers to getting out into the community. First, the lack of finances was described as a significant issue.

Some residents could not afford to go out and participate in the community, not having the funds to even buy a coffee or pay for the bus. Another barrier for respondents who require extra assistance was not being able to afford a companion to go out into the community with. Another significant barrier was illness or side effects of medication. The degree of some of the respondents' illness made it too difficult to go out on their own, requiring a companion to assist them, which was not often financially viable. One respondent reported that his medication had side effects that made him need to use the bathroom regularly, which has stopped him from going out into the community. Howard describes how he is frustrated that he can no longer get out due to his illness and requiring assistance to get around:

I have to have somebody to help me to operate this chair, and I get tired really easily. So it's very difficult . . . I wish I could just go for coffee things like that get on the bus and just go. I've done it before, I used to go and take the bus to see my wife.

Residents who are unable to get out into the community on their own, or who are not able to afford a companion to assist them, do not often have the opportunity to be a part of the community, even if they have the desire to do so. More than half of the respondents expressed the significance of being able to get out into the community, participate in things they enjoy, and being able to get out of the facility. For many, having the freedom and opportunity to be able to get out improved their quality of life. Others, who were not able to get out thought that having the opportunity would increase their quality of life. A few reported that

they did not have anywhere that they wanted to go or did not want to bother with their wheelchair and that staying within the facility was acceptable.

Family and friend relations and support outside of the facility was assessed by asking the respondents to discuss their relationships with their friends and family and to rate their perceived level of social support. Over half of the respondents named at least one family member or close friend that they were in contact with and would visit the care facility. For most, they described one or two people that visited, who were their confidant and connection to the outside community. For half of these respondents, the close family member would be children who would come visit, usually bringing them goodies, or for some, taking them out. The other main family member that was mentioned by the respondents was sibling(s) who would visit regularly and often take them out. One respondent named a close long time friend who visited often. Having a confidant is seen to be an important factor regarding quality of life as it provides emotional support (Watt & Konnert, 2007). Most of these respondents who had at least one close family member or friend who visited, expressed good family relations and a satisfaction with their level of social support. On the other hand, the other eight of the respondents reported their family living far away, having passed away, or poor family relations. Five respondents described the majority of their family living far away, which can be difficult, as Ryan explains his level of social support:

It's not as good as I would like it. If only this was all happening in Ontario. Then I would have lots more relatives visiting me. They could take time out to come

and see me like they do for everybody else with Huntington's especially with a terminal condition like this.

One woman, Betty, whose family lives far away describes the difficulty of even maintaining a phone relationship with them, as she cannot afford the long distance bills. Not having a close family member or friend, Betty describes the need for a confidant:

if I had someone like you as a friend I would probably tell you about it. What do you do about this? What do you do about that? But I don't know who to go to because they'll tell, they'll go and say something. I don't know who to talk to

Two other respondents talked about having poor relations with their family, expressing their low levels of social support and their desire to have more visitors. One code that was evident within the interviews was the common loss of friend contact. About half of the respondents reported a gradual loss of friend contact due to friends being too busy, friends having a hard time dealing with the situation, moving into the facility and losing contact or not being able to go out to renew old acquaintances. Many of the respondents did not keep in contact with old friends, and for some, it was described as being for the best. Some respondents were in the facility due to negative aspects of the lifestyle they were living, and distance from old friends was seen as positive. Another interesting code described by five of the respondents was the feeling of being a bother or nuisance to friends or family. Some saw themselves as physically being a burden on friends and family, feeling guilty that they could not go visit them and

requiring them to always come to the facility. Roger explains how he feels like nuisance being in a wheelchair:

then I would have to call somebody to come and get me or take a cab and go down or whatever. You know, so why bother. I'll have a beer here, you know Then you have to get somebody to help you up the stairs or carry this stupid thing. You might as well just not go. So it was nice, but like I say, I would like to go more but I'm a pain in the ass . . . but this way people feel they are all obligated or something like that. And I don't want that to happen.

He would prefer to not go out rather than feel like a nuisance to his friends and family. Having an assistive device such as a wheelchair or walker made some feel that they were too cumbersome, and found it too difficult to try to go out with it. Another respondent, Jack described himself as being an emotional burden to his friends and family. Living with high anxiety he described how he often phoned his brother everyday for help and now "he is sick of it." The feeling of being a nuisance or burden deterred these residents from asking for help or going out into the community.

Being able to get out into the community and participate in activities they enjoy was reported as being very important for most of the respondents. The degree of community connection seemed to depend on various factors. The main factor affecting the capability of getting out into the community was physical ability. Those respondents that were more physically active and independent were able to get out into the community easier and more often. Financial resources also played a large role in getting out into the community, either as a

means to purchase goods or to pay for a companion for assistance. Another aspect of community connections is one's family and friend relationships. Those who had at least one close family member or friend had more visitors and more social support outside of the facility.

4.4.2 Interaction with Other Residents

When asked about the quality of social interactions with the other residents, the responses were varied. All the residents mentioned that they got along with the other residents and "say good morning," however the level of social interactions varied as well. One group of residents discussed having very limited social interactions with the other residents. Some attributed this to their personality of always being a "loner," preferring to spend time alone. Others attributed it to being much younger than the rest of the residents. Some described their socialization as saying hello or asking how their day went, but as Trevor describes it "real contact is not that much." When asked about any socialization with other residents, Anthony laughed at the idea explaining that "socializing is just too weird, people are too weird." On the other hand, the other group of respondents reported that they had made friends in the care facility, having a good relationship with a few. Some specifically expressed having good relationships with the younger residents. Rose states, "I've got good relationships. I've got a few friends on the second floor. There's a lady on the second floor, who is around my age, and I get along very well with her." Many of the younger residents seek out each other and socialize together. The vast

majority of the younger residents smoke, and the interviews reveal an evolving culture around the smoking younger resident. Many of the respondents talked about socializing with the other smokers in the smoking area, which contains mostly younger residents. This group of smokers has become a social sub-group for the younger residents, a place that they congregate in and share something in common. Roger describes the smoking group in this way:

Well I guess the smoking bunch is always the same pretty much you know. So it's like a little club out there. You pretty much know somebody every time you have a cigarette. You know what I'm saying this is like a little community out here. Everybody out there doing is the same thing, and they all seem to be fairly decent and everything. Nobody ever gets personal or anything like that. You talk about the weather or sports or this place, whatever you know. Well I guess it's our little social circle.

Both facilities have smoking areas where people who smoke congregate and often stay to socialize or enjoy the company with people their own age. This social circle brings people together from different floors or wings of the facility, creating an area that they belong to. Within this smoking culture, residents get to know each other while smoking together, often lending cigarettes or helping each other by pushing wheelchairs or sharing lighters. Friendship and trust are created by residents going on cigarette or beer runs for others within the group. The smoking group in both facilities is an important aspect for socialization for many of the respondents.

The last significant code seen in the interviews is the younger residents' depiction of being either an advocate or babysitter for many of the older, more

“confused” residents. A few residents felt that they needed to be an advocate for some of the residents, Denis explains, “I put my foot in, because I’m kind of an advocate for people that cannot defend them self. I don’t like when people take advantage like that.” He described in situations with the care staff as well as with resident’s families where he felt the need to stand up and say something about the treatment they were receiving. Another experience was feeling like a babysitter towards some of the residents, especially residents with dementia. Residents with higher cognitive ability often find themselves helping the more confused residents. Residents with dementia often become lost in the facility unable to find their bedroom, and sometimes wander on the wrong floor. A few respondents mentioned having people come into their room confused, thinking it is theirs, some described taking the time to help them to the right place – “it’s like I’m a babysitter.”

4.4.3 “Staff are good”

The respondents were also asked to describe the quality of social interactions with the staff within the facility. There were no complaints made regarding the social interactions with the staff. The vast majority said that they liked the staff and described the social interactions with them as “good,” “fine,” “receptive,” “nice” and “get along.” Some described their social interactions as “good,” however, often short due to the staff being busy all the time. They described getting along with the staff, maybe sharing a joke or asking about their day, but rarely engaging in a long conversation. A few respondents had specific

staff members that they liked better than others and had good social relationships. None of the respondents reported any problems with the social interactions with the staff. On the contrary, many respondents spoke that they actually get along better with the staff than they do with the other residents. Seven of the respondents stated that they get along better with the staff members and prefer to socialize with them than with other residents. A few respondents described how they preferred to talk with the staff because they “can deal with them better” since they are “on the same plane.” Alice, a woman with MS, admits that it is easier to interact with the staff rather than the other residents “because a lot of the staff are there upstairs, the residents...not really.” Many of the residents that these respondents live with have some form of dementia and are often difficult to understand or speak to. The younger residents are also often closer in age to the staff in the facility than they are to the majority of other residents. A few residents have become close friends with staff members. Denis, since living in the facility for three years, has become friends with a nurse and her husband in and outside of the facility. Denis explains his relationship with them:

[Susan’s] a nurse and her husband [Jim]. That’s where I’m doing lots of work. I’m invited whenever... One time last year for my birthday, took me to one of the Filipino karaoke place . . . [Susan] might buy me Christmas gifts. They go back to the Philippines, around Christmas time so I go take care of their dog, you know, they tell me- [Denis] you are like family now.

This is one extreme example of the relationships between some of the staff and the residents. For some residents, the relationships with the staff are important

and very meaningful to their lives and define their social life within the facility. Anthony explains the effect that the staff's social interactions have on some of the residents, "the staff are the ones that make it fun in here. I don't care for the residents. I'm supposed to get along with the residents, but instead I get along with the staff. So in that sense I get along okay." Staff members within the care facility provide much more than medical care, recreation, or a safe and secure place to live. They also provide the residents with emotional and psychological support in their daily lives.

4.5 Focus Group Findings

In each facility, one staff focus group was conducted. Facility A's focus group consisted of five staff members: one nurse, two care aides, one activity aide and the social worker. Facility B's focus group consisted of four staff members: one nurse, one care aide, one activity aide and the social worker. The focus group participant numbers were lower than anticipated, as it was difficult for the facilities to pull staff from the floor to participate in the study. However, each focus group contained at least one staff member from each department and obtained rich data, as each member had more opportunity to speak. Each focus group was conducted in the facility's boardroom during the staff's lunch hour, and lunch was provided. The focus group's interview guide was based on the questions from the younger resident interview guide, as well as the main themes from the residents' interview data (See Appendix B). The focus groups were conducted in order to obtain the staff's perspectives on the topics and themes

from the younger resident interviews. Overall, the younger resident interviews and staff focus group findings were in correspondence. The staff's perspective gave valuable insight into their outlook on the younger residents' life in residential care and explored issues they face while caring for the younger residents.

Notably, the staff had similar definitions for the term quality of life as the residents. The idea of being able to do what you want to do, freedom, choice and being happy were all expressed while defining quality of life. Defining the younger residents' quality of life was not as easy. One nurse said that under the circumstances, the staff members do the best they can and for the most part, the residents have good quality of life. The staff in Facility A all agreed that they saw a difference between the younger and older residents' quality of life and that the younger's quality of life was worse. Throughout the focus groups, the staff discussed many of the younger residents' unmet needs within the care facility and also discussed the challenges they faced caring for this population. It was expressed that the younger residents' social and emotional needs are higher than the older population, a need that they often look to the staff to fill. The staff also questioned whether the younger resident's physical needs were adequately being met. The importance of privacy and maintaining one's independence was seen as an important issue with the younger population. Financial ability was seen as the number one unmet need for the younger residents and included the lack of finances and cutbacks within the facility as well. The need for age-appropriate and meaningful activity programming geared towards the younger residents was discussed as well. Lastly, the staff gave their perspective on the

social interactions between the younger residents and other residents, as well as the younger residents and themselves.

A common theme that occurred with the staff was the idea that the younger residents were less physically demanding with their care, however, they were perceived as more emotionally and socially demanding. Many of the younger adults do not need much assistance with their daily care such as getting dressed or showering; however, the staff described a greater social or emotional need that was evident in the younger population. The staff described the emotional need to be difficult to fill and time consuming. They explained that the younger residents take up a lot of time on a daily basis due to the emotional and mental health issues and they felt guilty for not having the time to spend with them. The social worker discussed having to do much of the younger resident's paper work and personal organization due to the lack of involved family for this population. The activity aide described the difficulties of keeping the younger residents involved and engaged; the activity aide explained ironically:

It makes our job harder when the individual is well, because then they need more time. They need more activities. They've eaten they've got themselves dressed, what do they do with the other 10 hours of the day? You know. It's a big void to fill."

Many of the younger residents also have mental health issues as well, which the staff members describe as not being adequately addressed. The social workers expressed the difficulties of getting mental health support or services to the residents. They spoke about the difficulties of finding low income social support options such as counselling, as many psychiatrists will not follow their patients

into long term care, leaving many residents without proper mental health support. For many of the younger residents, once the physical needs are cared for and stable, the primary need for these residents is the social and emotional needs. One social worker describes the need for more attention towards the social programming in residential care:

[If] they came from the hospital they might have had a lot of complex medical stuff going on. And that was the main focus. And now they come here and that tends not to be the focus. I mean still their stable, but what I think is lost then is that health care system particularly this facility doesn't realize that it's a different kettle of fish altogether in the sense that the social support and social programming.

One main discussion within the focus group was the lack of options for these younger residents. It was argued that many of the younger residents become quite stable within residential care, however social services does not provide enough housing where these residents could go that still has the much needed nursing component. It was felt by the staff that many of the residents did not need to be in a \$4,000 a month residential care bed, however, there are not other housing options. "There is no place for them to go back in to the community because there is not enough support, it's either all or nothing," says one social worker.

Another unmet need outlined by the staff members at these facilities was the availability of appropriate physical activities. The staff were worried that due to the institutional setting they are living in, which mainly geared towards people with less physical abilities, the younger residents are not getting the physical activity people of their age need to maintain health and strength. Many of the

daily fitness programs in the facility are geared towards getting the older population moving, with programs such as arm chair exercises or balloon toss. The fitness equipment, as one social worker points out, is geared towards rehabilitation, not regular maintenance. Many of the staff felt that more appropriate physical activity needs to be available and encouraged for the younger resident population.

From the perspective of the care staff, the most difficult part of caring for the younger residents was described as maintaining their privacy and independence. One nurse explains that for all the residents, privacy is important; however, it is apparent that this is especially important for the younger residents. A care aide remarked how showering a younger resident is a little more awkward because they do not want assistance, even if they require it. Some are embarrassed or frustrated that they cannot do it themselves. “It’s infuriating to her,” losing her independence, reports a care aide about one resident. One care aide expressed how it is different with the younger residents:

They don’t want us there . . . They are more resistant when we have to be hands-on . . . The ones that are older, I think they are more accepting of us touching them and helping them and they accept it.

For the care staff, physical care with the younger residents can be a challenging and sensitive job. Losing their privacy and independence is difficult, however perhaps more challenging for the younger population.

Resident finances was characterized as a major issue in both focus groups, with the staff calling it “the number one” issue. The older adults were

characterized by the staff as being more financially content and finances being less of an issue compared to the younger residents. The financial difficulties of the younger residents were described as “the big white elephant in these facilities”, which was killing the residents’ spirit and self-esteem. The staff described how many of the younger residents, especially those on social assistance, cannot afford such things as a private room, cable, companions to take them out, outings into the community, or even simple pleasures such as a treat from the store. The lack of finances inhibits many residents from doing what they enjoy in life and is seen by the staff to diminish their quality of life. One social worker states that younger residents on social assistance are actually being subsidized a lot more from the government since they are paying their rent, however they see a lot less of the money and they often feel like prisoners. From the staff’s perspective, the younger resident’s financial situation can have a major impact on their quality of life.

The organizational financial situation can also have an impact on the younger resident’s quality of life, according to the staff. Money was described as a big issue when it comes to time, staff, and supplies, within each facility. The staff talked about the funding cuts that have been happening, and will continue to happen. One care aide talked about cutbacks affecting the resident care in the facility; with less staff on shift, the Care Aides only have time to give personal care and nothing else. More programs, activities and supplies would be beneficial in providing activities for the residents, but without funding this is not attainable. The decreasing number of staff is an issue, as there is not enough

staff to meet the needs of all the residents. For the younger residents who take up a lot of time with emotional care and one to one programming, there is not enough staff to go around. The lack of staffing is an issue that frustrates the staff, as they do not have enough time to appropriately address everyone's needs. As the facilities bring in younger residents with multiple diagnoses, and a range of mental health issues, many staff members believe that more training is necessary. In order to properly care for this clientele, more training and understanding is needed, as one activity aide explains:

I think it's fine to care for people but to actually move people forward. I mean, they probably still have another 40 years to live. I think it's fine to take care of people, but it's more difficult when you need to get people to move forward like . . . I don't think that we have necessarily enough trained staff in that regard.

The staff would like to know how to not only care for the residents, but help them grow and move forward in life, a skill that needs some understanding of the resident's psycho-social condition.

Activity programming was discussed by the staff as an area where they try hard to accommodate the younger residents, but they recognize, however, that more needs to be done. Residential care has traditionally been home to the older generations and therefore caters towards their needs and interests. With an increase in younger residents in these care homes, the recreation staff has the challenge of trying to accommodate a larger range of age groups. Staffing levels are a major issue as more individualized, age-appropriate, small group or one to one programs are needed to cater to the younger residents. One social worker states that facilities need to nearly triple the recreation staff in order to

cater to all the age groups and design relevant social programming, and as one recreation staff member puts it, “it’s offensive to them to be sitting in an exercise program, where you’re bouncing around a balloon that is just so not age appropriate.” One social worker mentioned the idea of having a staff member that specialized in creating programs for younger adults, researching events in the community and had proper mental health training.

A recent article by Parsons (2007) touched on this idea arguing that activity personnel accustomed to an older adult clientele may not have the time or ability to create alternate programs for the younger residents. She believed that it was advantageous to invest in a position with the qualifications to deal with complex psychosocial needs that could counsel adults, and who could research free community activities to get involved in. However, one social worker in the focus group cautioned that it is has been difficult for her to try to partner up with community organizations, as people are “weary to partner up with a care home that’s got a bunch of people with a bunch of mental health issues.” With the higher emotional needs of the younger residents, one recreation staff member explains that the younger residents need smaller group or one to one programs to meet their needs. Staff from Facility B discussed how they are aware of their younger resident population and gear activities towards them, such as sailing or going to the Pacific National Exhibition (PNE) in Vancouver. These extra outings within Facility B are included in the monthly rent. On the other hand, staff members from Facility A recognize that they do not actively gear many programs towards the younger residents, and community outings cost extra, an additional

expense that many cannot afford. One staff member expressed that throughout the years she has worked at the facility, the programming has changed with the management direction in the care facility. She feels that in order to make younger resident programming a priority, it is important that the management team supports the programming direction.

One social worker observed that that many of the younger residents do not want structured activities, but would prefer to have the freedom to do what they enjoy doing or helping out in a meaningful way. The staff mentioned how they often see the younger residents helping out other residents by pushing their wheelchair or “they take time out of their day, they hold their hands, they talk to them, they think it’s a volunteer job.” The staff members feel that this is gratifying for the residents, as they feel proud and productive, and it brings empathy to towards the other residents. The staff members feel that the residents helping out within the facility is beneficial; however this sometimes causes difficulties for the staff. Although, setting up a resident to volunteer within the home has many advantages for the residents, it can be very time consuming and sometimes difficult for the staff to maintain. As the staff explains, they are responsible if they have somebody do something and sometimes the sustainability is difficult to uphold. This can be very time consuming as a staff member needs to check in and oversee all the jobs. Often, members of the staff do not have the time to figure out what the residents need, set up, and oversee individual volunteer programs while also running the daily programs within the facility. The most difficult part of the job, described by the Recreation Aide, is trying to

accommodate and create programs for all the diverse groups and individuals, “you got a bunch of enthusiasm, but you don’t have enough hands to physically get them together.”

Regarding the social interactions with the other residents, the staff members see a range of interaction. Some younger residents do not want to interact with others and spend most of their time in their rooms after meals. Other residents interact often with other residents and are more involved in the facilities community. Staff agreed that often the younger residents will seek each other out within the facility, they “seek out people that [they] can relate to.” One aspect of the younger residents’ social interaction that all the staff agreed on is that for many younger residents, the smoking group is their social outlet. Many of the younger residents smoke and being outside with the smoking group is an important aspect of their daily interaction and socialization. One nurse agreed saying, “some of them smoke just to be together.” The staff also expressed empathy for the younger residents who constantly have to deal with other residents who have dementia, who will often wander into their room and go through their stuff, “it can be really frustrating” for the residents says one sympathetic Activity Aide. The staff talked about their relationships and interactions with the younger residents in the facility as being different from the older population. The staff described how they converse differently with the younger population, often telling jokes and being more casual in the way they communicate. The younger residents are often closer in age to the staff than the older population, “we are like peers” making it easier to feel like a friend to them.

The staff members recognize that the younger residents can relate better to the staff than to many of the other residents, and often look to fill their social void with the staff. “They want somebody they can talk to,” says the social worker, “they often share personal information about their emotions,” recalls one activity aide. Relying on the staff to fill this emotional and social aspect in their lives can, however, be time consuming and can be difficult for the staff. The staff stated that it can be difficult with the younger residents not to cross professional boundaries. An Activity Aide acknowledged that “you have to keep a real balance to keep professional boundaries, when to actually bring in professional help, or when they just need somebody to vent with just in general.” The staff understands that while working in this capacity, you do get attached and involved in the residents lives, and as a result it is important to balance and know when to be an advocate for them, when to be a friend to them, and when to draw the line.

Caring for the younger resident can be a unique and difficult task for the residential care staff. The staff talked about the challenges of dealing with some of the younger residents’ choices in leisure activities, such as heavy drinking or smoking marijuana and the behavioural problems that are a result of it. Some of the younger residents will come home from the pub “belligerent” and causing problems with the other residents. It becomes a safety issue having these types of behaviours with frail older residents in the facility. An article by Parsons (2007) discussing younger residents in residential care, described three common types of dangers for the staff and the residents seen with this population; sexual aggression, alcohol and drug abuse and gang related violence. These

uncommon behavioural issues in a traditional care home are becoming reality with the shift in clientele, and needs to be acknowledged for the resident and staff safety. The Social Worker in Facility B talked about how their facility has “pushed the envelope” in order to care for this population. The Social Worker admits to allowing some stuff to go on in the facility that “would be looked upon with horror at other facilities” in order to meet the needs of this younger population. The Social Worker explains:

But in so many ways, in terms of quality of life. We have had to push the envelope and push the envelope at times that would make other facilities or people in the Bureaucracy uncomfortable. (Agreement by others) the question is, if you never push the envelope. If you always play, very conservative and safe with these residents, you’ll never run into any issues. But then you’ll never actually move forward or allow these people to have spirit.

One example is allowing one resident, Denis, to landscape in the community for extra money, which affords him a sense of purpose in life. As the Activity Aide states, being able to work “is his quality of life.” Another example was allowing a companion, paid by the wife of the resident, to take him to a weekly downtown “peep show”. These are examples of how the facility had to push the envelope on its traditional way of running a residential care home to meet the needs of this different population. Pushing the envelope in this facility is their way of allowing these residents to do what they love doing, enhancing their quality of life and taking chances in order to achieve it.

4.6 Management Interviews

In each facility, one brief twenty minute interview was conducted with an available member of upper management. In order for the staff participating in the focus group to feel comfortable providing answers, the upper management was interviewed separately. These interviews focused on the facility's organizational care practices, policies and any major issues with regards to the younger residents living in their facility (see appendix C).

In facility A, the Director of Care was interviewed. Facility A's philosophy of care was described as "everybody has the right to live at risk", one reason that it has the reputation to accept "hard to place" younger residents. However, it was mentioned that the facility is not given enough support to take them all; many have to be refused due to behavioral issues as the facility does not have the resources to care for them within the current setting. The director of care, having the opinion that the young and old should not be mixed, expressed the desire to renovate a wing of the facility, making a suitable area for the younger residents, if only they had the funding. Presently she sees the younger residents "get old before their time" as they begin to become apathetic and stop looking after themselves in an environment that is not suited to their needs. The director of care explained that at this time, there are no policies regarding the younger residents as it would be impossible to put them all in a box and make a policy. If however they had their own area, appropriate criteria for younger resident care could be implemented. The biggest issues that are seen by the director of care within the younger resident population is sex, drugs, food, no appropriate

programming, and no peer group or anyone to talk to which can lead to isolation. Formal education seminars have been given on topics such as addictions, sex and violence in the past; however the director of care feels that it has done little good. Her feeling is that formal training does not affect everyone and informal day to day training on the floors needs to be done in order to make it a way of work. The director of care explained that there is a connection with the mental health team and that all of the residents who need it are connected with mental health and has bi-weekly psychiatric support. An addictions nurse also visits the facility when needed.

In Facility B, the Residential Manager, who recently just accepted the role as the Director of Care, was interviewed. Facility B runs under the Gentle Care philosophy created by Moyra Jones. It encompasses a “Three P” structure: people, place and program, and strives to make the residents feel normal and foster independence. The philosophy contains five main principles. The first is “hush no rush,” as the residents should not be rushed and a calm, quiet, environment should be created. In this model the schedule is more flexible, residents should not be forced to wake up in the morning and their breakfast will be kept warm for them until they are ready. The second principle is the importance of creating a home-like environment by encouraging personal effects and furniture and having a memory box outside their room. The third principle is to provide a non-human caregiver which could include a stuffed animal, a doll or a magazine as it is not feasible for the staff to be with the residents twenty-four

hours a day. The fourth principle is for the staff to always recognize the residents, to greet them as they walk by and, if time permits, stop to talk with them or to go for a walk. The last principle is to remind the residents of their legacy, to make them feel important and remind them of their achievements. The Gentle Care model believes in individualized and resident centered care and has a strong emphasis on personhood, believing that one can reach out and connect with a person better if they know about their history and can connect with their past.

Facility B houses many younger residents and has built a reputation for being able to adequately care for this population. The Director of Care described that before they accept a resident, they always have an interview with the candidate and assess if the person is a suitable fit for the facility. They do not accept every new admission, as safety is their main priority, and they must ensure that the new admission is compatible with the existing residents, and recognizing if they have the resources to take care of their needs. The Director of Care explained that with the younger population, the staff really needs to work with them and be flexible as every individual's mental health needs are different. Time and staffing shortages were described as a continuous problem as funding is tight, "at times you can only do the basic, you would like to give them more, but you only have so many hours in the day." The Director of Care also noted that a key challenge in caring for younger residents was their lifestyle. Many of these residents have a history of drug or alcohol abuse and will go out into the community where the facility has no control and come back under the influence.

Facility B does provide some suitable programming for the younger residents; however the Director of Care mentioned that many residents are still bored as there are not enough activities offered for them to participate in. The facility can only provide so many activities as there is limited funding and man-power available.

The Director of Care at Facility B is a strong believer in education and training for the staff. She believes that training on mental health issues would be beneficial and is in the process of providing it. She mentioned that there has been some discussion with the health authority to provide support and education with mental health in hopes that they will become specialized in this area. When asked, the Director of Care explained that she believes having the younger and older residents mixed in the facility works well, as the younger residents often help the older residents. Having a separate wing for younger residents was not seen as beneficial, as the younger residents are currently placed into the facility based on need and diagnoses, not age, a system that the Director of Care feels works well and is more operational. In terms of programming the arrangement could provide more challenges as their needs are often different and smaller, individualized programs are needed.

4.7 Discussion

This study drew quality of life domains from the literature as a guide to explore their relevance for the younger residents in residential care. The domains used, such as security, safety, comfort and environmental quality, are

common qualities applicable to any QOL assessment. Many of the findings regarding the quality of life domains for younger residents may not be significantly different from the needs and desires of the older population. Studies have found that older adults living in residential care also identified many similar aspects of quality of life, such control, independence, privacy, meaningful activities, and a community connection outside of the home as important for good quality of life in residential care (Mozley et al., 2004). The purpose of this study was to explore the relevance of those identified QOL domains for younger residents and understand additional issues, variations and nuances that contribute to their quality of life. In order to be able to develop policy and practice guidelines for enhancement of QOL for the younger resident population, it is essential to understand the individual differences and similarities within these domains.

This exploratory study focused primarily on the younger resident and staff perspectives utilizing a qualitative approach. This was achieved through acquiring an account of their subjective quality of life, which acknowledges their experiences and documents what they describe as being meaningful and salient. The findings indicate several similarities and connections to the QOL in residential care literature, as well as provide new insights. This section highlights major connections to the existing quality of life and younger resident literature, emphasizing key findings that contribute to this growing body of literature. In addition, this section attempts to integrate the themes toward a conceptual understanding of their relevance for QOL in younger residents.

Donnelly et al. (2007) outlined eleven domains that were identified by the residents as important to their quality of life. Personal qualities or characteristics were mentioned to achieve a positive quality of life and were described by the residents as being adaptable, having a positive attitude, being flexible, accepting fate and determination (Donnelly et al., 2007). This study found *acceptance* to be a common code within the interviews in regards to adapting to life in residential care. Many respondents described “making the best of it,” a phrase Kahn (1999) titled his study, *Making the best of it: Adapting to the Ambivalence of a Nursing Home Environment*. Kahn found that this was a widely used phrase popular with the residents when describing the adapting process. One dimension that he described was the belief that the respondents had “no other option” (Kahn, 1999), making it the best place to be, as they could imagine life being much worse. This study found similar findings as many respondents talked about acceptance of life in residential care due to lack of any alternative, or by viewing the current life circumstances in a positive way. The idea of acceptance may not be unique to the younger population as all residents entering a care home have to adapt to the situation, however the transition for the younger residents may be atypical.

Entering a residential care facility at a younger age violates the culturally constructed age norms regarding when one should reside in a care home, an issue which arose in other studies regarding younger residents (Jervis, 2002 & Watt & Konnert, 2007). This creates an untimely life course timetable, as society’s age norms dictate that individuals of a certain chronological age should

be engaged in certain activities (Hagestad, 1996). For the younger residents, it may be more challenging to accept and make the best of the situation when they feel that they do not belong to the residential care environment. Other studies have found that a significant consideration in resident's quality of life is the "goodness of fit" between the resident and the facility's social and physical environment (Mozley, 2004). It may be more difficult for a younger resident to adapt or accept their new life if the facility does not fit their needs. It could also be disadvantageous for the younger resident to adapt or accept the way things are, as one active resident mentioned that in order to adapt, he had to "slow right down." This raises some concern regarding the potential functional and mental decline of the active younger residents if they have to 'slow down' to the pace of the older residents in order to fit in and adapt.

Several studies looking at the quality of life of older adults in care facilities have found that independence, choice, and control have been central themes (e.g., Garner, 1998; Kane et al., 2003; Mozley et al., 2004). This is a common quality of life domain; however there may be differences in what aspects are emphasized. Within the younger resident responses, their independence, choice, and control were often described as problematic issues when it came to the rigid and structured environment in the home. One issue was losing control of financial matters when they were still able to manage their own finances. Another aspect of the structured routine of the environment that may be specific to a younger resident was the complaint that the doors to the facility closed at 8 p.m., not allowing any visitors or residents to be out. This may not be an issue

with the older residents, but may affect a younger resident's way of life. Issues faced with having a roommate were prominent with residents that shared a room, a quality of life issue that is most likely not specific to the younger resident, however many younger residents are unable to afford a private room in facilities that charge different rates. Research conducted on the topic of single versus shared rooms in institutional settings has highlighted many advantages for single rooms for all residents. Chaudhury et al. (2005) examined the advantages and disadvantages of single versus multiple-occupancy rooms in acute care environments finding that "the advantages of single-occupancy rooms are improvements in patient care, reduction in the risk of cross-infection, reduction in patient stress [from roommate issues], an improvement in patient privacy and control, and greater flexibility in operation." The main disadvantages to having a private room were cited as "feelings of isolation and the need for more social contact and the quality of care in private rooms" (Chaudhury et al., 2005). Looking more specifically at the residential care environment, Calkins & Cassella (2007) found that private rooms had better outcomes than shared rooms in the vast majority of factors in residential care. Psychological issues had better outcomes, in terms of resident, family and staff preference and satisfaction. Residents and family members preferred a private room and reported having better visits in a private room. Clinical factors suggest that there is reduced risk of developing a nosocomial infection in a private room. Operational factors show that the staff spends more time trying to market shared rooms, managing difficult roommate situations and transferring and cleaning resident rooms due to

roommate problems in shared rooms. Construction costs suggest that private rooms do cost more to construct, however “the cost of construction and debt of a private room versus a shared room can be recouped in less than eight years” (Calkins & Cassella, 2007), making it feasible to construct newer homes with private rather than shared rooms. Many of the respondents who did not have a private room expressed the desire to have one, due to wanting the privacy, space or not liking their roommate(s). Most of the respondents who had their own private room discussed how they appreciate having a private room and how it is an important quality of life factor to have their own bedroom and bathroom. Throughout the interviews, it was clear that having the option of a private room in residential care has the potential to increase the resident’s quality of life and their quality of care.

One aspect that seems to be unique within this younger resident population, compared to the older population, is the number of residents who do not require any daily physical care. Of the 19 respondents interviewed in the two care facilities, 11 (58%) of them reported needing no assistance in their daily care. Many younger residents do not require the heavy “activities of daily living” care often seen in residential care. For the younger residents, especially the ambulatory residents, the care is more focused on emotional or psychological care. This may be unique regarding the younger population’s care needs and an important quality of life concern for residential care facilities. This focus on the emotional need was evident in the resident interviews, staff focus groups and management interviews. This finding is a significant contribution to the literature

on younger residents in residential care as it has not been reported in the past studies. Understanding and acknowledging the different psychosocial needs for the younger population may contribute to policy and programming changes to enhance their quality of life.

Younger residents who were eligible for this study were chosen based on age, functional ability and cognitive ability. The resident's physical, functional and mental health capabilities may play a large role in understanding their differing needs, regardless of what age they may be. Older residents who have higher cognition and functional ability may resonate more with the needs of the younger residents than with the older population. Leisure activities such as volunteering, helping out or preferring independent activities may not be specific to younger residents, but to all residents that are functionally and mentally able and interested. Chronological age may not be as meaningful as the residents' functional or perceived age. Physical and mental health issues may have been used in understanding the differing needs of residential care residents, as an additional issue beyond age.

All residents living in residential care are constantly surrounded by residents in ill health. For the younger residents, this social context may be emotionally challenging to deal with, and potentially cause them to quicker functional or mental decline or to become more anxious about death. Some studies looking at death anxiety related to age in nursing home residents indicate that the fear of death decreases as age increases, however the preoccupation with death increases with aging (Mullins & Lopez, 1982). Mullins and Lopez

(1982) compared the incidence of death anxiety among the young-old (>75) and old-old (<75) residing in nursing homes. They found that among the young-old subjects, death anxiety was higher with residents with poor subjective health, poor functional ability, poor social support, and extended stays in the facility. Mullins and Lopez (1982) suggested that younger residents may still generally hope for recovery, however as the length of stay becomes longer and the social support decreases, concerns about death may increase. As younger residents are faced with their own vulnerability, they may become more anxious about death. For many younger resident participants, living closely with older frail and ill residents often made them feel either sad that they couldn't help or fear that they might end up like that. Being surrounded by illness and death on a consistent basis may have psychological implications for the younger residents, who may have many years left to deal with this issue of loss on an ongoing basis.

The literature on QOL reveals that a key component to one's quality of life in residential care is influenced by the ability to participate in meaningful activities or stimulation. The definition of a meaningful activity may vary for each resident based on previous lifestyle, personal preference or ability. Satisfaction with recreational activity has been found to play an important role in enhancing the quality of life of older adults residing in residential care homes or in the community (Haberkost et al., 1996). For younger residents, one of the main issues with participating in activities as discovered in the interviews, is that the programmed activities are often geared towards the likes of the older adults and do not interest the younger residents. Several respondents commented that they

avoided the offered planned activities. They were not interested in those activities, as the activities were not geared to their levels of needs and abilities, or perceived as being planned for the older adults. It is also possible that the primary social context of the activities, i.e., older and frail residents, act as a discouraging factor for participation of the younger residents. This finding corresponds with Jervis's (2002) study which reported that younger residents tend to avoid formal activities in the home, and prefer activities that take them out into the community. The opportunity to get out of the home into the community was identified as an important aspect to many of the younger resident's quality of life. This is not specific to younger residents, as it has also been found with studies focused on older adults, as well (Mozely et al., 2004). Getting out into the community is an important aspect of quality of life, however the trips may need to be designed differently based on the resident's interests, abilities and social group.

Independence and freedom to engage in their own meaningful activities was a prominent aspect expressed by the respondents. In regards to meaningful activities, the younger residents seemed to prefer independent activities or volunteer activities within the home, a finding that may be unique to the younger residents with more cognitive ability and provides a significant insight into enhancing this population's quality of life. Instead of participating in the planned activities, many residents preferred to engage in their own independent activities, such as reading, art or playing the guitar, and just needed the support and encouragement to do so. The interviews with the younger residents also

revealed that many enjoyed volunteering in the home, often giving them a sense of pride, appreciation and purpose. The unique aspect of this population is their physical and mental capabilities to perform the volunteer tasks on a daily basis with minimal assistance from the staff.

Financial security is often seen as a quality of life indicator for residents living in residential care as it ties into lifestyle opportunities and allows the resident to engage in other quality of life options (Stewart & King, 1994). Allen & Mor (1997) discuss how many people who have been disabled or diagnosed with a disease at a younger age may have limited work histories, consequently acquiring fewer assets and savings. Many younger residents with disabilities are also often dependent on social assistance, which can be very limiting and challenging. The literature on financial security corresponds with many of the younger resident issues regarding financial need. Several respondents were dependent on social assistance and did not have the money to engage in other quality of life enhancing factors such as bus outings, private rooms, or personal expenses. The care facility's social workers explained that in British Columbia, social assistance for younger residents living in residential care covers their rent to live in the care facility and an extra \$95 a month for all other expenses. For older adults, financial security can be a difficulty, however the staff reported that for many older adults, financial security was not seen as such a major concern compared to the younger population. The majority of the younger population struggled with financial difficulty, which could affect the other quality of life aspects.

Social environment, social participation and family involvement have been noted as important aspects of quality of life in the current literature on quality of life. In studies on younger residents, findings have varied. Watt and Konnerts' (2007) study found that the younger residents felt somewhat disconnected from friends, relatives, other residents and social events. On the other hand, Dunne et al. (2007) reported high levels of self reported social support through the Medical Outcomes Study Social Support Survey (MOS-SSS). Even within this study's small sample, the responses to their social support outside of the facility also varied. The majority of the respondents stated that they had at least one family member or close friend come to visit, however it was not known how involved the family/friends were in their lives. The rest of the respondents explained that they had no family involvement as family lived far away, deceased or estranged. The social worker in Facility A stated that she observed less family involvement in the younger resident population compared to that for the older adults, often having to spend more time working with them.

Beyond the differing levels of family involvement and social support for the residential care residents, a few distinctive issues regarding the younger residents' social life should be highlighted. As the majority of the residents in residential care were older adults, the social environment for the younger residents contained fewer peers of their own age. All of the younger residents said that they converse with the older residents and are friendly with them, however many younger residents seek each other out to socialize with or be around. A smoking culture was seen in both facilities, formed mostly of the

younger residents, where they have created a social group of peers. For the younger residents, the peer group within the facility was small and having a place where they can meet and socialize seemed to be very important for their social interactions. The other significant code seen in both the interviews and the focus groups was the peer support and relationships that were often formed between the younger residents and the staff. Many younger residents expressed how they got along better with the staff as they were closer in age as well as “on the same plane” as them. This was a significant issue to emphasize as the staff raised concerns about maintaining a professional boundary while providing the best daily care. As the younger residents find themselves in a facility with the majority of people being older adults, social interaction and integration may be a more difficult challenge and represents an area requiring further exploration.

The four themes identified in this research make up the younger residents’ overall experiences and perceptions regarding their quality of life. All the themes are inter-related and influence each other, and no theme acts in isolation. In order to enhance or improve the quality of life of younger residents living in residential care, all the themes must be considered and improved upon simultaneously. However, there are a few themes, such as *money matters* that have a significant influence on several other themes. Both residents and staff viewed money as a very important issue affecting many other areas of quality of life such as affording a private room, community outings, companions, or personal needs such as clothes or dental care. Availability of adequate financial resource is a quality of life characteristic that has a great influence on many of

the key factors of quality of life; however it does not act in isolation, nor is money the sole contributor to the areas of quality of life mentioned above. Thus, all the quality of life themes need to be taken into consideration as they are inter-related and work collaboratively in forming ones' perception of quality of life.

The themes created in this study have added to the growing body of literature and contributed to the conceptual understanding of younger resident's quality of life. Within the themes created, many are general quality of life themes, which may be applicable to all residential care residents; however, it is the detailed nuances and perspectives that are specific to the younger residents, which have been identified in the research that are important to recognize. The theme of social life, for example, is an important quality of life aspect for all residential care residents, however the findings regarding the younger residents in this theme demonstrate specific behaviours, such as congregating in a "smoking group" or comfort in relating with staff on a peer level, seem to be unique to the younger residents. These variations and nuances within the findings are particularly significant and notably contribute to the understanding of younger residents' quality of life in residential care facilities. Many of the findings within the themes support past younger resident literature, reinforcing and enhancing earlier findings on the topic. Themes such as the importance of volunteering and greater flexibility in community outings are new concepts that contribute to the understanding of the key factors that affect the younger resident's quality of life.

The research methods in this study obtained data from three different perspectives within the care home, i.e., interviews with residents, focus groups with staff and interviews with management. The hour-long interviews with the younger residents was the predominant focus for the study as it explored the younger residents' perceived quality of life through their own words, stories and experiences. The focus groups were included in order to obtain the perspectives of the staff members who care for the younger residents on a daily basis. The focus groups inquired as to how the staff perceived the younger residents quality of life, what they thought were the major quality of life facilitators or barriers for the younger residents and if there were any specific challenges or issues that they faced in caring for the younger resident. The staff focus groups allowed for a greater understanding of the quality of life domains from a different perspective, as well as additional issues that arose within each department while caring for the younger resident. The findings from the interviews and the focus groups were aligned, expressing similar quality of life issues on many topics. The combination of resident and staff perspectives contributed to the depth and validity of the overall findings. The final interviews were with members of the upper management team, specifically the Directors of Care in both facilities. Those interviews aimed to identify the facility's philosophy of care, care practices and procedures with regards to the younger residents, and to outline any major challenges that they faced caring for this population. The interviews revealed the organizational and management point of view on the topic. The interview brought to light challenges, such as funding shortages, which are major barriers

to implementing change or improvement within the facility. The triangulation of methods was beneficial in order to obtain multiple perspectives regarding the same topic of interest, and contributed to a broader and deeper understanding of multiple aspects of the findings.

5: IMPLICATIONS AND CONCLUSION

This chapter discusses the implications for care practices, recognizes the limitations of the study and offers suggestions for further research regarding this topic area. It concludes with a review of the research questions and findings.

5.1 Implications for Practice

The purpose of this exploratory research is to add to the growing body of research regarding younger residents, and to bring awareness and understanding of this particular group of residents who live in residential care settings. The in-depth interviews with the younger residents have been instrumental in recognizing and understanding the many positive and negative aspects of living in residential care as a younger resident. The focus groups were also critical to the study in order to acknowledge the perspectives of the members of the staff regarding the issues outlined by the younger residents and to, in turn, recognize the issues and challenges that the staff face while caring for the younger residents. The findings have shown that there are both positive and negative issues at work for the younger residents living in residential care. Some residents found the move to residential care to be positive for their health and their quality of life. Others characterized the transition in more negative tones, describing their quality of life in residential care to be poor or dismal. Further,

many residents were found to be somewhere in the middle, adapting to the situation and trying to make the best of it. Within the variety of responses expressed, there were many common themes that were established in the findings section. The specific knowledge and understanding gleaned from the expressed perspectives of the residents and the staff members of the facilities adds to the literature and provides information and knowledge on how to improve this population's quality of life. Dissemination of the findings to the two care facilities is also an important step in bringing awareness, understanding and perhaps change regarding younger residents needs. Once the research has been approved, an in house presentation and discussion period will be offered to the facilities as a way of sharing the findings to the staff and residents in an interactive manner. A hard copy of the study will also be made available to the residents and staff. The hard copy will be a summary of the research, with the exclusion of the direct quotes to protect the identity of the residents and staff. Due to the small sample size and intimacy of the facilities, it is a concern that residents and staff could name each other from the direct quotes, even with the use of pseudonyms. The main themes and codes will be discussed and summarized without the addition of direct quotes from the participants. Within these themes, many of the issues discussed can be used to guide understanding and change within the residential care facilities' organizational and care practices. Three implications for practice are made as suggestions for improving the quality of life of younger residents with consideration of the staff's concerns.

The implications concern the organizational policy, housing content and considerations for provincial/regional health authorities.

5.1.1 Organizational Policy

The two facilities in this study house a larger percentage of younger residents as they are known in the community, and by the health authority, as facilities that are willing to house this population. It was seen through the interviews and focus groups that the younger residents seem to “seek each other out” to create friendships and social circles within the younger population. Placing younger people together in certain care homes seems to be beneficial for the younger residents, who then have a group of peers to socialize with or a group to belong to. Housing younger residents in common care facilities also allows for appropriate organizational policies and practices to be implemented what will better accommodate the younger residents’ needs. Organizations that house these younger residents need to recognize the shift in clientele and the issues that come with it. Instead of trying to fit the younger residents into a system created to care for the older adults, the organization has a responsibility to try to make certain changes in order to accommodate the needs of the younger population. For this reason, Facility B indicated that they needed to “push the envelope” in order to properly care for the younger residents’ needs and quality of life. The staff interviewed at Facility B felt that in order to allow some residents to have the quality of life they desired, they had to bend some of the organizational ‘rules.’ The organizational policies in residential care have

been created to fulfil the needs of older adults during their last years, however many of the younger residents have the potential to live for another 20-30 years and have different interests and needs as they come from a different generation. Putting them into a system built for the older adults can make the younger residents “get old before their time,” as the Director of Care explained.

Organizations that have an increase in the younger resident clientele need to strive to accommodate their needs. As indicated by the residents and the staff, activity programming is one major issue that needs to be addressed, and an issue which is feasible for the organization to change. In order for the activity department to plan and accommodate the needs of the younger residents, the organization and management need to acknowledge the situation and need. The interviews showed that less formal activities that promote the individuals' independence, increase connection to the community, and provide more appropriate physical fitness, were needed and preferred. Independent and volunteer activities were seen as preferable to many of the respondents, giving them meaning and independence in their daily lives. The staff believed that volunteering in the home was beneficial to all parties, however expressed that it was often too time consuming to set up and maintain these programs. The staff needs to be given the time, resources, and financial support to create appropriate programs. One suggestion would be to have specialized staff members who can dedicate their time to meet these needs. This staff member could focus on leisure activities that foster and promote independence such as volunteering in the home or building connections and opportunities to volunteer in the

community. The creation of the younger adult smoking group illustrates the need for more social opportunities within the younger population, which could be advanced with little resources. Few younger residents are seen to participate in the everyday planned activities; therefore appropriate activities need to be created and independent activities need to be fostered.

With the shift in clientele, long-term care organizations should invest in specialized training for the staff. With the younger clientele, issues arise that may not be as common with the older population such as mental disorders, emotional issues, drugs, sex or violence. Staff who are used to working with the older adult population would benefit from specific training within these areas. The Director of Care from facility A stated in an interview that formalized training sessions are relatively ineffective, as they do not seem to change the behavior of the care staff. Instead she suggested daily training on the floor, talking to the staff when an issue occurs, or discussing issues daily in a less formal way. The Director of Care in facility B stated in an interview that she believes formalized training is beneficial for the staff. Perhaps a mix of the two approaches would benefit the staff by acknowledging and addressing the issues they face and how these issues can be dealt with, within the classroom and on the floor as they occur. In the focus group, the staff expressed how the emotional support needed by the younger residents can be a difficult and time consuming job. One Activity Aide mentioned in the focus group, she would like more training in order to care for the residents emotionally, not just physically. It is imperative that organizations understand the importance of spending time talking to the

residents, and providing them the mental health knowledge needed to understand and provide quality care.

The younger residents, staff and management all discussed the unique relationships between the younger residents and the staff within the facility. Many younger residents reported that they get along better with the staff and prefer to socialize with them than with the other residents. The staff reported interacting with the younger residents in a more informal and friendly manner, getting along more as peers than as care providers. The staff recognized that the younger residents had a larger emotional or social void, which they would often turn to the staff to fill. Due to this relationship, some staff members mentioned that it is sometimes difficult not to cross professional or organizational boundaries with the younger residents. The staff reported that they may make inappropriate jokes or want to take the resident out in their personal car, which is not allowed. Organizations policies and practices should take into consideration the need for a more personal and friendly approach to care which is preferred by some residents.

5.1.2 Housing Content

In order for facilities to properly care for this younger resident clientele, support and resources need to be available for them to create appropriate housing, care and activities. In an interview with the director of care in facility B she stated that for their facility the mix of younger and older resident's works well

for them as the younger often help the older and their policy is to organize residents by need not age. In facility A younger residents are placed throughout the multiple floor facility making it difficult to organize activities, specialize staff or create an area for them to socialize. Facility B is approximately one half the size of facility A, and expressed that creating a dedicated wing within the facility would be beneficial for their situation. With differing care philosophies, environment and management each facility manages their own unique solutions to the challenges they face.

A consideration of a housing option is to create a separate facility specifically for this population, alternatively (and perhaps more economical) solution, as suggested by the director of care of facility A, is to create a wing or area in the existing facility to house younger residents. A separate house or area in a facility, it would allow for care policies and practices to be implemented that are more appropriate and meet the needs of the younger population. Activity programming could be more focused on the needs of the residents such as, promoting independence through assisting residents to do what they enjoy, planning outings into the community, partnering them with community organizations or have inside programs more catered to their preferences. Volunteer jobs for younger residents could be arranged in the care home or in the community. Creating a wing in the facility would still allow younger residents to volunteer within the larger facility, such as delivering papers, serving meals, or helping out the staff, creating meaningful activities for the younger residents. The philosophy behind the organizational policy could be a belief more focused on

helping out within the 'home' and helping yourself and others when able. The residents would be required to do more for themselves such as pick up their meals and drop off their plates, jobs they are able to do but are, however, normally performed by the staff. The medical care would still be present and available; however there would be more access to mental health and emotional care. The staff could receive specific training and be able to concentrate on fulfilling their needs. This 'group home' idea would allow for more independence and freedom for the younger resident, an issue that was seen as essential for their quality of life.

5.1.3 Considerations for Provincial / Regional Health Authority

One of the greatest barriers to change or advancement is funding. In order for the organizations to create larger changes in programs or create more appropriate housing for this population, the facilities need more incentive and funding. Facilities that take on the challenge of housing this population should be able to apply for funding in order to better accommodate them. The Director of Care mentioned that the health authorities are having a hard time finding homes for these "hard to place" individuals as many facilities will not accept them. Often, when patients cannot be placed in the system, it results in longer stays in the hospitals with expensive one to one care. Facilities need incentives for taking in younger residents who may have 'problem' or difficult behaviors. Funding is needed for facilities to be able to care for a range of clientele with diverse care needs in appropriate ways.

5.2 Limitations and Further Research

One limitation of this study is the sole focus on the younger residents without a comparison group of older residents. This study only identifies the key characteristics that impact the quality of life of younger residents. Therefore, the results solely determine the quality of life characteristics for this specific group and without a comparison group it is unknown if these characteristics are unique to the population or common issues within these two residential care facility populations. Future research might analyze a comparison between the two age groups to examine the perceived quality of life of the younger residents to the perceived quality of life of the older residents. This data would enable a better understanding and comparison of younger resident's quality of life in residential care compared to the majority of older residents living in care. In addition, the study is limited in that it only seeks a greater understanding of the younger residents and the perception of the staff members of the facilities, which, though significant and central groups, are not the sole stakeholders. Further research would benefit by including the perceptions from other parties such as the other residents (age 70+) living in the home and the younger resident's family members. Acknowledging the perspectives from all involved parties would produce a greater understanding of the issues at hand.

Another limitation of the study is the small, non-random sample size. Due to the little information currently available regarding the prevalence of younger residents living in residential care within Metro Vancouver, a purposive sample

was used to explore the issues. At this point in time, relatively little is known about the prevalence, rate of increase, or needs of the younger residents living in residential care within British Columbia, or Canada as a whole. The topic area would benefit from further research into the prevalence of younger residents residing in residential care in British Columbia, identification of the number of cases, and where they reside, could lead to a better understanding of the issues and ways to accommodate this segment of the population. A larger identified population would allow for more research to be done on a much larger scale. The findings and issues raised in this exploratory study could be used to create a questionnaire on quality of life domains that can be applied to a larger sample size.

This study looked at all people under the age of 70 in facilities A and B who met the studies criterion which were largely based on their level of cognition using their mini mental (MMSE) scores. However the younger population is not homogeneous, many differences occur within the group. The most notable and significant difference regarding this population is the residents illness or diagnoses and subsequently their level of need. Within the participants two main groups were distinguished. The first group consisted of more physically independent, ambulatory residents who generally had more mental health or abuse issues; the second group consisted of more physically dependent residents who were confined to a wheelchair and had heavier care needs, often due to a degenerative or neurological disease such as multiple sclerosis or Huntington's. These two groups have different levels of care needs and different

diagnoses which may affect their perceived quality of life, overall care practices or appropriate housing needs. Separating the two groups to compare and contrast may provide a more in-depth analysis of this population.

It would also be beneficial to have more studies looking at information-rich cases in greater detail. One phenomenon that is increasing in frequency is the co-residence of multiple family generations living in the same care facility; recently this has occurred twice in facility A. As younger residents and their aging parents both need higher levels of care, both the parent(s) and the child are living in the same care facility. As generations of a family start to live together in care, many positive and negative implications may be observed. As the frequency of this situation increases, research examining this family dynamic would be of great benefit as it would allow for a better understanding of its implications and, in turn, the creation of appropriate policies and practices within these care facilities. As younger adults with disabilities enter nursing homes, many new and unforeseen issues are likely to arise, creating many more gaps in the research that will necessitate further investigation.

5.3 Conclusion

This research has explored the segment of younger residents living in residential care, for the purpose of determining the characteristics that define their quality of life, and the key factors that contribute to it. The study was conducted to better understand and serve this group that has often been

marginalized and overlooked. One recognizes that the experiences of this population group are not uniform. As within all populations, there are a variety of different groupings, all with their own unique desires, challenges and needs.

This exploratory research examined key aspects that impact the quality of life for a younger resident living in residential care through the perspective of the younger residents, and the staff who care for them on a daily basis. The characteristics of quality of life identified in this study include, the physical environment of the facility, the finances available to these young adults, ability to stay engaged through formal and informal activities, social life and personal adaptation to the situation of residential care. The research indicated and discussed many key factors within the quality of life characteristics that are seen to contribute to the younger resident's quality of life. This study was undertaken to raise awareness to the issues surrounding this population, and create appropriate changes within residential care. It is with this greater understanding and knowledge of this segment of the aging population that new strategies and new policies must be developed to better meet their needs. The identified issues and implications allows institutional policy makers, administrators and program planners to better understand the needs of this population, undertake informed policy and planning decisions, and pursue funding allocation in an effort to improve the quality of life of the younger resident population under their care. It is especially important to recognize and address the needs of this population, a segment of the aging population that is projected to increase, making it relevant and pertinent for ongoing gerontological research.

REFERENCES

- Allen, M. S. & Mor, V. (1997). The Prevalence and Consequences of Unmet Need Contrasts Between older and Younger Adults with Disability. *Medical Care*. 35(11), 1132-1148.
- Arksey, H. & Knight, P. (1999). *Interviewing for Social Sciences*. London: Sage Publications.
- Belle Brown, J. (200). The Use of Focus Groups in Clinical Research. In B.F. Crabtree & W.L. Miller (Eds.). *Doing Qualitative Research 2nd Ed.* 109-124. Thousand Oaks: Sage.
- Calkins, M. & Cassella, C. (2007). Exploring the Cost and Value of Private Versus Shared Bedrooms in Nursing Homes. *The Gerontologist*. 47(2), 169-183.
- Chan, YL. H. & Pang, MC. P. (2006). Quality of Life Concerns and End-of-life Care Preferences of Aged Persons in Long-Term Care Facilities. *Journal of Clinical Nursing*. 2158-2166.
- Chaudhury, H., Mahmood, A. & Valente, M. (2005). Advantages and Disadvantages of Single of Single –Versus Multiple-Occupancy Rooms in Acute Care Environments. *Environment and Behavior*. 37(6), 760-786.
- Donnelly, L. M., Nesbitt, K., Dunne, J., Lee, D., Bradley, C. & Roodenburg, K. (2007). Understanding Quality of Life of Ventilator-Dependent Residents

Living on a Long-Term Care Unit, Part 2: Qualitative Study. *Canadian Journal of Geriatrics*. 10(2), 68-71.

Dunne, J., Donnelly, L. M., Nesbitt, K., Lee, D., Bradley, C. & Roodenburg, K. (2007). Understanding Quality of Life of Ventilator-Dependent Residents Living on a Long-Term Care Unit, Part 1: Quantitative Study. *Canadian Journal of Geriatrics*. 10(2), 64-67.

Esterberg, G. K. (2002). *Qualitative Methods in Social Research*. Boston: McGraw-Hill.

Fries, E. B., Walter, P. W., Blaum, C., Buttar, J. D. & Morris, N. J. (2005). A National Study Showed that Diagnosis Varied by Age Group in Nursing Home Residents Under Age 65. *Journal of Clinical Epidemiology*. 58, 198-205.

Garner, D. (1998). Quality of Life in Long-Term Care. *Health and Social Work*. 23(1).

Gerritsen, D.L., Steverink, N., Ooms, M. E. & Ribbe, M. W. (2004). Finding a Useful Conceptual Basis for Enhancing the Quality of Life of Nursing Home Residents. *Quality of Life Research*. 13, 611-624.

Gray, David. (2004). *Doing Research in the Real World*. Sage Publications.

Greenbaum, L. T. (1998). *The Handbook Focus Group Research (2nd ed.)*. Thousand Oaks, California: Sage Publications.

Gutman, M. G. (March 1995). *Literary Review: Characteristics, Service Needs and Service Preferences of Younger Adults with Severe Physical*

Disabilities.. The Gerontology Research Centre, BC: Simon Fraser University.

Gutman, M. G., Anderson, G. K. & Killam, B. J. (April 1995). *Younger Adults with Severe Physical Disabilities in the Capital Region*. The Gerontology Research Centre, BC: Simon Fraser University.

Gutman, M. G. & Killam, J. (1989). *Environmental Design, Staffing and Programming Needs of Younger Adults in Long-Term Care Facilities: Residents' and Staff's Perceptions*. The Gerontology Research Centre, BC: Simon Fraser University.

Haberkost, M., Dellmann-Jenkins, M., & Bennett, J. (1996). Importance of Quality Recreation Activities for Older adults Residing in Nursing Homes: Considerations for Gerontologists. *Educational Gerontology*. 22, 735-745.

Hagestad, O. G. (1996). *On-time, Off-time, Out of Time? Reflections on Continuity and Discontinuity from an Illness Process*. In V. L. Bengtson (Ed.), *Adulthood and Aging: Research on Continuities and Discontinuities* (pp. 204-222). Springer Publishing Company: NY.

Healy, P. (2003, December 10). Nursing Homes Face Challenge as the Young Fill the Beds. *The New York Times*, pp. B5.

Hulsman, B. & Chubon, J. S. (1989). A Comparison of Disabled Adults' Perceived Quality of Life in Nursing Facility and Home Settings. *Public Health Nursing*. 6(3) 141-146.

Jervis, L. L. (2002). An Imperfect Refuge: Life in an 'Old Folks's Home' for Younger Residents with Psychiatric Disorders. *Social Science & Medicine*. 54, 79-91.

Johnson, M. J. (2001). In-depth Interviewing. In G. F. Gubrium & J. A. Holstein (Eds). *Handbook of Interview Research: Context & Method* (pp.103-120). Thousand Oaks, California: Sage Publications.

Kane, A. R., Kling, C. K., Bershadsky, B., Kane, L. R., Giles, K., Degenholtz, B, H., Lui, J., & Cutler, J. L. (2003). Quality of Life Measures for Nursing Home Residents. *Journal of Gerontology: Medical Sciences*. 58A(3) 240-248.

Krueger, A. R. (1998). *Analyzing & Reporting Focus Group Results: Focus Group Kit 6*. Thousand Oaks, California: Sage Publications.

Lassey, R. W. & Lassey, L. M. (2001). *Quality of Life for Older People: An International Perspective*. Upper Saddle River, New Jersey: Prentice Hall.

Lincoln, S. Y. & Guba, G. E. (1985). *Naturalistic Inquiry*. Newbury Park: Sage.

Morgan, L.D. (1998). *The Focus Group Guidebook: Focus Group Kit 1*. Thousand Oaks, California: Sage Publications.

Morgan, L. D. (1998). *Planning Focus Groups: Focus Group Kit 2*. Thousand Oaks, California: Sage Publications.

Mozley, C., Sutcliffe, C., Bagley, H., Cordingley, L., Challis, D., Huxley, P. & Burns, A. (2004). *Towards Quality of Care: Outcomes for Older People in Care Homes*. Burlington: Ashgate Publishing Company.

Mullins, L, C. & Lopez, M, A. (1982). Death Anxiety Among Nursing Home Residents: A Comparison of the Young-old and the Old-Old. *Death Education*. 6(1), 75-86.

- Parsons, Y. (1997). No Shades of Gray. *Contemporary Long Term Care*. 20(9), 42-47.
- Patton, M. Q. (2002). *Qualitative Research & Evaluation Methods: Third Edition*. Thousand Oaks, California: Sage Publications.
- Seidman, I. (2006). *Interviewing as Qualitative Research: A Guide for Research in Education and Social Sciences*. New York: Teachers Collage Press.
- Stewart, W. D. & Shamdasani, N. P. (1990). *Focus Groups: Theory and Practice*. Newbury Park: Sage Publications.
- Stewart, W.D., Shamdasani, N.P. & Rook, D.W. (2007). *Focus Groups: Theory and Practice*. Thousand Oaks California: Sage Publications.
- Watt, A & Konnert, C. (2007). Quality of Life in the Nursing Home: Perspectives of Younger and Older Residents. *Canadian Journal on Aging*. 26 (4), 403-410.
- Weyrich, C, D. (1994). Caring for the Younger Resident. *Provider*. 20(8), 20-26.

APPENDIX A

Interview Guide

General

- What does quality of life mean to you?
- Could you please describe what your quality of life is like for you living in (name of facility)?
- How has your quality of life changed living in (name of facility). How have you adapted?

Environment

- What do you think about the facility's physical environment? (quality of space in your room, activity area, dining area, other common spaces)
- How would you describe your current level of privacy or the amount of personal space?

Quality of Care and Staff Interaction

- How would you characterize the quality of care by staff in the facility? (In your opinion, are they adequately trained? Do they meet your needs?)

Meaningful Activity

- Do you enjoy participating in any of the facilities' planned activities?
If yes, what activities do you participate in?
If no, what do you not enjoy about the activities?
- Can you think of other activities or programs that you wish were offered within the facility?

Social interaction/Sense of belonging

- How would you describe your the quality of social interactions with the other residents? (staff?)
- Can you tell me about your relationships with your friends and family?
- “Sense of belonging” is the feeling of being involved, accepted and fitting into the environment you are in. How would you describe your sense of belonging in this care home?
- How would you describe your connection to the larger community?
- Would you like to be more connected? If no, why not?
If so, can you think of any ways to encourage this for yourself and other resident’s?

Unmet needs

- Do you have other needs that you feel are not being met? (physical, social, emotional, nutritional)
If so, what are they and how are those not being addressed?
How do you feel they should be addressed?

Financial

- Could you tell me about your current financial situation? (sources of income?)
- Do your finances limit your involvement in the Residence and in the Community? If so, how?

APPENDIX B

Focus Group Guide

- How would you define quality of life and what is your perception of the younger residents' quality of life in this facility (compared to the older resident population)?
- How does the physical environment support their needs and preferences?
- How would you describe the nature of social interaction and relationships between the younger residents and other residents?
- How would you describe the relationships that the younger adults have with the facilities staff members? Do you think it is different than with the older adult population?
- Are there any challenges associated with providing care to the younger residents?
- How meaningful are the planned activities for the younger residents?
- Are there any physical, social or emotional needs of the younger population that are not currently being met?

APPENDIX C

Management questions

- Can you talk a bit about the facility's philosophy of care
- This facility has a relatively large population of younger residents, is the company aware of this? Is the facility aware of this? To the best of your knowledge is this an issue in any of the other facilities? Why does your facility house a larger percentage of this population?
- Has there been any talk on a policy or practice level regarding the younger residents either within the facility or within the company?
- Within the facility do you see any challenges or issues regarding the younger residents?
- With a high population of younger residents, different illnesses may be present, such as various mental illnesses that may not be as prevalent in the older population, does the staff get any specific training to deal with these issues? Do you feel that specific training is necessary?

APPENDIX D

Younger Residents' Background Questionnaire:

1. What is your Gender?

01 Male

02 Female

03 Other

--	--

2. When were you born?

--	--	--	--

3. How long have you lived at (name of facility)?

--	--

4. What is your current marital status?

01 Married

02 In a relationship

03 Divorced/separated

04 Widowed

05 Never married

--	--

5. Do you have any children?

01 No

02 Yes

--	--

6. What city or community do you have the most affiliation with?

7. What is the highest level of education that you have attained?

01 Less than high school

02 High school graduate

--	--

- 03 Some college or university
- 04 College diploma or other specialized non-degree training
- 05 University degree

8. Were you born in Canada?

01 No

02 Yes

--	--

9. What country were you born in? _____

10. If born outside of Canada, what year did you immigrate to Canada?

--	--	--	--

11. On a scale of 1 to 10 with 1 being "Not important" and 5 being "very important" how important are your religious/spiritual needs?

--	--

12. How would you rate your overall physical health at the present time?

01 Excellent

02 Good

03 Fair

04 Poor

--	--

13. Do you suffer from any chronic conditions, serious health problems or disabilities?

14. Do you have any difficulty / limitations to your physical functioning on daily basis?

(Do you need assistance with your activities of daily living, such as bathing, toileting, medication... ?)

APPENDIX D

INFORMED CONSENT FORM (Younger Residents)

Good day, my name is Kara Hay and I am a Graduate student at Simon Fraser University. Thank you for agreeing to participate in my thesis requirement research study. Part of this study entails interviewing adults who are 70 years old or younger who are currently living in residential care. Background questions will also be asked. The interview will be tape recorded and should take approximately an hour of your time.

My study is focused on exploring the quality of life of individuals living in residential care who are under the age of 70 years old. Specifically, I would like to know more about your personal thoughts and experiences living in residential care. Topics that will be discussed include relationships, belonging, activities, staffing, finances, spiritual well-being, and perceived health. Results from this study will add to the growing body of literature in this topic area and bring awareness to this population's quality of life concerns.

You are encouraged to ask any questions at any time about the nature of the study and the methods that I am using. You may contact me at anytime at 778-928-5272 or knh1@sfu.ca. If you would like to obtain the research results, please let me know or contact me via phone or email. The study is being conducted through Simon Fraser University. My Senior Supervisor is Habib Chaudhury, Associate Professor, Department of Gerontology. If you have any questions or concerns he can be reached at 778-782-5232 or can be contacted by email at chaudhury@sfu.ca.

Participation in this study is voluntary, you do not have to answer any questions that you do not feel comfortable with and you are free to withdraw at any point of the study. All of your answers to my questions will be kept strictly confidential; your names will not be revealed at any point of the study. Your answers will be coded for your privacy and pseudonyms will be used. For the purpose of transcription and analysis the interview will be tape recorded. The research has been approved by the SFU Office of Research Ethics, if you have any concerns or complaints regarding this study please contact the director, Dr Hal Weinberg at hal_weinberg@sfu.ca or 778-782-6593.

Thank you very much for your help with this project.

I have read this consent form, understand my rights and agree to the terms of this study:

Respondent signature _____

Date _____

APPENDIX E

INFORMED CONSENT FORM (Staff)

Good day, my name is Kara Hay and I am a Graduate student at Simon Fraser University. Thank you for agreeing to participate in my thesis requirement research study. Part of this study entails conducting a focus group with 5-6 staff members from the residential care facility. The focus group will be tape recorded and should take approximately an hour of your time.

My study is focused on exploring the quality of life of individuals living in residential care who are under the age of 70 years old. I am interviewing the younger adults in order to know more about the resident's personal thoughts and experiences living in residential care. Through the focus groups I would like to get the perspective of the staff members who work with the younger adults on a daily basis, on the themes generated from the younger adult interviews. Topics that will be discussed include relationships, belonging, activities, staffing, finances, spiritual well-being, and perceived health. Results from this study will add to the growing body of literature in this topic area and bring awareness to your quality of life concerns.

You are encouraged to ask any questions at any time about the nature of the study and the methods that I am using. You may contact me at anytime at 778-928-5272 or knh1@sfu.ca. If you would like to obtain the research results, please let me know or contact me via phone or email. The study is being conducted through Simon Fraser University. My Senior Supervisor is Habib Chaudhury, Associate Professor, Department of Gerontology. If you have any questions or concerns he can be reached at 778-782-5232 or can be contacted by email at chaudhury@sfu.ca.

Participation in this study is voluntary, you do not have to answer any questions that you do not feel comfortable with and you are free to withdraw at any point of the study. All of your answers to my questions will be kept strictly confidential; your names will not be revealed at any point of the study. Your answers will be coded for your privacy and pseudonyms will be used. For the purpose of transcribing and analysis the focus group will be video recorded. The video will be kept confidential and only used for the analysis. The research has been approved by the SFU Office of Research Ethics, if you have any concerns or complaints regarding this study please contact the director, Dr Hal Weinberg at hal_weinberg@sfu.ca or 778-782-6593.

Thank you very much for your help with this project.

I have read this consent form, understand my rights and agree to the terms of this study:

Respondent signature _____

Date _____

APPENDIX F

INFORMED CONSENT FORM (Management)

Good day, my name is Kara Hay and I am a Graduate student at Simon Fraser University. Thank you for agreeing to participate in my thesis requirement research study. Part of this study entails conducting a face to face interview with a member of the upper management within the residential care facility. The interview will be tape recorded and should take approximately 20-30 minutes.

My study is focused on exploring the quality of life of individuals living in residential care who are under the age of 70 years old. I am interviewing the younger adults in order to know more about the resident's personal thoughts and experiences living in residential care. I am also conducting focus groups with the staff in order to get the perspective of the staff members who work with the younger adults on a daily basis, on the themes generated from the younger adult interviews. The interview with the upper management is to collect information on the organizational care practices, policies and procedures within the facility. Results from this study will add to the growing body of literature in this topic area and bring awareness to your quality of life concerns.

You are encouraged to ask any questions at any time about the nature of the study and the methods that I am using. You may contact me at anytime at 778-928-5272 or knh1@sfu.ca. If you would like to obtain the research results, please let me know or contact me via phone or email. The study is being conducted through Simon Fraser University. My Senior Supervisor is Habib Chaudhury, Associate Professor, Department of Gerontology. If you have any questions he can be reached at 778-782-5232 or can be contacted by email at chaudhury@sfu.ca.

Participation in this study is voluntary, you do not have to answer any questions that you do not feel comfortable with and you are free to withdraw at any point of the study. All of your answers to my questions will be kept strictly confidential; your names will not be revealed at any point of the study. Your answers will be coded for your privacy and pseudonyms will be used. For the purpose of transcribing and analysis the focus group will be tape recorded. The transcripts will be kept confidential and only used for the analysis. The researcher will retain the data for two years for the purpose of publication and then destroy it. The data will be locked securely in a locked file cabinet for the two year duration. The research has been approved by the SFU Office of Research Ethics, if you have any concerns or complaints regarding this study please contact the director, Dr Hal Weinberg at hal_weinberg@sfu.ca or 778-782-6593.

Thank you very much for your help with this project.

I have read this consent form, understand my rights and agree to the terms of this study:

Respondent signature _____

Date _____