

"I've still got a lot of living left to do":

The Experience of Being Young and Living in Geriatric Residential Care

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Acknowledgement: The author would like to acknowledge the mentorship and advice received from Dr. Paule McNicoll, Dr. Vaughan Marshall and Dr. Margaret Wright at the UBC School of Social Work throughout the duration of this research project, and to also extend thanks to colleague Patricia Johnson for her input on an earlier draft of this article. Correspondence concerning this article should be addressed to Sarah Chapple, The Jack Bell Building, School of Social Work, 2080 West mall, The University of British Columbia Vancouver, B.C. Canada V6T 1Z2

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### Abstract

This article explores the perceptions of a 57-year-old woman with a physical disability who faces unique challenges while living in a residential care facility designed for a geriatric population. This pilot study used an exploratory, qualitative research methodology.. The objectives of the study sought to answer the following question: How do working-age adults with physical disabilities experience living in a residential care facility designed for a geriatric population? The key themes arising from this study that will be discussed in this article include coping and adjustment, autonomy and choice, institutional culture and environment, relationships, and hope.

*Keywords:* advocacy, coping, health care, hope, institutional care, relationships

“J’ai encore beaucoup de vie à vivre” : L’expérience d’être jeune et de vivre dans un centre gériatrique résidentiel

### Résumé

Cet article explore les perceptions d’une femme de 57 ans, ayant un handicap physique, et qui se trouve confrontée à un problème particulier en vivant dans un centre gériatrique résidentiel. Cet article utilise les résultats d’une étude qualitative préliminaire qui a servi d’étude pilote pour un projet plus détaillé mené par après, de huit adultes entre 22 et 59 ans, vivant dans la région de la vallée Fraser, près du centre urbain de la ville de Vancouver , en Colombie-Britannique. Cette étude entreprend de répondre à la question suivante: Quelles expériences vivent les adultes faisant partis de la population en âge de travailler, et ayant des handicaps physiques, qui vivent néanmoins dans un centre gériatrique résidentiel? Les thématiques clefs émergeant de cette étude seront examinées, incluant les stratégies d’adaptation et d’ajustement, l’autonomie et le choix, la culture et l’environnement institutionnel, les relations personnelles et l’espoir.

*Mots Clefs:* défense des droits, adaptation, soins de santé, espoir, soins institutionnels, relations personnelles

“I’ve still got a lot of living left to do”:

The Experience of Being Young and Living in Geriatric Residential Care

### **Introduction and Context**

There is a large body of qualitative research that has been conducted with people over the age of 60 who live in a residential care facility , yet little is known about the experiences of younger residents who are residing in a geriatric residential care facility. This exploratory, pilot qualitative research study aimed to reveal how a younger adult with physical disabilities experienced living in a residential care facility designed to meet the needs of a geriatric population. The case study interview described in this article was conducted in the Fraser Valley region of British Columbia, Canada. The Fraser Health region is one of seven health regions in the province of British Columbia and spans a geographical area of over 200 kilometers, serving a population of approximately 1.6 million or 36% of the total provincial population (Fraser Health, 2011). The number of residents under age 60 in care facilities at the time this study was conducted was approximately 5-8% (personal communication, Fraser Health Residential Services, 2009). These numbers are comparable to estimates of 10% in Calgary and the surrounding area (Watt and Konnert, 2007) and the 8-12% of young people with a physical disability who live in geriatric care facilities in New South Wales and Queensland, Australia (Australian Government, 2010).

The concept for this research study evolved out of the author’s experiences employed as a medical social worker in a rural community hospital and 173-bed residential care facility. Through this work, it became obvious to me that there was a significant need for services to address the needs of this population. As there are so few care options available outside of the city of Vancouver, these adults often have little other options.. Social workers in residential care

advocate for the improvement of many aspects of daily life in a care facility including attention to physical comfort and a home-like environment, respectful treatment of the residents, engagement in meaningful activities, relationship building and increased autonomy and choice (Solomon, 2004). The staff who work in residential care attempt to be resident-focused whenever possible; however, I have found that often the health care team gives more consideration to the wishes of family members or other professionals than to the resident themselves. Advocating for the residents’ needs and wishes can be met with resistance by the facility management and other staff due to the institutional culture in long-term care (Ronch, 2004). The author’s hope in pursuing this research is to highlight a number of resiliencies and continued concerns of younger residents who live in a geriatric care facility and, furthermore, to impart information that can assist with informing future residential care policy.

### **Background and Literature Review**

Throughout my review of the existing literature, the terms “nursing home” and “residential care facility” are frequently used interchangeably. Research from the United States often refers to 24-hour nursing care in a residential facility as a “nursing home.” In Canada, and more specifically the Vancouver area, health care professionals refer to a nursing home as a “residential care facility.” Therefore, this article utilizes the term “residential care facility” to describe the type of facility that is commonly referred to as a “nursing home” both within the literature and general public knowledge. A residential care facility typically provides 24-hour care including personal care, assistance with activities of daily living such as toileting, dressing and eating, assistance with transfers and referral to higher levels of care, including acute hospital care if needed. Residential care facilities in Canada often have private and semi-private rooms and strive to maintain a home-like environment, embracing concepts such as the Eden

Alternative, which recommends the use of elder centered care and contact with plants, animals and children (Fraser Health, 2009).

The majority of existing Canadian literature on adjustment to residential care facilities is based on the experiences of adults over age 65. Adjustment may be defined as a period of altering behaviour in order to reach a harmonious relationship with one’s environment and searching for balance or acceptance of the situation (Wendell, 1996). However, some of the findings are also applicable to younger residents who live in a care facility environment and this article also draws upon research and policy in the United States and Australia in order to contextualize the issue within a broader view. Nevertheless, younger residents face many unique challenges not shared by residents over age 60, as the services in most care facilities are designed specifically for a geriatric population and often do not meet the needs of residents under age 60. Residential care facilities that serve a geriatric population construct an environment that focuses on the health and interests of elderly residents, and often fail to consider the needs and interests of younger residents. Young residents are also more likely to be at a different stage of life than elderly residents and may have a working spouse and children who are not yet grown. Due to the staffing ratios and end-of-life care traditionally offered in care homes, staff are required to perform tasks in the most time-efficient manner, which often results in young people who are admitted to residential care facilities losing independence with their activities of daily living. Many young adults are admitted to residential care as a direct result of no other care options being available to meet their needs.

Research in Australia has shown that most young people would prefer to remain in their homes and access community supports or 24 hour in-home care instead of care facilities (YoungCare, 2011). Watt and Konnert (2007) examine the relationship between quality of life,

health, social support and leisure activities in residential care facilities for two groups of residents. Measures of social support and leisure activities included frequency of visitors, presence of a confidant relationship, frequency of involvement in activities and frequency of leaving the care facility. Unique threats to quality of life of care facility residents include being physically separated from loved ones, limited social support, and a perceived loss of control (Franks, 2004; Watt & Konnert, 2007). Nursing home facility care is primarily based on the medical model, which focuses on the biological needs and functioning of each resident. Sacco-Peterson and Borell (2004) found that the residential care facility routine often discourages residents from maintaining a level of independence due to the regimented structure of the daily routines. An approach of person-centered care allows an expansion of choice and autonomy in a setting where there is often little of either (Ronch, 2004; Roth, 2005). Linzer (2002) reminds us that it is important to honour clients’ autonomy while still promoting safety and attempting to minimize the risk of harm.

Institutional policies and the residential care facility philosophy of care are similar for both younger residents and residents over the age of 65 (Franks, 2004; Watt & Konnert, 2007). Goffman (1961, p.4) details the dehumanization of institutions, including the care facility, and suggests the atmosphere be revitalized, describing the setting as within the concept of a total institution. In the basic social arrangement of Western culture, an “individual tends to sleep, play and work in different places with different co-participants and under different authorities and without an overall rational plan” (Goffman, 1961, p.5). Most facets of life are controlled and carried out in an unnatural way within an institutional setting and residents of a care facility are usually unable to choose their co-residents and the staff who care for them (Goffman, 1961). Ronch (2004) notes the struggle to change the culture of care facilities and “humanize” care to

make the environment less institutional. The daily structure within a care facility is usually suited to organizational procedures rather than each individual residents’ needs and wishes. Ronch (2004) also hypothesized that the quality of life of the residents would improve when life inside a residential care facility more closely resembles life outside a care facility, moving away from institutional efficiency and giving greater consideration to individual resident requests and needs.

There is little data available on working-age adult residents who live in residential care facilities in Canada. However, one exception includes the current research utilizing the Minimum Data Set (MDS) assessment, which is widely used in the United States. It has been a useful tool for obtaining demographic information about residents of care facilities,.. Miller (2007) states that the number of care facility admissions for working age clients age 18-64 has increased from 10% to 12% in some areas of the United States over the past ten years. According to the MDS, this increase is most significant between 2000 and 2004,.. Likely factors in this rise in care facility admission are related to cuts in community home support services and pressure from hospitals to discharge patients who no longer require acute hospital care, but may be unable to return to their previous living situation. The MDS data from the United States also shows that care facility residents under age 65 are predominately male, of ethnic minority status and of low socioeconomic status (Miller, 2007). There appears to be a correlation between low socioeconomic status and likelihood of admission to a care facility, as clients who can hire private support services appear to be less likely to require admission to a care facility if they can be supported to remain in their own home. Common conditions of younger residents in Miller’s study included cardiac disease, diabetes, paralytic symptoms and a prior stroke, all of which precipitated admission to a care facility (2007).

It is important to understand the Canadian health policy that is involved in subsidized residential care admission. The policy that regulates residential care facilities in Canada is both national and provincial in nature. All residential care facilities must follow basic licensing standards in order to remain functioning. There are two types of care facilities in British Columbia: fully government funded health region “owned and operated” facilities and care facilities owned and run by private companies. Residential care facilities in British Columbia are primarily funded by the provincial government, although there are a number of care facilities that are owned and run by private companies and may also receive government funding for a certain number of beds. Clients may access publicly funded care facilities through the provincial health authorities and can often wait for months before being admitted to a publicly funded care facility bed. In order to address the long waiting period for these beds, the BC Ministry of Health developed a FAAB (first appropriate available bed) policy that indicates clients must accept the “first available bed” in the region. This can result in clients being placed in a less than ideal setting, and there is little client choice in facility location unless one can afford to pay for private care.

The FAAB policy (2009) states that:

Based on residential bed availability, specific care requirements, level of urgency (risk to the client) and acute care congestion, the patient/client may be required to accept a bed outside their preferred geographic area but still within the FH boundaries. (p. 1)

Clients who are deemed eligible for residential care are obligated to accept the “first appropriate and available bed” offered in their preferred geographic area. Depending on residential bed availability, specific care requirements, level of urgency and acute care facility congestion, clients may be required to accept a bed outside their preferred geographic area (p. 1)

but still within the Fraser Health region boundaries, which are from Burnaby to Boston Bar; a geographic area spanning over 200 kilometers in the lower mainland of British Columbia. These geographic challenges are unique to the areas outside of the Metro Vancouver area, where there are many residential care facilities within the urban city centre. It is important to gain an understanding of the process of residential bed access, as this is also the beginning of the process that admits young clients to residential care. Most of the residential care facilities in Fraser Health follow the process as outlined above, although some make exceptions based on compassionate grounds, such as significant distance from family. Despite this process, there has been no exploration of alternative services for young residents in the Fraser Health region.

As the number of working-age residents who live in residential care facilities continues to grow, the unique needs of these residents needs to be addressed. When a young working-age adult is residing in a facility designed for seniors, there is significant risk of loss of autonomy and choice, which can be even more dramatic for younger residents, especially in cases where the resident has limited social support. Working-age residents need to be given the opportunity to maximize their independence, explore alternative services and improve upon their quality of life which includes an opportunity to remain living near their loved ones within a facility designed to meet their needs.

### **Methodology**

The primary research question arose out of a desire to understand the experience of individuals who reside in a setting that is not specifically designed to meet their needs. The case study included in this article sought to provide a venue for the participant to share her experiences, concerns and suggestions about the residential care environment. The mode of inquiry is a descriptive narrative approach, which tells the story of individuals while collecting

data that consists of conversations or “stories” through the reconstruction of life experiences and situating them within a broader context (Creswell, 2007, Lincoln & Guba, 1985).

A descriptive narrative approach assumes that human beings organize their experiences of the world into narratives. Additionally, the stories that are told depend on the individual’s past and present experiences, values, and when and where these stories are told (Maxwell, 1996). The audience of a story can also influence what information is shared and when. This research design allows many aspects of the participant’s experiences to be explored in a way that allows for richness and breadth of the data, and also validates these experiences as being significant and valuable. The results of the study are therefore a combination of the researcher’s interpretation of the meaning of the experiences being shared and results of “member-checking” which is a process of respondent validation that systematically solicits feedback about the data and conclusions from the participants in the study (Maxwell, 1996, p.111). In qualitative research, a member check, also known as informant feedback or respondent validation, is a technique used to help improve the validity and credibility of a study.. These checks may be done during the interview process or at the conclusion of the study. (Maxwell, 1996, p.111). In this pilot study, member checks were performed during the interview, at the conclusion of the interview and during a second meeting after the interview had been transcribed and reviewed for preliminary themes.

The data analysis process of the research began shortly after the interview was transcribed in its entirety and I reviewed the transcript in order to search for potential themes and significant statements. Thematic analysis is a method for identifying, analyzing and reporting patterns within data. One of the main benefits of thematic analysis includes its flexibility (Braun & Clarke, 2006). I began formal data analysis with thorough readings of the transcribed

interviews by highlighting recurrent and significant statements. Then, I began to identify recurring topics of discussion among the transcripts and identify preliminary groupings. Next, I grouped related statements under broad categories and reorganized the statements within the categories to generate sub-themes. From this process, I was able to define themes that seem to capture the participant’s experience of being a working-age adult who is living in a geriatric nursing home. I also had an opportunity to meet with the participant after the interview to review my preliminary themes and obtain her feedback on the groupings to ensure her experience had been captured effectively. Themes in qualitative analysis should capture something important about the data in relation to the research question as well as formulate meaning and a patterned response within the data (Braun & Clarke, 2006). This article also includes a “rich description” of the data set, in keeping with the descriptive narrative methodology (Braun & Clarke, 2006; Creswell, 2007).

The recruitment criteria for this pilot study specified that participants must be between the ages of 19 and 60 years old, be residing in a geriatric care facility for a minimum of six months, have a physical disability, be able to communicate in fluent English, and to be capable of providing voluntary and informed consent to participate in research. This study was reviewed and approved by the Research Ethics Boards of the University of British Columbia and the Fraser Health Authority. This participant interview was conducted by the author and then audio recorded, transcribed, and individually reviewed with a thematic approach to analysis.

The participant in this biographical study is a 57-year-old woman named “Rebecca.” A pseudonym has been assigned by the researcher in order to protect confidentiality and consent was given by the participant for her story to be included in this research article. At the time of the interview, Rebecca had lived in a residential care facility for six years in the same town where

she and her husband had lived for many years prior to her illness. Rebecca moved into the care facility after a severe stroke left her unable to walk. She is married, has one son and many supportive friends. Rebecca describes herself as a hopeful person and very social.

### **Case Study Findings**

A diverse range of topics arose during the course of this research interview and a subsequent follow-up interview to review the themes and interpretations of these themes. The main themes that emerged from the research data include coping and adjustment, loss of autonomy and choice, institutional culture, relationships and hope. These themes create a powerful picture of the complex experience of being an adult with a physical disability who lives in a care facility that has not been specifically designed to meet the needs of non-geriatric clients. The quotations are taken directly from the transcribed interviews, and some of these excerpts have been slightly edited for clarity and conciseness where necessary. All potentially identifying information has been removed from the data in order to protect confidentiality.

### **Personal Narrative**

In order to gain a fuller picture of the circumstances that brought Rebecca to her present living situation, Rebecca was asked to describe what her life was like prior to her move into a residential care facility:

My life before was very, very busy. I worked full time and I had a black lab dog that was the love of my life. I would walk him for a good 45 minutes in the morning before I went to work and then I would walk to work. I worked in a meat store at that time, a fresh meat store, high end. It was a really good place to work. The employers were terrific and in fact have become very good friends over the years. I still miss my dog and I miss running a home. I love to bake and cook and entertain which of course none of that can be done in

here. When I was 52 I had two severe strokes, which took away my ability to walk and the ability to use my left hand. And my husband still works but his job entails that he travels out of the province for long periods of time. We did try home care, 24-hour care at home, but we weren’t really blessed with our choice of homemaker unfortunately, and we had some severe problems with her. So just to have ease of life, I guess, without confrontation and worry, my husband and I decided this was probably the best place for me while he still works. And I agreed to that (Research interview, March 29, 2009).

Rebecca describes a busy working and family life typical of someone who is in middle adulthood, married and has older children.. This description highlights the difference between the life structure of someone Rebecca’s age who moves into a residential care facility, and most new residents, who are elderly, retired and often have a retired spouse as well.

### **Coping and Adjustment**

Rebecca shared her thoughts about the transition from hospital to a residential care facility and lack of information she and her husband received during the process of planning for her care needs:

No, actually I didn’t have a tour beforehand. I just, my doctor recommended it and my husband and I both agreed. I didn’t really know what to expect, but I figured it would be just another part of the hospital really. I came from the hospital to here and I figured it was just an extension of the hospital. I knew it was primarily older people. And I’ve only ever lived in a government-subsidized residence. I have never lived in a private care facility, which I understand is different (Research interview, March 29, 2009).

Rebecca made it clear that navigating the admission process was a challenge and it appeared there were few other care options available that would meet her needs. Rebecca stated several times throughout the interview that her ideal situation would be to remain living in her own home with a caregiver coming in to assist with personal care. However, Rebecca shared that she appreciates the space in the facility where she lives, even though it isn’t ideal, stating she had looked at a group home that was “small and depressing.”

I do like the space in here especially now that I’m in a power chair. You know, I’ve got room to move around. I can go to Tim Horton’s whenever I want. Like a group home facility would probably not suit me at all. But this is good because I do have a lot of space to wander. But you know, I’d rather not be here. I’d say, ‘Kick me out!’ if there was a way for me to be at home again (Research interview, March 29, 2009).

Though Rebecca tries to make the best of her situation, experiences of grief and loss can be common during the process of adjustment when changing one’s living situation, especially in cases where one may feel a lack of control or choice in the situation. Rebecca spoke about loss related to living separately from her family:

You know, I thought just before my stroke that my life couldn’t get any better other than becoming a grandmother, which hasn’t happened yet. I lived in a community that I loved. I had a half acre piece of property, which I had transformed into woodland garden and I loved it as well. I would spend time out there every day. And on free days off, I would spend all day in there with my dog. When you are removed from your family home to residential care [*starts crying*] one of the things you really miss...one of the things you miss is the sense of touch because you’re no longer with your family members. If it wasn’t for the care aides and of course visits from my husband, I would, I would forget

what it’s like. And I am still obviously grieving for my losses [*pauses to cry*] (Research interview, March 29, 2009).

### **Autonomy and Choice**

Rebecca spoke about frustrations over loss of autonomy and control over her life situation. Loss of autonomy and choice appeared to be a prevailing theme throughout the interview, particularly when describing the decision to move out of the home she shared with her husband. While describing the facility she now lives in, Rebecca points out that decision making is often removed from the residents and given to families and that many of the elderly residents do not speak up for themselves for fear of upsetting the staff:

I think there’s some fear, I would say especially among the elderly. You know, they’re afraid to question anything because they don’t want to be in trouble or cause upset or, you know, be at risk, being kicked out or asked to leave (Research interview, March 29, 2009).

Shawler, Rowles & High (2001) discuss the how life in a nursing facility is often structured with a “repeated daily cycle of predictable activities” (p. 612). Institutional settings typically do not lend themselves to involving the residents in decision making about the daily routines and structure such as placement of furniture, timing of meals and the seating plan in the dining room. Shawler et al. (2001) also found that individual decisions affecting each resident’s life are often designated to a surrogate decision maker, such as a family member, even when the resident is able to contribute to the process. These findings are clearly represented in Rebecca’s experience and she also spoke about feeling like she had lost her identity when she moved into a residential care facility:

I have been in residential care for six years now. I can’t believe how quickly the time has gone. Overall I do not enjoy living here because I no longer make my own decisions. They’re all made for me the minute I entered those front doors. And I lost my autonomy completely and in some ways I feel I have lost my identity (Research interview, March 29, 2009).

Rebecca outlines a significant shift in her feelings about her personal autonomy after moving to a residential care facility. Sherwin & Winsby (2010) explain that residents have a right to make significant decisions about their own lives, bodies and medical care and that personal autonomy is often overridden when a person experiences increased dependence and vulnerability. There is a significant risk of paternalism when clinicians substitute their own judgment for a resident’s opinion or rely solely on a surrogate decision maker such as a family member, when the resident is able to contribute to the discussion.

### **Institutional Culture**

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

Sometimes the staff, they forget to ask me what I think. It’s the same with my doctor when he comes in to visit. He goes to the nurses and asks, ‘How is she?’ I know my body and I know my own health. I know what the concerns are and I can see whether they’re getting better or not (Research interview, March 29, 2009).

Rebecca also shared what a typical day is like in the facility she lives in, in order to provide context to the situations she was describing during the interview. The culture and institutional

nature of the care facility was also a prevailing theme. Dissatisfaction with the food in the facility arose in response to the question “what would you change about your living situation?” as there is little choice in the food options. Food service was contracted out to a private company in most residential care facilities in 2002 (Hospital Employees Union, 2009).

I know a lot about the food here because I actually sit on the food services committee.

But until we go back to cooking the food on the premises, I don’t think it’s going to change. It was a budget cut by the provincial government so we went to this system (Research interview, March 29, 2009).

Discussion of the lack of choice in such a significant part of one’s daily life highlights how life in an institutional setting presents challenges not typically faced by young people who live independently and have greater autonomy and individuality in choices they make about their day to day life.

## **Relationships**

Relationships were a predominant theme that emerged over the course of the interview and included discussion of relationships with family, including spousal relationships, relationships with children and social relationships with friends and extended family. Rebecca also spoke about relationships within the facility, including her relationships with older residents and care facility staff. Rebecca describes why it was important to her to remain living in the same community as her friends and family:

I live here and my support group is here. So, yes, and the house that we’re in right now, we’ve lived [there] for 22 years. You know, I’ve always worked in this community and

our son went to school in this community so a lot of our friends are here. I wasn’t going to leave (Research interview, March 29, 2009).

Maintaining one’s support system is important at any stage of life but particularly so when facing a significant life change such as serious illness. Rebecca highlighted the importance of her friends and family during the transition to life in a care facility and spoke about the challenge to maintain the relationship with a spouse after moving into a care facility:

You have to consciously work on relationships in here if you’re still married, you know. It’s been very different for me, but it’s been very different for him as well. I have to keep that in mind. He is ready to retire and I’m sure he did not visualize himself having a handicapped wife when he decided to retire, if he thought about it at all. It just changes everything. My relationship with my husband can be strained at times just because of his time constraints and because I have so much time on my hands. I want to be home and I want to be with him more than he can handle. And that’s unfortunate but it’s not something a married couple should have to go through (Research interview, March 29, 2009).

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

I have some very dear girlfriends who live quite close and one of them comes in every Wednesday afternoon with her dog. I really enjoy their visits and I look forward to their visits. I have another girlfriend that has two small dogs and she comes in on a regular basis to see me. [*pause*] But my friends are always trying to tell me what would be good for me [*laughs*] (Research interview, March 29, 2009).

Rebecca also spoke about the experience of living in an environment with elderly residents, some of whom have cognitive impairments. Rebecca shared that for the most part, she enjoys the company of the elderly residents: “I know most of them by name and some of the older residents can be very, very humorous just from their point of view and their age, you know? They can crack you up [*laughs*] when you least expect it.” Another emerging theme was relationships with the facility staff. Rebecca describes the skill of the recreation staff at her facility in dealing with potentially difficult situations:

We have a wonderful therapeutic recreation team on this floor that are just terrific. Every week there is a big bus outing that we go on out to a restaurant or we go gamble and have lunch. I’d go nuts with boredom if it wasn’t for these ladies. Next week we are going to a park for a picnic and there will be a mixture of young and old and skill level. There’s some people that are really on their own little planet. But they are always included in the recreation activities and these ladies are very, very good [at] diverting people’s attention. Somebody that has real mental deficiency sometimes starts acting out or interfering with the other residents. They can handle those situations with tact and firmness and nobody’s feelings get hurt (Research interview, March 29, 2009).

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

Most of the staff are residential care aids and the majority of them are gems. They really are. A couple of them actually give you hugs and kisses which you may think kind of sloppy but it’s not (Research interview, March 29, 2009).

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

I think they are grossly overworked. The demands on them are very, very high and I think their morale is low because of that. The residential care aides work their butts off from the time they come on shift until the time they leave. You know, in the evening, for example, the care aide that works this side has about thirteen people to put to bed between the hours of six and nine. And that means toileting, washing up and getting them into bed. I’m not doing my own transfers yet and so they have to do some type of mechanical lift (Research interview, March 29, 2009).

## **Hope**

Hope for the future was an emerging theme particularly when discussing future plans. Rebecca has plans to move to another care facility so she can retire with her husband: “We are getting ready to move. We bought a new house three years ago, so I have to look for another residential care facility closer to our new house.” Rebecca remains positive about her life and looks toward her future goals, stating that even though she shares space with elderly residents, she does not feel like she is in the same stage of life as the others:

I do not feel that I am any different than I was the day before I had my first stroke. You know, I still feel ‘me’ inside me and today I’m young and I’ve still got a lot of living left to do. And I think compared to a lot of the other seniors in here or all of the seniors in here, a lot of them know that they will probably die in here. And I don’t see that for me (Research interview, March 29, 2009).

The theme of hope is particularly noteworthy, as a significant portion of the existing literature on residential care facilities discuss the challenges of living in an institutionalized setting and it is apparent that Rebecca maintains hope for the future as a coping mechanism to deal with her living situation. As Rebecca states above, working-age residents are at a different stage in their life cycle than elderly residents, so they should not be viewed in the same manner or be expected to ‘fit’ into the same environment as the elderly.

### **Discussion**

The findings of this study encompass many aspects of how working-age adults experience residing in a care facility designed for a geriatric population. The theme of institutional culture and environment looks at the culture within the residential care facilities and how this environment can limit autonomy and independence. Rebecca spoke about trying to fit into the setting, rather than the facility being designed to meet the needs of younger residents. Wendell (1996) explains that the social model of disability indicates that systemic barriers, negative attitudes and exclusion by society are measurements of disability in society, so the argument can be made that the very environment of a care facility is “disabling” since the culture discourages independence and autonomy. As Rebecca so aptly stated, “Overall I do not enjoy living here because I no longer make my own decisions. They’re all made for me the minute I entered those front doors. And I lost my autonomy completely and in some ways I feel I have lost my identity.” The very environment of a care facility limits autonomy and choice in a way that is not replicated outside the facility, as Goffman (1961) details in his classic work, *Asylums*. Goffman also details how residents of institutions often adapt by subscribing to behaviours such as situational withdrawal, intransigence, colonization and conversation. Situational withdrawal occurs when the resident withdraws from institutional life. Intransigence is displayed when a

resident openly refuses to cooperate with staff, colonization occurs when a resident is expected to remain in the institution until they die. Whereas, conversation occurs when the resident adapts to his or her life circumstances and becoming a “good patient.” Though these concepts may apply more broadly to geriatric residents in care facilities, these behaviours are often also adopted by younger residents.

The theme of relationships, addresses the many relationships and social supports that the Rebecca has in her life. Family relationships were also a significant topic of discussion,. Rebecca spoke about the ways that her relationship with her family members had shifted or changed since their illness and subsequent move into a care facility. Serious illness or disability and living separately from one’s family are unexpected events that can change the dynamics within a family, and the developmental goals of individual family members can be interrupted when a serious illness occurs, since the family as a whole can be disrupted (Rolland, 1999). The participant also spoke about how living in an institutional setting shifted how she related to her spouse and children. There appeared to be a sense of trying to “protect” family members from the realities of living in a care facility.

Another emerging subtheme was the relationships with staff and older residents in the facility. Rebecca spoke about feeling a sense of family and relayed how she created a support system within the facility. Residing in a setting where one feels different from others, in this case being part of a younger generation, can also contribute to issues of relocation stress and depression. Rebecca shared how it was extremely difficult to adjust to living in a residential care setting, but also stated she had made the best of the situation. It is important to note that specialized residential services are a resource that is certainly appealing to some residents, but Rebecca made a valid point about wanting to be close to family and remain near their support

network which is obviously preferable to moving further away in order to access specialized services. Despite this, many health regions are moving towards centralized services due to cost effectiveness. The final key theme in this study was hope. Rebecca spoke about having hope for the future and many referred to plans and goals such as moving back into a community setting or improved mobility. Hope is also an important factor in looking at aspects of the environment that can be improved or changed.

### **Study Limitations**

As this was a pilot for a larger study, this article captures the narrative of only one young adult and is reflective of her experience. Additionally, participation in the study was limited to residents who live in facilities run by the Fraser Health Authority, mainly because the author was an employee of Fraser Health at the time the research was conducted and was able to access methods of recruitment of research participants as an employee of the organization. The study recruitment criteria also did not include residents who do not communicate in English and this is a limitation as these residents would likely share significant cultural and language considerations. Residents who live in a care facility owned by a private company were also excluded from recruitment and these residents would likely have unique experiences, particularly with regards to financial considerations.

### **Implications for Policy and Practice**

It is clear that further research is needed to understand the complex needs of this growing population, particularly within a Canadian context. It is clear from the literature that most young people would prefer to live at home with their family or in a community-based setting instead of a care facility but some are unable to do so due to a lack of supports and funding. Many of the positive statements about the residential setting appeared to be an attempt to make the best of a

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

The findings from this research suggest that working-age adults with physical disabilities face multiple challenges residing in a residential care facility designed for geriatric clients and exploring what, if any, other care options may be available is a necessity. Rebecca’s remarkable insight into her living situation and ability to articulate the many issues and successes within the facility provide a unique opportunity to understand the perspective of someone living the reality of care that clearly does not meet her needs. Her willingness to share her experiences so openly and honestly is greatly appreciated.

Rebecca spoke about making the best of the facility she lives in, yet describes it as being unlike her ideal “home” The reality is that many of these adults will live ten to twenty years or longer in a facility that does not meet their needs unless alternative services can be developed (YoungCare, 2011). As the number of working-age adults with physical disabilities living in all types of residential care facilities continues to grow, the lack of appropriate services certainly needs to be addressed. The interest in this topic from young adults in residential care and other health professionals working with people who have a disability indicates that it is a topic worthy of further study, and further research is needed in order to address the needs of this growing population.

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