

UNIVERSITY OF CALGARY

Quality of Life in Younger Continuing Care Residents

by

Ashli D. Watt

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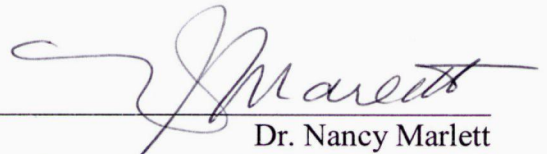
The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled "Quality of Life in Young Continuing Care Residents" submitted by Ashli D. Watt in partial fulfillment of the requirements for the degree of Master of Science.



Supervisor, Dr. Candace Konnert  
Department of Psychology



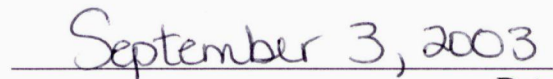
Dr. David Hodgins  
Department of Psychology



Dr. Nancy Marlett  
Department of Applied Psychology



Dr. Susan Boon  
Department of Psychology



Date

## Abstract

Adults aged 65 and younger with chronic disabilities make up a significant proportion of continuing care residents, but no previous research has examined the quality of life (QOL) of this group. To do this, two separate studies were conducted. The first study examined the content validity of an instrument called the Quality of Life Profile:Version for Persons with Physical and Sensory Disabilities (QOLP:PD; Renwick, Rudman, Raphael, & Brown, 1996). Based on content validation results, a new version of the instrument was created, called the Quality of Life Profile:Version for Persons with Physical and Sensory Disabilities in Continuing Care (QOLP:PD-CC). Using this new version, the goals of the second study were to: (1) assess the QOL of younger residents, (2) compare the QOL of younger and older residents, and (3) compare staff and younger residents' perspectives on QOL. The sample consisted of 43 younger residents ( $M = 53.7$  years, ranging from 25 to 64), 38 older residents ( $M = 79.92$  years, ranging from 66 to 97), and 65 continuing care staff. The QOLP:PD-CC demonstrated good psychometric properties, with an alpha coefficient of .95 for the instrument as a whole. Factors that were strongly related to QOL were perceived physical health/mobility, physical environment, and leisure activity. No differences were found between the QOL of younger and older residents, with the exception that younger residents rated daily activities related to work/school and self-care significantly less important than older residents. Moreover, staff and younger residents had similar perspectives on what is most important to a younger resident's QOL. Thus, results of these two studies provide support for the use of the QOLP:PD-CC with younger continuing care residents and identified areas that should be targeted for QOL interventions.

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## Introduction

Continuing care facilities provide a home for many people and it is important to examine the quality of life (QOL) that these residents experience. Previous research has examined the QOL of residents aged 65 and older (e.g., Bitzan, 1998; Bowsher & Gerlach, 1991; Cox, Kaeser, Montgomery & Marion, 1991; Loomis & Thomas, 1991), and most of the recent research has focused on those residents with dementia (Albert & Logsdon, 2000; Lawton & Rubenstein, 2000). While it is undisputed that the majority of people living in continuing care facilities are elderly, the diversity in these settings is often overlooked. Due to disability and disease, younger adults also live in continuing care facilities. Despite the presence of younger adults in this type of setting, there is currently a dearth of information on this population.

While some of the challenges and concerns that face younger and older residents are similar, it seems reasonable that differences in daily life experiences would also exist. For example, the generation gap between younger residents and the majority of people living in continuing care facilities may cause feelings of alienation (Lewis, 1992; Parsons, 1997). Also, although the physical care that continuing care facilities provide is often good, the services, programs and activities offered may not be tailored to address the unique needs and interests of younger adults with chronic physical disabilities (Buchanan & Lewis, 1997; Ceol, 1994; Lewis, 1992; Weingarden & Graham, 1992). Whether these factors influence a younger resident's well-being is important to assess. As such, it is not only the overall QOL that is of interest, but also what determines QOL for this specific population.

The following two studies will assist in promoting the QOL of younger continuing care residents by achieving the following goals: (1) clarify the conceptualization of QOL by examining the content validity of the BBB model of quality of life as applied to this specific population, (2) determine what factors have the greatest impact on the QOL of younger residents, (3) examine the differences and similarities in QOL that younger and older residents experience, (4) determine the differences and similarities in the way staff and younger residents view what is important to QOL in a continuing care facility, and (5) ascertain from younger residents and staff what changes could be made in the continuing care facility to improve younger residents' QOL.

The introduction is organized as follows. First a description of younger continuing care residents will be given. Second, definitional issues of QOL will be discussed and the model of QOL that will be used in the proposed study introduced. Third, previous research on contributing factors to QOL for older continuing care residents and community-dwelling young disabled adults will be summarized. Finally, the purpose and significance of the studies will be outlined.

### *Description of Younger Continuing Care Residents*

In Alberta and the United States, younger residents with chronic physical disabilities account for 9-10% of the continuing care population (Alberta Health, 1991; Spector, Fleishman, Pezzin, & Spillman, 1996). It is projected that this percentage will grow because, although cures are still elusive, medical advances have enabled the lives of people with chronic physical disabilities to be prolonged (Family Economic Review, 1993). While it is recognized that everything should be done to help disabled adults remain in the community, the level of care that some require may make this goal

impossible (Gutman, 1989). When family members can no longer provide the necessary care, either because the disabling condition has become too severe for the family to manage or because of familial abandonment, the only alternative may be placement in a continuing care facility (Buchanan & Lewis, 1997; Weingarden & Graham, 1992). Ensuring that these adults maintain a good QOL is extremely important.

### *Defining Quality of Life*

While the emergence of “quality of life” research has been relatively recent, a plethora of definitions and measures for the construct exist (Lawton, 1997; Murrell, Kenealy, Beaumont, & Lintern, 1999; Raphael, Renwick, Brown, & Rootman, 1994). The majority of research on adults with chronic physical disabilities has focused on “health-related” quality of life, where what is of interest is the burden associated with illness (Gladis, Gosch, Dishuk, & Crits-Christoph, 1999). As such, the emphasis of health-related QOL is typically on symptoms, impairment, functioning, and disability. The health-related approach to QOL has been criticized, as it cannot be assumed that measures of health or functional status adequately tap the QOL experienced by individuals (Renwick & Friefeld, 1996). In fact, there is little empirical data to support equating health to QOL (Day & Jankey, 1996; Renwick & Friefeld, 1996). Instead, the domains that most researchers feel contribute to a person’s QOL include not only a persons’ physical health, but also psychological health, social support, financial resources, leisure and recreational activities (Felce & Perry, 1996; Ferrans & Powers, 1985; Lawton, 1997; Spilker, 1990; The WHOQOL Group, 1998). Using this more holistic framework, a person’s health is only one of a multitude of factors that contributes to overall QOL.

Once one has chosen between the health-related and holistic approach to QOL, the next choice is whether to use objective or subjective measurement tools. The emphasis of an objective approach is in measuring verifiable conditions (Raphael et al., 1994). For example, a professional may define physical health in terms of medical status or observable mobility. When measuring QOL subjectively, however, a person's own perception of how satisfied they are with various aspects of his or her life is what is important (Frytak, 2000). Using a subjective perspective to define physical health, it is self-reported health status or self-rated mobility that is of interest. Due to the frequent finding that patient reports of satisfaction do not correlate well with objective indicators (Raphael, 1996), the subjective approach has been emphasized recently when gathering information about QOL (Gladis et al., 1999). When the goal is to determine how good people feel their lives are, it is necessary to assess their subjective interpretations of events and the meaning they find in these events (Murrell et al., 1999).

#### *The Centre for Health Promotion Model*

Most definitions of QOL in the literature lack a comprehensive conceptual framework (Renwick & Brown, 1996). To address this problem, the research team from the Centre for Health Promotion at the University of Toronto developed a much-needed conceptual approach to QOL, namely the BBB model. The model was originally developed for persons with developmental disabilities; however, the basic, untested, assumption behind the conceptualization is that the criteria for QOL are the same for all people. As such, the model has been applied to community-dwelling older adults, adolescents, and people with physical and sensory disabilities (Raphael, Renwick, Brown, & Rootman, 1994).

The BBB model was used to conceptualize QOL in this study for a number of reasons. First, this model was developed using an empirical approach. The developers reviewed the existing literature on QOL and consulted with prominent researchers in the area. They also conducted qualitative research by examining the perspectives on QOL held by persons with disabilities, their family, and service providers (Renwick & Brown, 1996). Second, this model was developed with the intention that it would form the basis for both quantitative and qualitative measures of QOL, both considered important when measuring the construct. Third, the model was used in a study conducted by Liza Stelmach and Candace Konnert from the University of Calgary. These researchers sought to determine the overall QOL in older continuing care residents and the specific subcomponents of the model that contribute the most to QOL for this population. By using the same model, direct comparisons between younger and older residents with respect to QOL can be made.

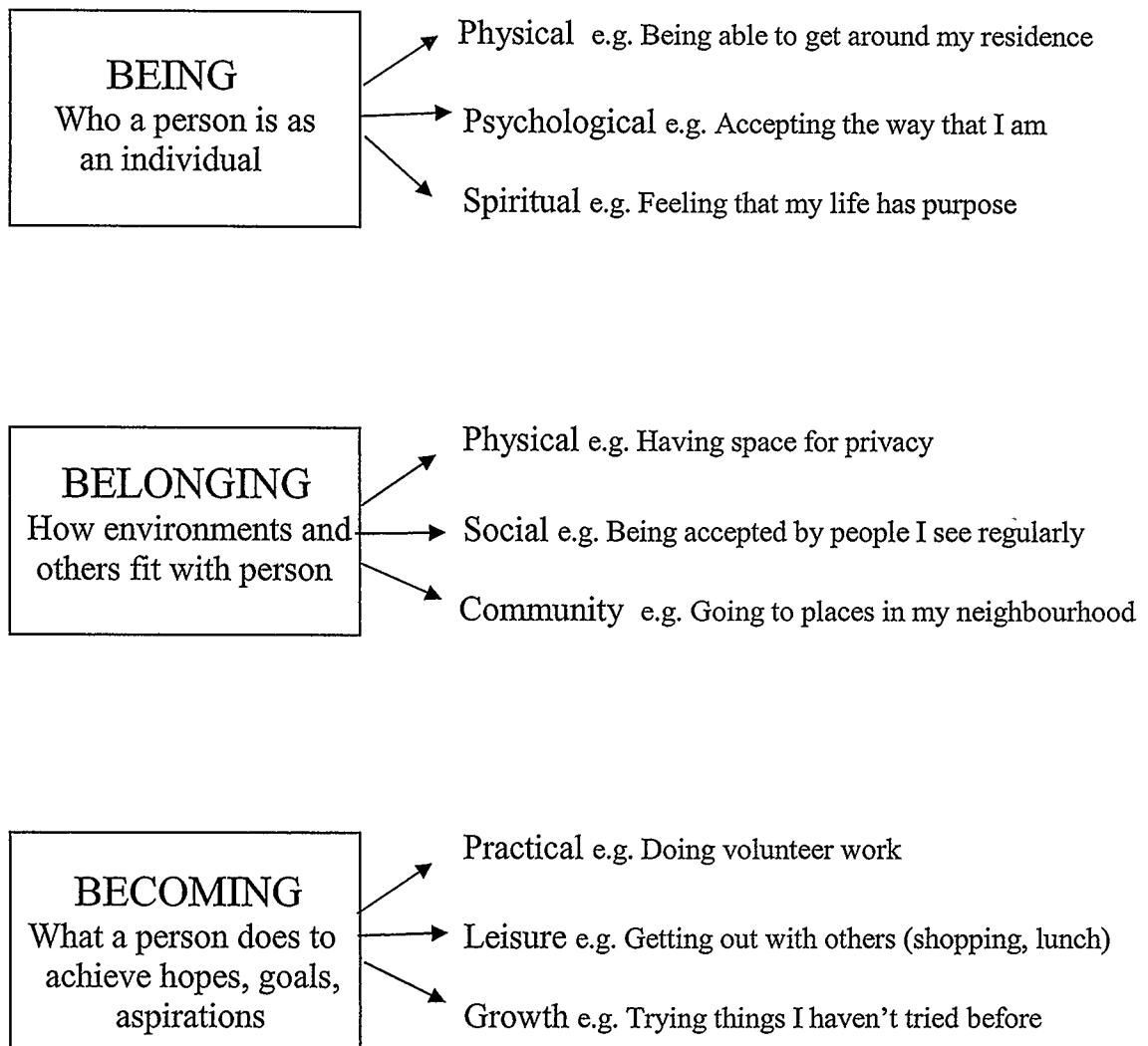
The BBB model defines quality of life as “the degree to which a person enjoys the important possibilities of his/her life” (Renwick & Brown, 1996, p. 23). Enjoyment is viewed as both the person’s subjective satisfaction with, and their achievement of some characteristic or state. Possibilities refer to the opportunities and constraints in people’s lives and the balance between these (Renwick & Brown, 1996). The BBB model of quality of life recognizes that not all possibilities are equally important to all people, and incorporates importance ratings into its measure to ensure that QOL is uniquely identified for each individual (Raphael et al., 1996; Renwick & Brown, 1996).

The BBB model focuses on an individual’s possibilities in three broad fundamental areas of life, which are referred to as components. Each component is further divided into

three subcomponents in which all people strive for quality (Renwick & Brown, 1996; refer to Figure 1). The first component is called Being. This refers to the most basic aspects of “who one is” and is composed of the following subcomponents: (1) physical being, which includes a person’s body and health, (2) psychological being, which consists of a person’s feelings, cognitions and evaluations of the self, and (3) spiritual being, which encompasses the person’s beliefs and values. The second component of the model is called Belonging. This component concerns the person’s fit with their various environments and is composed of the following subcomponents: (1) physical belonging, which refers to the connection the person has with his or her surroundings, (2) social belonging, described as the links the person has with his or her social environment, and (3) community belonging, which involves access to community resources. The third component is called Becoming. This component focuses on the purposeful activities that are engaged in in order to achieve goals, and is composed of the following subcomponents: (1) practical becoming, which consists of practical, purposeful activities, (2) leisure becoming, which includes activities that promote relaxation and stress reduction, and (3) growth becoming, which refers to things the person does to maintain or improve his or her knowledge and adaptation to change. The quality of life in each of these nine areas is determined by both the importance the person attaches to the dimension and the extent to which he or she is satisfied with that dimension.

#### *Contributing Factors to the Quality of Life of Older Continuing Care Residents*

Previous research has found that control (Bowsher & Gerlach, 1990; Cox, Kaeser, Montgomery & Marion, 1991), physical health (Fry, 2000; Loomis & Thomas, 1991), and financial status (Ryden, 1983) consistently predict the quality of life of older continuing



*Figure 1.* BBB model of quality of life (Renwick & Brown, 1996).

care residents without significant cognitive impairment. Inconsistent predictors include social support from family (Faulk, 1988; Pearlman & Uhlmann, 1989), functional health (Faulk, 1988; Gould, 1992), mental health (Cox et al., 1991; Pearlman & Uhlmann, 1989), leisure and recreational activities (Faulk, 1988; Bitzan, 1998) and religiousness (Bitzan, 1998; Pearlman & Uhlmann, 1989; Rai et al., 1995). These variables are similar to those included in the BBB model, making this a useful model when studying the quality of life of older continuing care residents. The relevance of the subcomponents of the BBB model to young continuing care residents has yet to be determined as, to the author's knowledge, no study has yet assessed QOL determinants in this population. However, the BBB subcomponents appear to be highly relevant to young adults with chronic physical disabilities that live in the community. It is this literature that will be discussed in the following section.

*Contributing Factors to QOL of Community-Dwelling Adults with Physical Disabilities*

Physical health, functional health, social support, mental health, leisure activities, spirituality, and environmental factors have all been examined as predictors of QOL, well-being, and life satisfaction in community-dwelling younger adults with chronic physical disabilities. Previous research, however, has usually examined only three or four predictors of QOL at a time and did not have a conceptual basis. Although there are a number of chronic disabling conditions, the ones reviewed are those commonly leading to continuing care placement and include multiple sclerosis, traumatic brain injury, and spinal cord injury.



### *Multiple Sclerosis*

Multiple sclerosis (MS) is the most common neurological disease that disables younger adults. MS is a progressive disorder of the central nervous system, characterized by inflammatory demyelination and axonal loss. The average age of onset is around 30 years. Despite such an early onset, the majority of people with MS live 35 to 40 years after initial diagnosis is made (Lezak, 1995). According to the national medical advisor of the Multiple Sclerosis Society of Canada, an estimated 50,000 Canadians have the disease ([www.mssociety.ca/en/NRMay2002.htm](http://www.mssociety.ca/en/NRMay2002.htm)) and as many as 350,000 adults in the United States have been diagnosed (Buchanan, Wang, & Ju, 2002). About five percent of people with MS eventually will need care provided by a continuing care facility (Buchanan, Wang, & Ju, 2002).

A number of different factors have been studied as predictors of QOL among community dwelling adults with multiple sclerosis (MS). Psychological health (Coyle et al., 2000; Gulick, 1997), social support (Stuifbergen, 1995, Stuifbergen, Seraphine, & Roberts, 2000), intimacy (Gulick, 1997) and recreation (Gulick, 1997) have all been found to predict QOL in this population. The role that physical health plays in the QOL of people with MS, however, is less clear. Coyle et al. (2000) and Gulick (1997) found that pain ratings predicted QOL, but functional abilities did not. Stuifbergen (1995) also found that perceived health and self-rated health abilities account for a large amount of variance in QOL, whereas objective measures (severity of illness) did not. While these studies suggest that it may be one's subjective judgement of health that is most important to assess, other researchers have found no relationship between subjective ratings of perceived health and QOL (Coyle et al., 2000), and still others have reported a significant

relationship between objective health measures and QOL (Koch, Rumrill Jr., Roessler, & Fitzgerald, 2001). Financial resources (Coyle et al., 2000; Koch et al., 2001; Stuifbergen, 1995), education (Coyle et al., 2000; Koch et al., 2001) and employment (Coyle et al., 2000; Koch et al., 2001) also inconsistently predict QOL.

### *Traumatic Brain Injury*

Persons with traumatic brain injury (TBI) often experience significant physical, cognitive, and behavioural changes. One might expect that perceived physical health and functional status would significantly predict QOL in this population. While Warren and Wrigley (1996) did find that bowel independence was positively related to life satisfaction, other researchers have reported that neither self-rated physical health or functional status predicted the QOL of people with TBI (Granger, Divan, & Fiedler, 1995; Smith, Magill-Evans, & Brintnell, 1998; Steadman-Pare, Colantonio, Ratcliff, Chase, & Vernich, 2001). Instead, psychological health (Granger et al., 1995; Steadman-Pare et al., 2001) and social support (Brown & Vangergoot, 1998; Smith et al., 1998; Steadman-Pare et al., 2001) have been found to account for a significant amount of variance in QOL ratings for this population. In addition, Corrigan and colleagues (2001) found in their study of 218 adults with TBI that social integration, defined as involvement in leisure activities, traveling outside the home and having friendships, accounted for a significant amount of variance in the QOL measure. Burleigh, Farber, and Gillard (1998) also found that social integration predicted QOL, and Granger et al. (1995) demonstrated the importance of transportation to the life satisfaction of people with TBI.

### *Spinal Cord Injury*

Among persons with spinal cord injury (SCI), perceived health is a consistent predictor of QOL (Boschen; 1996; Fuhrer, Rintala, Hart, Clearman, & Young, 1992; Kinney & Coyle, 1992; Richards et al., 1999). Other consistent predictors of QOL are financial satisfaction (Boschen, 2001; Kinney & Coyle, 1992; Richards et al., 1999; Weitzenkamp et al., 2000), social support (Fuhrer et al., 1992; Rintala et al., 1992; Weitzenkamp et al., 2000), and leisure (Kinney & Coyle, 1992; Weitzenkamp et al., 2000).

Religion has also been found to play a role in the QOL of community dwelling adults with SCI. Kinney and Coyle (1992) found that satisfaction with religion accounted for a significant amount of variance in their life satisfaction measure and in Riley et al.'s (1998) sample of adults with SCI, those that considered themselves to be non-spiritual had significantly lower levels of life satisfaction.

Other factors are more inconsistent predictors of QOL in community dwelling adults with SCI. The contribution that a person's mental health makes to QOL is less clear, possibly due to the number of different concepts used to define it. Boschen (1996) found that self-concept was a significant predictor of QOL. Similarly, Kinney and Coyle (1992) found that self-esteem accounted for a significant amount of variance in the life satisfaction measure.

The ability to access the environment may become a challenge for persons with SCI. While Richards et al. (1999) found that this factor accounted for a significant amount of variance in this population's QOL; other researchers have not (Kinney & Coyle, 1992). Functional health status and the ability to work and engage in other self-improvement

tasks have also inconsistently predicted QOL (Dijkers, 1999; Fuhrer, 1992; Richards et al., 1999)

In addition to the quantitative studies discussed above, qualitative studies on the predictors of QOL for young adults with SCI have been conducted. In an ethnographic study by Manns and Chad (2001), persons with spinal cord injury were asked what factors are important to their QOL. Factors that were identified included physical functioning and independence, accessibility, emotional well-being, stigma, spontaneity, relationships, occupation, finances and physical well-being. Boswell, Dawson, and Heininger (1998) also conducted a qualitative investigation to see how individuals with SCI defined QOL. Their results indicate that QOL is strongly influenced by three factors. The first is work opportunities. However, as the majority of the sample was in the work force, the authors speculated that this factor might also be equated to giving to the community and being creative. The second factor was level of resources, which included food, shelter, transportation and income. Lastly, a person's attitude toward life was found to influence QOL.

#### *Contributing Factors to the Quality of Life of Younger Continuing Care Residents*

The BBB model appears to be appropriate for younger continuing care residents, as it taps most of the important predictors of QOL for community-residing adults with physical disabilities. The literature reviewed above shows that psychological health, perceived health, social support, leisure, and religion are more consistent predictors of QOL for community-dwelling adults with chronic physical disabilities. More inconsistent predictors of the construct include functional health, income, and the ability to access the environment.

However, it must be noted that the factors contributing to the quality of life of young continuing care residents may be different than the predictors of quality of life for those disabled adults living in the community. Placement in a continuing care facility results in separation from significant people and maintaining employment in the community may no longer be achievable. The emphasis most continuing care facilities place on ensuring the resident's safety may contribute to a loss of independence. For older residents, research indicates that excessive helping can be standard procedure and may lead to further declines in resident competencies (Zarit, Dolan, & Leitsch, 1998). Excessive helping may also be a relevant issue for younger continuing care residents.

There are other issues that have been identified as concerns to older continuing care residents, and may be equally applicable to younger residents. The first is the loss of spontaneity that can accompany a continuing care placement. Great demands are placed on the staff in order to meet the needs of a large number of residents. As a result, the life of a continuing care facility is driven by routines (Haddad, 1994). Residents are often denied a voice in the decisions many of us take for granted, such as the choice of when to wake up, eat, bathe or sleep. Privacy is also an issue specific to continuing care facilities. That privacy can be very limited has been recognized by many researchers that work in such settings (Duffy, 2000; Lichtenberg et al., 1998; Rabins, Storer, & Lawrence, 1992). Often residents share a room and, even if the resident has a private room, it is common for nurses, nurses aides, visitors, recreational directors, and cleaning staff to come and go throughout the day. Adjusting to this lack of privacy may be difficult. Meeting needs for intimacy in such a setting may also pose a challenge for the younger resident.

Due to the fact that the environment of a continuing care setting may foster new QOL issues, there was a need to explore the content validity of the BBB model for young continuing care residents. Although the literature discussed above seems to indicate that the BBB model is appropriate for older continuing care residents, there might be unique factors that contribute to QOL for this younger population, or some components of the model may be less relevant. Revisions may need to be made to the model and corresponding measure in order to ensure that it represents all facets considered to be important to this population.

### *Contributions, Rationale, and Significance of Research Studies*

In order to fully investigate the concept of quality of life, as experienced by young physically disabled continuing care residents, two studies were conducted.

#### *Study One*

From the literature reviewed, it appears that this was the first study to explore QOL in younger continuing care residents. This study assessed the content validity of the short version of the *Quality of Life Profile: Version for Persons with Physical and Sensory Disabilities* (QOLP:PD) for use with young continuing care residents. This instrument measures the nine subcomponents included in the BBB model, with its items designed to assess the QOL of adults with physical disabilities that live in the community. As the instrument has not had prior use in continuing care settings, the degree to which items of the QOLP:PD are relevant to the QOL of young continuing care residents was examined. Content validity is the degree to which the data from the assessment instrument are relevant to and representative of the targeted construct (Haynes, 2001). Content validity is important to assess because data from an invalid instrument may over-represent, omit, or

under-represent some facets of the construct and/or reflect variables outside the construct domain (Haynes, Richard, & Kubany, 1995).

### *Study Two*

There are five main contributions that the second study made to the body of literature of QOL in continuing care residents. First, it provided information about younger (aged 65 and younger) adults that reside in continuing care. No research has yet examined the activities that these residents engage in or the amount of social support they receive. In addition, little attention has been given to the level of education these younger residents have received, their past and current employment status, or the chronic physical conditions that have led up to their continuing care placement. This information will be instrumental for future researchers with an interest in studying this population.

Second, the QOL experienced by younger residents was assessed, and importance and satisfaction ratings for factors believed to influence QOL identified. This is something that has not been studied in the past. To find literature on the subject, Medline (1966-present), PsycINFO (1974-present), HealthSTAR (1975-present), AARPAgeline (1978-December 2001), Academic Search Premier (1970-present), Article First (1990-present), and CINAHL (1982-April 2002) were searched using a combination of the terms ‘nursing home,’ ‘institution,’ ‘long-term care,’ ‘physical disability,’ ‘young and quality of life’ as keywords. Only one study on the topic was found in this search. This study examined the overall QOL of young continuing care residents with spinal cord injury, but the determinants of QOL were not assessed (Putzke & Richards, 2001). In addition, an e-mail message was sent to all List Serve members of the American Psychological Association, Division 12 Section 2 (Clinical Geropsychology) to determine whether they knew of

studies investigating QOL in younger continuing care residents. Many of these members are actively involved in research and service provision in continuing care. The consensus was that there is no research in this area, but that it is an important area of study, particularly given the projected increase of this population.

The third contribution of the study was to compare the QOL experienced by younger and older residents. Despite a shared environment, it was expected that older and younger adults who live in continuing care facilities would differ in their experience of QOL, refuting the 'one size fits all' approach to care that often characterizes continuing care facilities. As Stelmach and Konnert used the *Quality of Life Profile: Seniors Version* (another instrument based on the BBB model that is very comparable to the QOLP:PD) to assess the QOL of elderly residents in the same continuing care facility, direct comparisons between the populations could be made. More specifically, differences and similarities between younger and older resident scores for each subcomponent of the BBB model and overall QOL were examined.

The fourth contribution was to determine whether there were differences and similarities between younger residents and staff perspectives on what is important for QOL. Again, this literature is very limited. Buchanan and Lewis (1997) surveyed 140 health professionals, including physicians, registered nurses, and social workers, to collect their opinions on what services, programs and equipment continuing care facilities should provide to residents with multiple sclerosis. From this survey, a list was generated detailing the most important services that should be provided to continuing care residents with multiple sclerosis, as well as other younger residents with chronic physical disabilities. Results indicated that mental health services are the most important service



that continuing care facilities should provide to younger residents, followed by physical therapy, recreation, occupational therapy, neurology services, general medical services, assistance in activities in daily living, education, family counselling, community involvement programs, and ways to access the environment (e.g., wheelchairs and outdoor transportation). However, because the researchers did not interview residents as to what was important, resident and staff perspectives could not be compared. It cannot be assumed that the opinions of the continuing care staff and the residents naturally coincide. Raphael (1996) points out that there is frequently divergence in the perception between an individual and their proxy rater in evaluations of QOL. Although the continuing care staff ultimately make decisions concerning service provision, when the goal is to provide services that will have the greatest positive impact on QOL, it is younger residents' opinions that are most important to determine. By comparing what younger continuing care residents and staff felt was important for this group's QOL, discrepancies and similarities in perspectives were identified.

Lastly, the study asked both younger residents and staff what changes they felt could be made in the continuing care facility to improve younger residents' QOL. This question provided both residents and staff the opportunity to express their opinions and offer valuable practical information to administrators in the continuing care facilities.

## Study 1: Content Validity of the QOLP:PD

### *Methods*

#### Participants

Consistent with recommendations regarding content validation (Haynes, Richard, & Kubany, 1995), six experts on the target construct and six people from the target population were included in this study. Experts on the quality of life of young continuing care residents consisted of: (1) faculty experts – University of Calgary faculty with expertise in rehabilitation and disability studies and an interest in QOL research, (2) staff experts - continuing care staff at the selected continuing care facility that were experienced in providing care to younger adults with chronic physical disabilities, and (3) companion experts -close family members or friends of physically disabled younger residents who had lived in the selected continuing care facility for more than one year. Two participants for each of the three groups were recruited, for a total of six participants. As young continuing care residents were the target population, six residents aged 65 or younger were recruited from the selected continuing care site operated by the Calgary Health Region - Carewest. This particular site provides a home to the largest number of young residents with physical disabilities in Calgary. The facility is composed of three young adult units, with 49 beds per unit. While there are some private rooms in the facility, the majority of the accommodations are semi-private. Most of the residents on the young adult units were aged 65 and younger ( $n = 128$ ), however, a small number of the residents were older than age 65 ( $n = 19$ ). Many of these older residents relocated to the facility before the age of 65 and, because of the ‘aging in place’ philosophy adopted by the site, remained on the young adult units.

### *Measure*

The QOLP:PD is an instrument designed for adults with chronic disabilities. There are two versions of the QOLP:PD, a long version (101 items) and a short version (54 items from the long version). Appendix A presents the long version of this instrument, with asterisks identifying items included only on the short version. Items from the long version were developed on the basis of a review of the literature and existing instruments grounded in the BBB model. In addition, ten adults living with physical disabilities (e.g., MS, SCI, visual impairment, arthritis, and neurological conditions) were interviewed using open-ended questions to elicit what ‘made life good and not so good’ for them. After generating an item pool, ten other adults with physical disabilities, ten rehabilitation service providers, and five researchers specializing in QOL and disability were asked to evaluate the items (Renwick, Nourhaghighi, Manns, & Rudman, in press).

The short version of the QOLP:PD was derived from the long form of the QOLP:PD, using items that were highly correlated with the long version items in each domain. The scale has not been used in published research, but the developers have validated the short version of the instrument with small sample of nine community-based participants (6 males, 3 females) with neurotrauma, ranging in age from 30 to 73 years (R. Renwick, personal communication, July 19, 2002). The internal consistency rating of the total QOLP:PD (short version) is .88, with internal consistency ratings for the nine subscales of the instrument ranging from .27 to .91. The developers reported that the QOLP:PD short version has been validated against the Memorial University of Newfoundland Scale of Happiness (MUNSH), with the Practical Becoming and Growth

Becoming subdomains correlating significantly with the total MUNSH scores, .70 ( $p < .04$ ) and -.82 ( $p > .01$ ), respectively.

### *Procedure*

Participants followed a content validation procedure proposed by Haynes et al. (1995). Using this method, participants rated the 'relevance' of each item on the QOLP:PD measure. Although the researchers were interested in examining the content validity of the short version of the QOLP:PD, participants rated the relevance of all 101 items on the long version. It was decided that the long version should be administered so that, should any of the 54 items appearing on the short version be rated poorly, items from the long version that were rated highly relevant would be available for substitution purposes and a new version could be created, called the Quality of Life Profile: Version for Persons with Physical and Sensory Disabilities in Continuing Care (QOLP:PD-CC).

### *Experts.*

The researcher met with each of the six experts individually and asked them to evaluate the long version of the QOLP:PD. Experts for each of the three groups were recruited in the following manner. First, individuals with expertise in rehabilitation and disability studies and an interest in QOL research were identified by reviewing the University of Calgary's websites for relevant departments (e.g., Community Rehabilitation and Disability Studies, Nursing, Social Work) and by soliciting recommendations from University of Calgary faculty. The researcher contacted these faculty experts and provided a full description of the study, including the purpose and goals of the study, and the amount of time to complete the interview (45-60 minutes). Informed consent was obtained from the first two doctoral experts that agreed to

participate in the study (see Appendix B for consent forms used in Study 1 and 2). Interviews were conducted in the participant's office. Second, the Program Leader from the continuing care site was asked to identify continuing care staff with extensive experience in providing care to younger residents. The researcher contacted these staff experts and provided them with a full description of the study. Informed consent was obtained and interviews were conducted in a private area in the continuing care facility. Third, the Program Leader from the continuing care site was also asked to identify friends or close family members of younger residents that had lived in the continuing care facility for a period of six months or more. The Program Leader asked these individuals whether they were willing to speak to a researcher from the University of Calgary about possibly participating in a research project that would evaluate the appropriateness of a QOL questionnaire for young adults who live in a continuing care facility. This procedure is in accordance with the University of Calgary Joint Faculties Research Ethics Committee that precludes researchers from asking friend/family members or residents to participate directly. The names of the first two people in agreement were forwarded to the researcher, who then contacted these friends/family members and provided a full description of the study. Interviews were conducted in a private area at the continuing care facility.

*Continuing care residents.*

Six younger continuing care residents with physical disabilities were asked to evaluate the long version of the QOLP:PD. Registered Nurses that worked on the young adult units were asked to identify residents that would be interested in participating in the study. Although the researcher did not specify exclusionary criteria, the residents that were identified had the communicative abilities to participate in an interview and did not

have a legal guardian. The nurses asked these residents whether they were willing to speak to a researcher from the University of Calgary about possibly participating in a research project evaluating the appropriateness of a QOL questionnaire for young adults who live in a continuing care facility. After six residents agreed to speak with the researcher, informed consent was obtained from the residents. None of the residents refused participation. Individual appointments between each resident and the researcher were scheduled to obtain his/her ratings of the relevance of the items in the long form of the QOLP:PD. The interview was conducted in a private room at the continuing care facility over one session.

Once experts and residents were recruited, they were asked to provide quantitative ratings and general evaluative feedback on the content of the scales.

*Quantitative ratings of scale content.*

The experts and younger residents evaluated the items of the long form of the QOLP:PD using a 5-point scale to rate the 'relevance' of each item (ranging from 0 = not at all relevant, to 4 = extremely relevant). An item from the short version of the QOLP:PD was dropped if it was rated more than two standard deviations below the mean relevancy score.

*Evaluative feedback regarding scale content.*

After rating the items, experts and younger residents were asked to supply feedback about any changes they would make to the instrument, such as item additions, item deletions, and item modifications. If three or more participants (25% of the sample or greater) suggested that a specific item should be removed from the instrument, the item

was deleted. Similarly, a new item was added to the instrument only if three or more of the participants recommended its inclusion.

## *Results*

### *Quantitative Ratings of Scale Content*

Mean expert ratings ( $N = 6$ ) for the 101 items of the QOLP:PD ranged from 2.71 to 3.70, with a mean relevancy rating of 3.23 ( $SD = .42$ ). In contrast, mean resident ratings ( $N = 6$ ) for the items of the QOLP:PD ranged from 1.75 to 2.69, with a mean relevancy rating of 2.32 ( $SD = .33$ ). Differences between expert and resident relevancy ratings were statistically significant, ( $t(10) = 4.20$ , at  $p \leq .01$ ), indicating that experts found the items more relevant than did residents.

Following Haynes et al.'s (1995) recommendations, expert and resident relevancy ratings ( $N = 12$ ) were combined. The mean relevancy rating for each of the items is also presented in Appendix A. The mean relevancy score of the long version of the QOLP:PD was 2.77 ( $SD = .60$ ). Of the nine subscales that comprise the QOLP:PD, three items from the Practical Becoming scale received a mean relevancy score that was rated less than 2 standard deviations below this mean. The poorly rated items were "The everyday things I do for a spouse or other adult (laundry, cleaning, etc)," "Doing work I get paid for," and "Looking after my children or other children." These items were replaced with items taken from the Practical Becoming scale of the QOLP:PD's long version that were rated above the total item mean score of 2.77. There were only three items that met this criterion. As such, replacement items included "Looking after a pet," "Going to appointments (doctor, dentist, therapist, etc.)," and "Shopping for myself and others."

### *Evaluative Feedback on Scale Content.*

Based on responses from experts and residents, some minor wording changes were made to some of the items on the QOLP:PD. These modifications were done in order to make the items more relevant to the young continuing care population. Wording changes can be seen in Appendix C.

In addition, because nine of the twelve participants reported staff as being important to a younger resident's quality of life, one item ("Being able to get quality nursing care") was added to the Community Belonging scale of the QOLP:PD, as it was judged to fit well with other items on the scale. As such, the revised short version of the QOLP:PD, now the QOLP:PD-CC, has a total of 55, rather than 54 items. None of the other suggestions for item additions generated by the experts and residents were endorsed by more than 25% of the sample, so no further changes were made. There were no requests from experts or residents that any item be deleted from the measure.

### *Discussion*

Generally, the items of the QOLP:PD's short version were considered to be relevant to the quality of life of younger continuing care residents, with most items approaching a "very relevant" rating. However, half of the items from the Practical Becoming scale were rated as less relevant. Items included on this scale focus on practical, purposeful activities. Young adults with physical disabilities often seek residency in continuing care centres because they are unable to continue to work and perform many daily care activities (e.g., cleaning and cooking for oneself). That experts and younger residents rated these areas of life as less relevant to this population seems reasonable.



Evaluative feedback from participants indicated that the measure assessed important areas of life for younger residents. Although some residents rated some items as “not at all relevant,” none of the participants recommended that any of these items be deleted from the measure when asked during the open-ended section of the interview. The only area of life that more than 25% of the sample identified as being omitted in the measure was the relevancy of continuing care staff to the quality of life of younger residents. As the QOLP:PD was intended for community-dwelling adults with physical disabilities, it is not surprising that this item was not included in the original version.

An interesting finding from this content validation study was that expert ratings of the relevancy of the items of the QOLP:PD for young continuing care residents were significantly higher than those ratings provided by younger residents. None of the items of the QOLP:PD were rated by the group of experts as being less than “somewhat relevant” to quality of life, while younger residents as a group indicated that some of the items were “not very relevant.” Younger residents were more likely to use their own individual situations to rate the items. This tendency to base in-group judgments on the self has been reported in the literature (Cadinu & Rothbart, 1996). Experts, however, appeared to rate the items based on how relevant they saw them to young continuing care residents as a group. In taking this different perspective when rating the items, experts may have been more hesitant to discount the relevancy of an area of life for younger residents as a group. For example, one family member of a younger resident indicated when rating the relevancy of spirituality and religion that this area was not at all important to her son, but rated the item as “somewhat relevant” because she knew that it was important for some other residents that she knew.

Although relatively few changes to items were deemed necessary, some differences between community and institutional life were identified. Examining the content validity of the QOLP:PD and creating the QOLP:PD-CC for use with adults with physical disabilities that reside in continuing care is an important initial step in facilitating a greater understanding of the QOL of this population.

Results from this content validation study indicate that the nine domains included in the BBB model are relevant to younger residents' QOL. However, the results do not provide information about whether some of the domains are more important than others in their contribution to the QOL of this population. As such, Study 2 utilized the QOLP:PD-CC to examine this question. Overall QOL was assessed and those areas of life that most contributed to QOL were examined. To investigate whether the needs of younger and older adults that live in a continuing care setting differ, younger and older residents were compared on overall QOL and the nine contributing factors. In addition, the study examined whether there were differences and/or similarities between younger residents and staff perspectives on what is important for QOL, and obtained recommendations from staff and residents on what could be done to improve the QOL in a continuing care setting.

## Study 2: Quality of Life of Young Continuing Care Residents

### *Methods*

#### *Participants*

##### *Continuing care residents.*

Forty-three residents were recruited from the young adult units of the continuing care facility. These residents have a variety of disorders including multiple sclerosis, brain injury, Huntington's Disease, spinal cord injury, and Cerebral Palsy.

Continuing care residents were excluded from the study for the following reasons: (1) over the age of 65, (2) moderate to severe cognitive impairment, as indicated by a score of less than 20 on the Folstein Mini-Mental Status Examination (Folstein MMSE; Folstein, Folstein, & McHugh, 1975; cut off recommended by Smith et al., 1998), (3) too physically ill to participate in the study, (4) lived in a continuing care facility less than six months, and (5) completely unable to communicate with the researcher.

All residents at the continuing care site spoke English. Residents that could communicate but required aides to do so were not excluded from the study. In order to promote understanding between the researcher and these residents, communication devices (e.g., talking computer, letter boards to spell responses) and changes to the existing protocol (e.g., use of cards with responses listed so that residents could point to their responses) were employed.

Table 1 presents data on recruitment and reasons for residents' non-participation. As indicated, of the 147 residents currently residing on the 3 units, 19 were over 65 years of age while another 19 had resided in continuing care for less than 6 months. Of the remaining 109, 27 (24.8%) had legal guardians. Ten of these guardians refused to

Table 1

*Resident Recruitment and Reasons for Non-Participation*

	<u>n</u>	<u>%</u>
Total number of residents:	147	100
Reasons for exclusion:		
Over age 65	19	12.9
Stay in continuing care < 6 months	19	12.9
MMSE < 20	10	6.8
Unable to communicate	23	15.6
Failed to provide consent/assent	13	8.8
Legal guardian refused	10	6.8
Legal guardian did not respond	10	6.8
Total sample	43	29.3

Note. Some percentages may not total to 100% due to rounding errors.

provide consent, while another ten failed to respond to the request for consent. The most common reason for non-consent among residents was lack of interest, while guardians were mostly concerned about residents' communicative abilities and/or the validity of their responses.

*Continuing care staff.*

The three units in the continuing care facility have 156 full-time and part-time staff members. All continuing care staff that interacted with the young adult population were targeted to participate in the study. This included a variety of occupations, including administrative staff, registered nurses, dietary staff, physical therapists, social workers, licensed practical nurses, nurses aides, and recreational therapists. By including employees with varied job descriptions, a wide range of employee perspectives on what is important for residents' QOL were obtained. Continuing care staff were excluded from the study if they had worked with younger residents in a continuing care facility less than six months.

Table 2 presents data on recruitment and reasons for staff non-participation. The sample consisted of sixty-five continuing care staff, which was 41.6% of the total staff on the young adult units. At least 25% of the total staff in each occupational group was interviewed during the data collection period from May 3, 2003 to June 18, 2003, with 56% of the Registered Nurses, 75% of the therapists (social workers, recreation therapists, physical therapists), 33% of the LPN/Nursing Aides, 50% of the dietary staff, and 82% of the administrative staff participating in the interview. The most common reason for non-consent among staff was lack of time.

Table 2

*Resident Recruitment and Reasons for Non-Participation*

	<u>n</u>
Total number of staff contacted	99
Reason for exclusion:	
Worked in continuing care < 6 months	4
Failed to provide consent	12
Requested contact later (no opportunity for follow-up)	13
Staff did not respond	3
Did not complete interview	2
Total sample	65

## *Procedure*

### *Continuing care residents.*

The Program Facilitator at the continuing care site provided the researcher with names of all residents who did not have a legal guardian and were aged 65 or younger. Continuing care staff then approached these residents about whether they would be interested in speaking with a researcher from the University of Calgary conducting a study on QOL. Residents that agreed were given a full description of the study by the researcher, including the purpose and goals of the study, as well as the amount of time it would take to complete the interview and informed consent was obtained.

If residents had a legal guardian, the Program Facilitator made initial contact with guardians and requested permission for the researcher to contact them. The researcher phoned those guardians that agreed to be contacted. If the resident's guardian gave informed consent, the researcher then approached the resident to obtain his or her assent to participate in the study.

All of the measures outlined below were administered individually to the resident. To accommodate for vision loss, motor problems, and to monitor the participants' emotional reactions to the questions, the measures were administered verbally.

Residents were interviewed in a private location in the continuing care facility, for no longer than 45-60 minutes at a time. Although at times multiple sessions were required due to fatigue or resident commitments, total interview time did not exceed 120 minutes. After demographic and open-ended questions were administered, the Folstein MMSE was administered to assess cognitive functioning. If a resident scored below 20 on this

measure, the resident was thanked for his/her participation and the interview was concluded.

*Continuing care staff.*

Staff in the continuing care facility were sampled with efforts to ensure each occupation in the facility was represented in proportionate numbers. On days when staff were targeted to be interviewed, the Program Leader of the continuing care site notified staff about the presence of the researcher on the unit and provided a description of the study. The researcher approached staff members about participating in the study and attended staff meetings to recruit participants. The purpose and goals of the study were further explained, and informed consent was obtained from interested staff. When providing a description of the study and obtaining informed consent, the researcher emphasized that non-participation had no bearing on the employee's record or job performance rating, and that all individual responses would be confidential. This was done to encourage staff participation and openness when responding.

The staff participants were interviewed individually or asked to fill out the protocol in a group format (depending on their preference) in a private area at the facility (10-15 minutes). If, due to time restrictions, staff members were unable to complete the interview in person, they were allowed to complete the rating scale component of the protocol during the remainder of their shift and return it to a locked area on the unit. Where the protocol was completed was recorded by the researcher.



### *Measures for Continuing Care Residents*

#### *Demographic information.*

Questions used to obtain demographic information are included in Appendix D. The following demographic and health information was collected from the continuing care residents: (1) gender, (2) age, (3) ethnicity, (4) marital status, (5) education, (6) current or previous occupation, (7) duration of residence in the continuing care facility, and (8) type of medical conditions. With separate consent, the resident's medical chart was reviewed to confirm information on date of birth, date of relocation to the continuing care site, and medical conditions.

#### *Leisure activities and social support.*

Questions used to obtain information on resident involvement in leisure activities and the amount of social support they receive are included in Appendix E. The following information was collected from younger residents: (1) activities/hobbies currently involved with, (2) frequency of participation in leisure activities, (3) how often they leave the facility and where, (4) who visits them, and how frequent these visits are, and (5) whether they have a confidant.

#### *Cognitive status.*

Due to the presence of cognitive difficulties in many of the residents, secondary to their disability, the Folstein Mini Mental Status Examination (MMSE; Folstein, & McHugh, 1975), a screening device for cognitive impairment, was administered. The MMSE is a 30-item measure that assesses orientation, registration, attention and calculation, recall, and language skills (see Appendix F). It has been found to be a valid and reliable instrument (Kaasalainen et al., 1998) and has been used when investigating

the QOL of non-elderly people with chronic medical conditions (Ormel et al., 1998; Smith et al., 1998). Smith et al. (1998) used a cut-off score of 20 to signify cognitive impairment in their study of quality of life in community-dwelling adults with traumatic brain injury. In the present study, data from those residents scoring under 20 was not included. If, because of physical disability, a resident could not complete a task (e.g. unable to write, unable to copy a design) his/her scores were prorated (converted into a score out of 30). Prorating was necessary for 27 out of the 43 residents who scored above 20 on the MMSE.

This study used both open-ended questions and self-report measures to assess contributing factors to QOL.

*Contributing factors to QOL as assessed by open-ended questions.*

At the beginning of the interview, residents were asked the following open-ended questions. First, residents were asked to identify *what things contribute most to your overall quality of life* (e.g., health, leisure, friends). In answering this question, residents were encouraged to generate three responses. Using 5-point scales, residents were asked to provide importance ratings (1 = not very important, 5 = extremely important) and satisfaction ratings (1 = not at all satisfied, 5 = extremely satisfied) for each response they generated, and were then asked to rate on a 5-point scale how much control they felt they have over each of the areas they indicated as being important to quality of life (1 = no control, 5 = a lot of control). Lastly, residents were asked “*What things could be done in the continuing care facility to improve your overall quality of life?*” For a more detailed presentation of these open-ended questions, refer to Appendix G.

*Contributing factors to QOL as assessed by self-report measures.*

The Quality of Life Profile: Version for Persons with Sensory and Physical Disabilities in Continuing Care (QOLP:PD-CC). The Quality of Life Profile: Version for Persons with Sensory and Physical Disabilities in Continuing Care (QOLP:PD-CC; see Appendix H) is a measure of QOL based on the BBB model of quality of life (Renwick, Rudman, Raphael, & Brown, 1996). This measure was derived from the QOLP:PD (see Study 1 for psychometric characteristics of this measure) and its content validity for use with young continuing care residents was examined in Study 1.

The QOLP:PD-CC consists of 55 items. One of the subscales consists of seven items, while the remaining eight subscales consist of six items each. Like the QOLP:PD, each item on the QOLP:PD-CC is scored according to its level of importance to the participant (1 = not important at all, 5 = extremely important), and the level of satisfaction (1 = not at all satisfied, 5 = extremely satisfied). Thus the measure provides information about both perceived importance and satisfaction with each component.

By applying a formula (see Appendix I), importance and satisfaction are combined to produce a basic score. These basic scores can be summed to reflect individual subscale scores and the total quality of life score, all of which can range from -10 (not at all satisfied with extremely important issues) to +10 (extremely satisfied with extremely important issues). Each subscale of the QOLP:PD-CC represents one of the nine subcomponents of QOL proposed by the BBB model (see Figure 1), and each served as a measure in this study.

Quality of Life Profile: Seniors Version. Many items in the QOLP:PD-CC are identical to the items from the *Quality of Life Profile: Seniors Version –Short Version (QOLP-SV)*, an instrument that was used in Stelmach and Konnert’s study of QOL of older continuing care residents. Despite similarities, twenty-six items found only on the QOLP:SV were added to the younger resident protocol. In adding these items, younger and older residents’ scores on the complete QOLP:SV could be compared. Appendix H presents both the QOLP:PD-CC and the QOLP:SV measures.

The additional measures outlined below were included because past research with community-dwelling adults with physical disabilities has identified them as important contributors to QOL. In addition, they were included to ensure that the constructs (i.e., perceived physical health, functional health, pain) were fully and adequately measured beyond what was assessed by the related QOLP:PD-CC subscales. To facilitate comparisons between data sets, the measures chosen for this study were the same as those used in Stelmach and Konnert’s study of QOL in older continuing care residents. Due to the fact that this study is the first of its kind, the following measures have not been used with young (aged 65 and younger) continuing care residents. However, they do have good psychometric properties when used with older continuing care residents .

Perceived Health Status. In addition to the questions in the Physical Being subscale of the QOLP:PD-CC, a single item self-report measure from the Multidimensional Functional Assessment Scale (OARS) was used to as a measure of perceived physical health (Center for the Study of Aging and Human Development, 1978; see Appendix J). Participants were asked to rate their current physical health using a four-point scale (1 = excellent, 4 = poor). Single item measures of perceived health are

commonly used in the disability literature (Coyle et al., 2000; Fuhrer et al, 1992; Richards et al., 1999; Steadman-Pare et al., 2001). For example, this item was used to assess self-assessed health status in Rintala et al.'s (1992) sample of 140 community-dwelling adults with spinal cord injury.

*Activities of Daily Living Scale.* In addition to the questions in the physical being subscale of the QOLP:PD-CC, functional health was measured with the Activities of Daily Living Scale (ADL, Morris et al., 1990; see Appendix J). The ADL asks residents how much assistance they require to complete everyday activities. This measure consists of six items that are scored on a 5-point Likert scale [(0 = no help required (independent or no assistance), 4 = total help/can't do at all (total dependence/assistance)]. The internal consistency in an older continuing care sample was found to be .80 (Dalzell & Konnert, 2000).

*Numerical Pain Rating Scale-11.* Pain has been found to be a significant predictor of QOL, especially in the MS population (Coyle et al., 2000; Gulick, 1997). To ensure that the younger resident's level of pain was taken into account, the *Numerical Pain Rating Scale-11* (NRS-11) was used (see Appendix J). The NRS-11 is highly correlated with the commonly used Visual Analogue Scale (VAS), and has approximately equal sensitivity (Stratford, & Spadoni, 2001). It also has fewer response errors than the VAS and good face validity. Breivik, Bjornsson and Skoulund (2000) found that patients and physicians prefer the NRS-11 to the VAS for ease in assessment and scoring. It also requires no motor response from the respondent, which is advantageous when being used with people with chronic physical disabilities.

*Quality of life outcome measures.* The following two measures were used to assess quality of life (see Appendix K): (1) the Life Satisfaction Index-A and (2) the Satisfaction With Life Scale.

The Life Satisfaction Index-A (LSI-A). The Life Satisfaction Index-A (LSI-A) was used as a measure of QOL (LSI-A, Adams, 1969). The LSI-A is composed of three factors. The first is Mood Tone, which represents happiness or a positive affect. The second dimension is Zest, which implies an optimistic and positive outlook of life at present and in the future. The last factor is Congruence, which is a cognitive assessment of the extent to which a person's life is in general satisfying or the degree to which one has attained one's desired goals (Liang, 1984). The LSI-A was originally a 20-item measure developed by Neugarten, Havighurst, and Tobin (1961), but due to problems with two of its items, an 18-item version is most commonly used. Participants respond to the 18 items using the response, "agree (1 point)," "disagree (0 point)," or "don't know (0 point)." The scores on the LSI-A can range from 0-18, with lower scores representing lower QOL. Although originally designed for older adults, it has been used recently with individuals with spinal cord injury and traumatic brain injury (Burleigh, Farber, & Gillard;1998 Fuhrer et al., 1992; Schulz & Decker, 1985; Warren & Wrigley, 1996; Webb, Wrigley, Yoels, & Fine, 1995). The internal consistency of the measure with community-dwelling adults with spinal cord injuries is .76 (Schultz & Decker, 1985) and .82 with community-dwelling adults with brain injuries (Smith, Magill-Evans, & Brintenell, 1998).

Satisfaction With Life Scale. The Satisfaction With Life Scale (SWLS) is a global measure of QOL, which depends on a comparison of life circumstances to one's standards (SWLS, Diener, Emmons, Larsen, & Griffin, 1985). The SWLS has repeatedly shown to

measure a single dimension that focuses on cognitive rather than affective subjective well-being (Pavot & Diener, 1993). This measure consists of 5 items that are scored on a 7-point Likert scale (1 = strongly disagree to 7 = strongly agree). Total scores on the SWLS can range from 5 to 35, with 20 representing a neutral point at which the respondent is equally satisfied and dissatisfied (Corrigan et al., 2001). The scale's internal reliability (coefficient alpha) is typically between .80 and .89 (Pavot & Diener, 1993). It is commonly used to assess QOL in people with spinal cord injury (Dijkers, 1999; Richards et al., 1999), with test-retest reliability in this population at .65 for the total scale. It has also been used in a population of patients with a number of different chronic illnesses (Riley et al., 1998).

#### *Measures for Continuing Care Staff*

##### *Demographic information.*

The following demographic data were collected from continuing care staff: (1) gender, (2) age, (3) ethnicity, (4) educational background, (5) position in continuing care facility where he/she is currently employed, (6) duration of employment in continuing care, (7) duration of employment on the younger resident unit.

##### *Open-ended questions.*

Staff were asked the following open-ended questions:

First, staff were asked to identify *what things contribute most to the overall quality of life of younger residents* (e.g., health, leisure, friends). Like residents, staff were encouraged to generate three responses when answering this question. Using a 5-point scale, staff then provided importance ratings for each response they generated (1 = not very important, 5 = extremely important) and rated on a 5-point scale how much control they felt residents had

over the important areas of life they had indicated (1 = no control, 5 = a lot of control). Lastly, staff were asked *what things could be done in the continuing care facility to improve a younger resident's overall quality of life*.

*Quality of Life Profile: Version for Persons with Physical and Sensory Disabilities in Continuing Care (QOLP:PD-CC).*

Continuing care staff rated the importance of the 55 items on the QOLP:PD-CC to the quality of life of younger residents, using the 5 point likert-scale specified in the measure (1 = not important at all, 5 = extremely important; see Appendix H for measure).

## *Results*

### *Sample Characteristics*

#### *Sample characteristics of younger residents.*

Table 3 presents demographic information on the younger resident sample. The mean age of the sample was 53.7 years (SD = 7.46), and ranged from 25 to 64 years old. The average length of time that the participants had resided in the continuing care facility was 5.62 years (SD = 5.65), with a range of 6 months to 25.5 years. Most participants were Caucasian (97.6%), and were diagnosed with Multiple Sclerosis (50%). Those residents with Huntington's disease, Cerebral Palsy, and non-specific neurodegenerative disorders were classified in the 'other' category of medical conditions. Although the majority of residents (81.4%) had worked before relocating to the continuing care center, none were currently employed. Only 7% of the sample currently volunteered, with all volunteer activities located in the continuing care facility (e.g., delivering mail to units, working for the facility's gift shop). Physical limitations related to their primary medical condition/disease was the primary reason for employment termination (74.4%).



Table 3

*Demographic Information for Younger Residents (N = 43)*

Demographic	<u>N</u>	<u>%</u>
Gender		
Male	22	52.2
Female	21	48.8
Ethnicity		
Caucasian (White)	42	97.6
Arab/West Asian	1	2.3
Age		
20-29 years	1	2.3
30-39 years	1	2.3
40-49 years	8	18.6
50-59 years	22	51.2
60-64 years	11	25.6
Marital Status		
Single	13	30.2
Married	14	32.6
Widowed	1	2.3
Divorced	11	25.6
Separated	4	9.3
Education		
5-8 years	2	4.7
High school incomplete	10	23.3
High school completed	11	25.6
Business or trade school	6	14
1-3 years of college completed	11	25.6
4 years of college completed	1	2.3
Post-graduate college	2	4.7
Disability		
Multiple Sclerosis	22	51.2
Traumatic Brain Injury	5	11.6
Spinal Cord Injury	2	4.7
Stroke	5	11.6
Dementia	1	2.3
Other	8	18.6
Currently employed		
Yes	0	0
No	43	100
Currently volunteering		
Yes	3	7
No	40	93

Note. Some percentages may not total to 100% due to rounding errors.

*Sample characteristics of older residents.*

Demographic information on the older resident sample is included in Table 4. Data on the QOL of older continuing care residents was obtained from a study conducted by Liza Stelmach and Candace Konnert at the University of Calgary. Their sample consisted of 38 older residents from the same continuing care site. The mean age of the older residents was 79.92 years old ( $SD = 8.08$ ), and ranged from 66 to 97 years old. The majority of the older residents were female (65.8%), Caucasian (100%), widowed (57.9%), and had completed high school (65.9%).

*Sample characteristics of staff.*

Demographic information on the staff participants is included in Table 5. The mean age of the continuing care staff sample at the time of the interview was 42.2 years old ( $SD = 11.58$ ), and ranged from 17 to 63 years old. The majority of the staff was female (95.4%) and Caucasian (69.2%). Most had completed between 1 to 4 years of college/university (53.9%). The average length of time that staff had worked in a continuing care setting was 10.46 years ( $SD = 7.75$ ), with a range of 6 months to 40 years. The average length of time that staff had worked with younger residents at the continuing care site where the study was conducted was 5.90 years ( $SD = 5.35$ ), with a range of 6 months to 25 years.

*Description of Younger Residents*

The first goal of the study was to obtain information on the characteristics of younger residents, their leisure involvement, and their perceptions of social support. Due to the fact that none of the sample was employed and very few volunteered, the ways in which younger residents occupied their time was of interest. Table 6 presents information

Table 4

*Demographic Information for Older Resident (N=38)*

Demographic	<u>N</u>	<u>%</u>
Gender		
Male	13	34.2
Female	25	65.8
Ethnicity		
Caucasian (White)	38	100
Marital Status		
Single	5	13.2
Married	8	21.1
Widowed	22	57.9
Divorced	3	7.9
Separated	0	0
Education		
5-8 years	5	13.2
High school incomplete	7	18.4
High school completed	8	21.1
Business or trade school	8	21.1
1-3 years of college completed	6	15.8
4 years of college completed	3	7.9
Post-graduate college	0	0

Note. Some percentages may not total to 100% due to rounding errors.

Table 5

*Demographic Information for Continuing Care Staff (N=65)*

Demographic	<u>N</u>	<u>%</u>
Gender		
Male	3	4.6
Female	62	95.4
Ethnicity		
Caucasian	45	69.2
Asian	7	10.8
East Indian	3	4.6
Black	3	4.6
Other	7	10.8
Age		
15-25 years	8	7.4
26-35 years	10	9.3
36-45 years	15	13.9
46-55 years	23	21.3
56-65 years	5	4.6
Education		
High school incomplete	2	3.1
High school completed	15	23.1
Post high school, business or trade school	9	13.8
1-3 years of college completed	20	30.8
4 years of college completed	15	23.1
Post-graduate college	3 (1 missing)	4.6
Job Position		
Administration	9	13.8
Dietary	4	6.2
LPN/Nursing Assistant	37	56.9
Therapist	6	9.2
Registered Nurse	9	13.8

Note. Some percentages may not sum to zero due to rounding errors.

Table 6

*Leisure and Social Support Information for Younger Residents (N= 43)*

		<u>N of</u> response	<u>% of</u> residents
Top 4 activities residents are involved in:	Trivia	15	34.9
	TV	11	25.6
	Physiotherapy	10	23.3
	Woodworking	8	18.6
How often resident is involved in activities:	Everyday	14	32.5
	5-6 times a week	2	4.7
	3-4 times a week	12	27.9
	1-2 times a week	6	14
	< once a month	9	20.9
How often resident leaves the CCF:	Everyday	2	4.7
	3-4 times a week	4	9.3
	1-2 times a week	13	30.2
	Once every 1-2 weeks	5	11.6
	Once a month	3	7.0
	< once a month	16	37.2
Top 4 Places where residents go:	Visit family members	21	48.8
	Shopping	8	18.6
	Out touring	3	7
	Lunch	3	7
Type of visitor:	Children	18	41.8
	Other family members	17	39.5
	Friend	14	32.6
	Spouse	13	30.2
	Parents	11	25.6
	Staff	2	4.7
Frequency of visitors:	Everyday	5	11.6
	5-6 times a week	2	4.7
	3-4 times a week	8	18.6
	1-2 times a week	17	39.5
	Once every 1-2 weeks	2	4.7
	Once a month	6	14
	< once a month	3	7

*Leisure and Social Support Information for Younger Residents (N= 43) cont'd*

		<u>N</u> of response	<u>%</u> of residents
Presence of a confidant:	Yes	28	65.1
	No	15	34.9
Confidant's relational role to resident:	Son	4	14.3
	Daughter	1	3.6
	Father	2	7.1
	Mother	1	3.6
	Spouse	6	21.4
	Sibling/Friend	14	50
Residence of confidant:	Inside the CCF	6	21.4
	Outside the CCF	22	78.6

Note. CCF = continuing care facility.

Some percentages may not sum to zero due the multiple response nature of some of the questions.

on the leisure activities (see Table 1 in Appendix L for all responses) and types of community involvement (see Table 2 in Appendix L for all responses) that were most frequently mentioned by residents. A total of 35 different leisure activities were identified. Most residents (60.5%) reported being involved with 2 or 3 activities ( $M = 2.39$ ,  $SD = 1.38$ ), with two residents reporting that they did not participate in any activities and one resident listing eight activities that he was involved in. In terms of community involvement, participants generated a total of 16 different places that they visited in the community, with most respondents (46.5%) listing one place ( $M = 1.2$ ,  $SD = .48$ ). A large number of residents (42.2%) reported that they left the facility once a month or less, and many (48.8%) visited family on these outings.

In addition to leisure and community involvement, the social support that younger residents received was also important to examine. Results on social support are presented in Table 6. All residents reported having at least one type of visitor (e.g., spouse, parents, siblings, friends). Children were most frequently mentioned as visitors and continuing care staff was the least frequent type of visitor. The majority of residents (65.1%) indicated that they had a confidant, with 50% of these participants indicating that friends and siblings served in this role.

#### *Quality of Life of Younger Residents*

The second goal of the study was to investigate the QOL of younger residents using both open-ended questions and quantitative measures.

*Open-ended questions.*

Using an open-ended format at the beginning of the protocol, residents were asked to identify three things that most contributed to their QOL, and rate these responses in terms of importance, their satisfaction with each of these factors, and how much control they felt they had over these areas. Table 7 presents the results of this open-ended question.

Participants had little difficulty answering this question, with most (59.5%) generating three responses ( $M = 2.5$ ,  $SD = .76$ ). Responses were coded into 19 different categories by the researcher and inter-rater reliability checks were performed, with 98% of the responses coded congruently. The two raters discussed responses that were coded differently until agreement was reached.

As some of the categories were mentioned by only a small number of residents, only the four most frequently mentioned categories are considered when discussing importance, satisfaction, and control ratings in the following section. These four categories include family, leisure activity, friends, and nursing care.

Out of the above four categories, family had the highest importance rating ( $M = 4.81$ ,  $SD = .40$ ), followed by leisure ( $M = 4.13$ ,  $SD = .62$ ), friends ( $M = 4.13$ ,  $SD = .92$ ), and nursing care ( $M = 3.90$ ,  $SD = .57$ ). In terms of satisfaction, leisure activities had the highest satisfaction rating ( $M = 4.00$ ,  $SD = .82$ ), followed by family ( $M = 3.95$ ,  $SD = .97$ ), friends ( $M = 3.67$ ,  $SD = 1.05$ ), and nursing care ( $M = 3.10$ ,  $SD = 1.29$ ). Examining control ratings, the highest rating of control was for leisure activities ( $M = 3.75$ ,  $SD = .93$ ) followed by family ( $M = 2.67$ ,  $SD = 1.35$ ), staff ( $M = 2.50$ ,  $SD = 1.43$ ), and friends ( $M = 2.27$ ,  $SD = 1.28$ ).



Table 7

*Younger Resident Responses to the Question "What three things contribute most to your overall quality of life?" (n = 42)*

Response	N of responses (n = 105)	% of responses	N who endorsed response (n = 42)	% who endorsed response	Importance rating		Satisfaction rating		Control rating	
					Mean	SD	Mean	SD	Mean	SD
<b>Family</b>	<b>22</b>	<b>21.0</b>	<b>21</b>	<b>50.0</b>	<b>4.81</b>	<b>.40</b>	<b>3.95</b>	<b>.97</b>	<b>2.67</b>	<b>1.35</b>
<b>Leisure Activity</b>	<b>17</b>	<b>16.2</b>	<b>14</b>	<b>33.3</b>	<b>4.13</b>	<b>.62</b>	<b>4.00</b>	<b>.82</b>	<b>3.75</b>	<b>.93</b>
<b>Friends</b>	<b>15</b>	<b>14.3</b>	<b>14</b>	<b>33.3</b>	<b>4.13</b>	<b>.92</b>	<b>3.67</b>	<b>1.05</b>	<b>2.27</b>	<b>1.28</b>
<b>Nursing Care</b>	<b>10</b>	<b>9.5</b>	<b>9</b>	<b>21.4</b>	<b>3.90</b>	<b>.57</b>	<b>3.10</b>	<b>1.29</b>	<b>2.50</b>	<b>1.43</b>
Psychological Attitude	6	5.7	5	11.9	4.17	.75	4.17	.75	3.67	.52
Work/Volunteerism	5	4.8	5	11.9	4.25	.50	2.50	1.73	2.25	1.50
Interaction with others	4	3.8	4	9.5	3.75	.50	3.5	.58	2.75	1.26
Physical Health	4	3.8	4	9.5	4.25	.96	3.25	1.71	2.75	2.06
Diet	4	3.8	4	9.5	4.00	.00	4.00	.82	3.00	2.31
Finances*	3	2.9	3	7.1	4.33	.58	3.00	1.41	2.67	1.53
Mobility/Physical Functioning*	3	2.9	3	7.1	3.67	.58	2.33	1.53	2.00	1.00
Education*	3	2.9	3	7.1	3.67	.58	3.33	2.08	3.00	1.73
Smoking*	2	1.9	2	4.8	4.00	1.41	3.00	.00	2.50	.71
Physical Residence	2	1.9	2	4.8	3.50	.71	3.00	2.83	1.50	.71
Exercise	1	1.0	1	2.4	-	-	-	-	-	-
Religion/Spirituality	1	1.0	1	2.4	-	-	-	-	-	-
Pets*	1	1.0	1	2.4	-	-	-	-	-	-
Independence making decisions	1	1.0	1	2.4	-	-	-	-	-	-
Personal Safety	1	1.0	1	2.4	-	-	-	-	-	-
All responses	-	-	-	-	-	-	-	-	2.76	1.23

Note. Percentages in the fourth column will not total 100% due to multiple answers generated by each resident.

\* indicates contributing factors that were identified by residents but not identified by staff

Although the logical next step would be to determine if any significant differences between these importance ratings exist, the multiple response nature of the question violated the assumption of independence among responses. As such, further statistical analyses were precluded.

In addition to calculating mean importance, satisfaction and control ratings for each contributing factor, total mean control ratings for each participant's top three responses were calculated to examine control's relationship with QOL. Overall control ratings for the contributing factors ranged from 1.00 to 5.00 (where 1 = no control and 5 = a lot of control) with a mean rating of 2.83 (SD = 1.17). Total mean control was significantly correlated with the LSI-A ( $r = .397, p \leq .05$ ) and the SWLS ( $r = .397, p = \leq .05$ ).

#### *Quantitative measures.*

In addition to using open-ended questions, self-report instruments were also administered to identify areas of life considered most important to younger residents' judgements of how good life is. These instruments have been found to measure factors that are important to the quality of life of older residents and community-dwelling adults with chronic physical disabilities.

*Descriptive statistics.* As little research has been done with young continuing care residents, the psychometric properties of the instruments with this population were unclear. Internal consistencies were calculated with Chronbach's Alpha and these alpha coefficients were evaluated using Cicchetti's (1994) guidelines. According to these guidelines, alpha coefficients less than .70 are unacceptable, coefficients between .70 and .79 are fair, coefficients between .80 and .89 are good, and coefficients equal to or

greater than .90 are excellent. In Table 8 the internal consistencies of all measures are presented, with alpha coefficients ranging from .64 for Practical Becoming to .95 for the QOLP:PD-CC.

Descriptive information for all of the measures is presented in Tables 9 and 10. All of the instruments demonstrated good ranges, suggesting that these measures are appropriate for young continuing care residents. Higher scores on the SWLS, LSI-A, and the QOLP: PD-CC indicate higher levels of life satisfaction. Scores on the SWLS, LSI-A, and QOLP: PD-CC were normally distributed. Average scores for all measures fell around the mid-point of the scales.

Lower scores on the Perceived Health Scale represent fewer symptoms or difficulties. On this measure, the majority of residents considered themselves to be in fair (25.6%) or good (44.2%) health, whereas only 11.6% of the residents rated their health as excellent and 18.6% rated their health as poor. On the NRS-11 rating scale of pain, where 0 represents no pain and 10 represents the worst pain imaginable, most residents (60.5%) rated their current pain at 3 or less. Participants' verbal reports indicated that most of the pain they experienced was related to the sores and stiffness associated with being immobile. On the ADL measure, higher scores indicate less functional ability. There was a broad range of perceived functional ability, with some residents indicating that they needed no support performing activities of daily living (11.6%), while some residents needed total help (14%). The average functional ability ( $M = 13.35$ ,  $SD = 7.95$ ) was slightly above the mid-point of the scale.

The range of scores on the MMSE was restricted (20.50 – 30), since the participants had to score 20 or greater on this screen for cognitive impairment in order to

Table 8

*Internal Consistency of All Measures (N = 43)*

Measure	Chronbach's Alpha for young adults with disabilities in continuing care	Cicchetti's (1994) Guidelines
Outcome Measures		
SWLS	.88	good
LSI-A	.82	good
Physical Health		
ADL	.89	good
QOLP:PD-CC:	.95	excellent
Being	.86	good
Physical being	.74	fair
Psychological being	.87	good
Spiritual being	.77	fair
Belonging	.87	good
Physical belonging	.82	good
Social belonging	.78	fair
Community belonging	.71	fair
Becoming	.91	excellent
Practical becoming	.64	unacceptable
Leisure becoming	.76	fair
Growth becoming	.80	good

Note. SWLS = Satisfaction With Life Scale; LSI-A = Life Satisfaction Scale – A;  
 ADL = Activity of Daily Living; QOLP:PD-CC = Quality of Life Profile: Version for  
 Persons with Physical and Sensory Disabilities.

Table 9

*Means, Standard Deviations, and Ranges of Contributing Factor Measures (N = 43)*

Measure	Mean	Standard deviation	Possible range	Range within sample
Quality of Life				
SWLS (N = 43)	17.51	8.82	5 - 35	5 - 30
LSI-A (N = 43)	8.19	4.24	0 - 18	1 - 16
QOLP:PD-CC (n = 42)	1.07	2.08	-10 - +10	-3.42 - +5.79
Physical Health (N = 43)				
PHS	2.51	.94	1 - 4	1 - 4
ADL	13.35	7.95	0-24	0 - 24
NRS-11	3.08	3.16	0-10	0-10
Cognitive Status (N = 43)				
MMSE	26.52	2.78	0-30	20.50 - 30

Note. SWLS = Satisfaction With Life Scale; LSI-A = Life Satisfaction Scale – A; QOLP:PD-CC = Quality of Life Profile: Version for Persons with Physical and Sensory Disabilities in Continuing Care; PHS = Perceived Health Scale; ADL = Activity of Daily Living; NRS-11 = Numerical Pain Rating Scale – 11; MMSE = Mini Mental Status Exam.

Table 10

*Means, Standard Deviations, and Ranges of Importance, Satisfaction, and Basic Scores of the QOLP:PD-CC (n = 42)*

Measure	Mean	Standard deviation	Possible range	Range within sample
Importance Ratings for QOLP:PD-CC subscales				
Physical being importance score	3.91	.68	1 - 5	1.67 – 5.00
Psychological being importance score	4.04	.63	1 - 5	2.00 – 5.00
Spiritual being importance score	3.98	.61	1 - 5	2.17 – 5.00
Physical belonging importance score	4.03	.60	1 - 5	2.17 – 5.00
Social belonging importance score	3.60	.68	1 - 5	1.83 – 5.00
Community belonging importance score	3.31	.68	1 - 5	1.83 – 4.83
Practical becoming importance score	3.03	.63	1 - 5	1.57 – 4.43
Leisure becoming importance score	3.35	.65	1 - 5	2.00 – 4.67
Growth becoming importance score	3.75	.61	1 - 5	2.00 – 4.67
Satisfaction Ratings for QOLP:PD-CC subscales				
Physical being satisfaction score	3.06	.79	1 - 5	1.17 – 4.83
Psychological being satisfaction score	3.27	.87	1 - 5	1.33 – 4.83
Spiritual being satisfaction score	3.39	.72	1 - 5	1.83 – 4.50
Physical belonging satisfaction score	3.45	.72	1 - 5	1.00 – 5.00
Social belonging satisfaction score	3.17	.74	1 - 5	1.84 – 4.67
Community belonging satisfaction score	3.17	.62	1 - 5	1.50 – 4.17
Practical becoming satisfaction score	3.24	.62	1 - 5	1.71 - 4.14
Leisure becoming satisfaction score	3.16	.66	1 - 5	1.50 - 4.50
Growth becoming satisfaction score	3.36	.66	1 - 5	2.00 - 4.50

*Means, Standard Deviations, and Ranges of Importance, Satisfaction, and Basic Scores of the QOLP:PD-CC continued*

Measure	Mean	Standard deviation	Possible range	Range within sample
Basic Scores for QOLP:PD-CC subscales				
Physical being basic score	.55	2.85	-10 - +10	-5.50 - + 7.50
Psychological being basic score	1.33	3.52	-10 - +10	-5.33 - + 9.17
Spiritual being basic score	1.74	2.92	-10 - +10	-4.00 - + 6.83
Physical belonging basic score	1.83	2.91	-10 - +10	-8.33 - + 8.00
Social belonging basic score	.95	2.85	-10 - +10	-3.33 - + 8.33
Community belonging basic score	.50	2.32	-10 - +10	-7.17 - + 3.83
Practical becoming basic score	.62	2.03	-10 - +10	-3.86 - + 4.00
Leisure becoming basic score	.63	2.41	-10 - +10	-6.50 - + 6.00
Growth becoming basic score	1.49	2.51	-10 - +10	-4.17 - + 6.17

Note. Basic Scores were computed by applying a formula (See Appendix I) that takes the importance an individual places on an area of life into account with their satisfaction with that same area. Basic scores were used for correlational analysis.

participate in the study. A score of 27 indicates mild cognitive impairment. Approximately half of the participants' MMSE scores were above 27 (52.2%).

The nine subscales of the QOLP: PD-CC, representing the nine areas of life proposed by the BBB model to contribute to QOL, were rated on both importance and satisfaction. By applying a formula (see Appendix I) that takes the importance an individual places on an area of life into account with their satisfaction with that same area, importance and satisfaction ratings were then combined to produce a basic score. Mean importance ratings, satisfaction ratings, and basic scores for each of nine subscales are presented in Table 10.

Mean importance ratings for all subscales of the QOLP: PD-CC were in the “somewhat” to “very important” range (3 – 4.99). To determine if any of the subscales were rated as significantly more or less important, a repeated measures ANOVA was first performed. As there was high correlation between the subscales of the QOLP:PD-CC, the assumption of sphericity was violated. As such, the Greenhouse-Geisser statistic was used. Results indicated that significant differences in the mean importance ratings for the nine subscales existed ( $F(5.7, 235.1) = 29.861, p = .000$ ). To prevent running all possible post-hoc comparisons (i.e., 32), the graphical presentation of means was examined as a way to generate logical comparisons (see Figure 1 in Appendix M). To determine if any significant differences between the four scales with the highest importance ratings existed (i.e., Psychological Being, Spiritual Being, Physical Belonging, and Physical Being) a repeated measures ANOVA was used. The sphericity assumption was not violated in this test and no differences were found between the importance ratings for these measures ( $F(1, 41) = 1.439, p = .237$ ). Paired t-tests between the remaining five subscales were



performed with results presented in Table 11. These results indicated that Physical Being, Psychological Being, Spiritual Being, and Physical Belonging were all rated equally in importance, and were rated as more important than the remaining five subscales. The next most important scales were Social Belonging and Growth Becoming (no significant differences in importance between the two subscales), followed by Community Belonging and Leisure Becoming (no significant differences in importance between the two subscales), and Practical Becoming was rated significantly less important than all other scales.

The mean satisfaction ratings for the nine subscales all fell in the “somewhat satisfied” range (3.00 – 3.99). To determine if residents were significantly more or less satisfied with the areas these subscales measured, a repeated measures ANOVA was first performed. The assumption of sphericity was again violated and the Greenhouse-Geisser statistic was used. Results indicated that significant differences in the mean satisfaction ratings for the nine subscales existed ( $F(5.7, 234.9) = 2.687, p = .017$ ). To prevent running all possible post-hoc comparisons (i.e., 32), the graphical presentation of means was examined (see Figure 2 in Appendix M). As the range of mean satisfaction was small, with Physical Being ( $M = 3.03$ ) the lowest rated in satisfaction and Physical Belonging ( $M = 3.45$ ) the highest rated, these variables were removed and another repeated measures ANOVA was run with the remaining seven subcomponents. The Greenhouse-Geisser statistic indicated that there were no significant differences between these seven subscales ( $F(2.9, 161.3) = 1.627, p = .171$ ). As such, paired t-tests were conducted between Physical Belonging and Physical Being, between Physical Belonging and the second highest rated

Table 11

*Differences in Resident Importance Ratings of Subscales of QOLP:PD-CC (n = 42)*

QOLP:PD-CC contributing variables	<u>M</u>	<u>SD</u>	<u>df</u>	<u>t</u>
Physical Being Social Belonging	3.91 3.60	.68 .68	41	3.609***
Community Belonging Social Belonging	3.31 3.60	.68 .68	41	2.459**
Community Belonging Practical Becoming	3.31 3.03	.68 .64	41	2.933**
Community Belonging Growth Becoming	3.31 3.75	.68 .61	41	-4.363***
Community Belonging Leisure Becoming	3.31 3.35	.68 .65	41	-.338
Social Belonging Growth Becoming	3.60 3.75	.68 .61	41	-1.771
Physical Being Growth Becoming	3.91 3.75	.68 .61	41	2.035*

\*  $p \leq .05$

\*\*  $p \leq .01$

\*\*\*  $p \leq .001$

scale, and between Physical Being and the next lowest rated subscale. Results are presented on Table 12 and indicate that the only difference in satisfaction ratings was between Physical Belonging and Physical Being ( $t(41) = -2.973, p = .005$ ) with residents being significantly less satisfied with their health (Physical Being) than their physical surroundings (Physical Belonging).

Basic scores on the QOLP: PD-CC Basic scores could range from  $-10$  to  $+10$ , with  $0$  indicating neither satisfaction nor dissatisfaction with that area of life. Mean basic scores on the 9 subscales of the QOLP: PD-CC were all positive (see Table 10), indicating that, as a group residents, were at least somewhat satisfied with the important facets of their lives.

*Relationships between contributing factors and QOL.* After coding marital status into three groups (never been married, married, no longer married), two one-way ANOVAs were computed with each QOL outcome measure as the dependent variable. Results indicated that participants' life satisfaction on the LSI-A ( $F(2, 40) = 2.747, p = .076$ ) and on the SWLS ( $F(2, 40) = 2.01, p = .148$ ) did not differ with marital status. To determine the relationships between QOL (LSI-A and SWLS) and the remaining hypothesized contributing factors (measures of activity participation, social support, demographic variables, pain, physical health, functional health, cognitive status, and the nine subscales of the QOLP: PD-CC), zero order correlations were calculated. Table 13 shows that perceived health status and pain were correlated significantly with the LSI-A but not with the SWLS. Lower scores on the measure of visitor frequency indicated more frequent visitors, and lower scores on the confidant measure indicated the presence of a

Table 12

*Differences in Resident Satisfaction Ratings of Subscales of QOLP:PD-CC (n = 42)*

QOLP:PD-CC contributing variables	<u>M</u>	<u>SD</u>	<u>df</u>	<u>t</u>
Physical Belonging	3.45	.72	41	-2.972**
Psychological Being	3.06	.79		
Physical Being	3.06	.79	41	-.790
Leisure Becoming	3.16	.66		
Physical Belonging	3.45	.72	41	-.577
Spiritual Being	3.39	.72		

\*\*  $p \leq .01$

Table 13

*Zero-Order Correlations Between Demographic Variables, Physical Health, Cognitive Status, and Quality of Life (N = 43)*

	1	2	3	4	5	6	7	8	9
1. SWLS	1	.716**	.088	-.212	.108	-.292	-.050	.005	-.020
2. LSI-A	.716**	1	.156	-.122	-.064	-.403**	-.346*	-.199	-.124
3. Age	.088	.111	1	.072	.359*	.236	.124	-.112	-.107
4. Education	-.212	-.122	.072	1	-.081	.122	-.091	.078	.232
5. Length of stay in continuing care	.108	-.064	.359*	-.081	1	.182	-.018	.138	-.114
6. PHS	-.292	-.403**	.236	.122	.182	1	.276	.241	.161
7. NRS-11	-.050	-.346*	.124	-.091	-.018	.276	1	.016	.265
8. ADL	.005	-.199	-.112	.078	.138	.241	.016	1	.118
9. MMSE	-.020	-.124	-.107	.232	-.114	.161	.265	.118	1

Note. SWLS = Satisfaction With Life Scale; LSI-A = Life Satisfaction Index-A; PHS = Perceived Health Scale; NRS-11 = Numeric Pain Rating Scale – 11; ADL = Activities of Daily Living; MMSE = Mini Mental Status Exam

\*  $p \leq .05$

\*\*  $p \leq .01$

confidant. As presented in Table 14, both factors were significantly related to QOL as measured by the LSI-A, but not the SWLS. Table 15 shows that all basic scores for the nine subscales of the QOLP: PD-CC were significantly correlated with the LSI-A and SWLS.

#### *Comparisons Between the QOL of Younger and Older Residents*

The third goal of the study was to compare the QOL experienced by older and younger residents. Conducting independent t-tests between the QOL outcome measures compared the overall QOL of the groups. Results of this comparison are presented in Table 16 and show that the groups do not differ on their ratings of QOL. Younger and older residents were also compared on importance ratings (see Table 17), satisfaction ratings (see Table 18), and basic scores (see Table 19) for each of the nine subscales on the QOLP: SV. The only significant difference between the groups was on the mean importance rating for the Practical Becoming scale ( $t(77) = -3.25, p \leq .01$ ), indicating that younger residents did not rate items on the Practical Becoming scale as important to quality of life as older residents.

#### *Comparison Between Resident and Staff Perspectives on QOL*

The fourth goal of the study was to determine if staff and younger residents differ on their perspectives as to what is important to a younger resident's QOL. This was accomplished using open-ended questions and the QOLP: PD-CC.

##### *Important areas of life generated by open-ended questioning.*

Staff members were asked to identify three factors they believed to be important to a younger resident's QOL, and rate these responses in terms of importance and how much

Table 14

*Zero Order Correlations Between Measures of Leisure Activity, Social Support and Quality of Life (N = 43)*

	1	2	3	4	5	6
1. SWLS	1	.716**	.001	.113	-.138	-.205
2. LSI-A	.716**	1	-.203	-.020	-.366*	-.347*
3. Frequency of involvement in activities	.001	-.203	1	.204	.300	.365*
4. Frequency of involvement in community	.113	-.020	.204	1	.346*	-.059
5. Frequency of visitors	-.138	-.366*	.300	.346*	1	.282
6. Presence of confidant	-.205	-.347*	.365*	-.059	.282	1

Note. SWLS = Satisfaction With Life Scale; LSI-A = Life Satisfaction Index-A

\*  $p \leq .05$

\*\*  $p \leq .01$

Table 15

*Zero Order Correlations Between Subcomponents of the QOLP:PD-CC and Quality of Life (n = 42)*

	1	2	3	4	5	6	7	8	9	10	11
1. SWLS	1	-	-	-	-	-	-	-	-	-	-
2. LSI-A	.716**	1	-	-	-	-	-	-	-	-	-
3. Physical Being	.426**	.603**	1	-	-	-	-	-	-	-	-
4. Psychological Being	.500**	.500**	.657**	1	-	-	-	-	-	-	-
5. Spiritual Being	.501**	.505**	.672**	.808**	1	-	-	-	-	-	-
6. Physical Belonging	.463**	.595**	.400**	.532**	.518**	1	-	-	-	-	-
7. Social Belonging	.552**	.574**	.541**	.669**	.777**	.478**	1	-	-	-	-
8. Community Belonging	.562**	.574**	.497**	.438**	.488**	.353*	.579**	1	-	-	-
9. Practical Becoming	.360*	.489**	.441**	.442**	.367*	.350*	.390**	.424**	1	-	-
10. Leisure Becoming	.597**	.623**	.512**	.522**	.541**	.379*	.591**	.822**	.507**	1	-
11. Growth Becoming	.358*	.466**	.582**	.763**	.545**	.445**	.540**	.439**	.561**	.570**	1

Note. QOLP:PD-CC = Quality of Life Profile: Persons with Physical and Sensory Disabilities; SWLS = Satisfaction With Life Scale; LSI-A = Life Satisfaction Index-A;.

\*  $p \leq .05$  \*\*  $p \leq .01$



Table 16

*Group Differences for Scores on Quality of Life Between Younger and Older Residents*

Measures	<u>Younger Residents</u> (n = 42)		<u>Older Residents</u> (N = 38)		<u>df</u>	<u>t</u>
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>		
SWLS	17.51	8.82	20.89	6.77	79	-1.95
LSI-A	8.19	4.24	9.52	4.02	79	1.250
QOLP:SV	1.15	2.12	1.30	1.88	72	-.32

Note. SWLS = Satisfaction With Life Scale; LSI-A = Life Satisfaction Index – A;  
QOLP:SV = Quality of Life Profile: Seniors Version.

Table 17

*Group Differences Between Younger and Older Residents on QOLP:SV Importance Ratings*

QOLP:SV contributing variables	<u>Younger Residents (n = 42)</u>		<u>Older Residents (N = 38)</u>		<u>df</u>	<u>t</u>
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>		
Physical Being	4.04	.63	4.04	.34	64	-.002
Psychological Being	4.15	.57	3.94	.46	76	1.78
Spiritual Being	3.95	.65	3.80	.51	76	1.16
Physical Belonging	4.15	.51	4.01	.32	71	1.40
Social Belonging	3.71	.55	3.85	.60	78	-1.065
Community Belonging	3.97	.50	3.87	.46	75	.846
Practical Becoming	3.32	.71	3.77	.48	77	-3.25*
Leisure Becoming	3.53	.54	3.63	.67	78	-.047
Growth Becoming	3.81	.64	3.81	.44	78	.16

\*  $p \leq .01$

Table 18

*Group Differences Between Younger and Older Residents on QOLP:SV Satisfaction Ratings*

QOLP:SV contributing variables	<u>Young Residents (n = 42)</u>		<u>Old Residents (N = 38)</u>		<u>df</u>	<u>t</u>
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>		
Physical Being	3.07	.71	2.94	.54	78	.875
Psychological Being	3.34	.78	3.47	.63	76	-.801
Spiritual Being	3.32	.75	3.32	.63	74	-.010
Physical Belonging	3.45	.62	3.32	.74	78	.868
Social Belonging	3.29	.65	3.46	.58	78	-1.264
Community Belonging	3.13	.63	3.32	.58	77	-1.388
Practical Becoming	3.25	.67	3.24	.60	77	-.444
Leisure Becoming	3.25	.66	3.29	.49	77	.107
Growth Becoming	3.31	.68	3.28	.49	78	.089

Table 19

*Group Differences Between Younger and Older Residents on QOLP:SV Basic Scores*

Variables	<u>Young Residents</u> (n = 42)		<u>Old Residents</u> (N = 38)		<u>df</u>	<u>t</u>
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>		
QOLP:SV						
Physical Being	.47	.28	-.31	2.07	77	1.40
Psychological Being	1.56	3.30	1.79	2.71	76	-.324
Spiritual Being	1.44	3.01	1.39	2.32	74	.080
Physical Belonging	1.97	2.53	1.46	2.91	77	.831
Social Belonging	1.25	2.56	1.89	2.15	78	-1.20
Community Belonging	.48	2.64	1.20	2.38	77	-1.27
Practical Becoming	.92	2.40	1.23	2.59	77	-.550
Leisure Becoming	1.02	2.52	.89	2.45	77	.243
Growth Becoming	1.23	2.864	1.21	2.09	78	.034

control residents have over these areas. Results from this open-ended question are presented in Table 20. In total, 194 responses to this question were generated, with most staff (90.8%) listing three contributing factors ( $M = 2.91$ ,  $SD = .29$ ). Responses given by the continuing care staff were coded into 24 different categories by the researcher, with 16 of the categories corresponding with resident responses and 8 categories mentioned only by staff. Inter-rater reliability checks were performed, with 93.7% of responses coded congruently. The raters discussed responses that were coded differently until agreement was reached. As some of the categories were mentioned by only a small number of staff, ratings of importance, satisfaction, and control for only the four most frequently named were considered. These categories include leisure activity, independence/control over decision-making, interaction with other people, and nursing care.

Table 21 indicates that both residents and staff listed leisure, nursing care, and friendships/interaction with others as important to a resident's QOL. The difference between the groups was that residents frequently mentioned family, while staff reported independence in decision-making more frequently. In this open-ended question, only one resident reported independence in decision-making as an important contributing factor to their QOL.

Staff's importance ratings were highest for nursing care ( $M = 4.74$ ,  $SD = .45$ ), followed by independence ( $M = 4.57$ ,  $SD = .51$ ), interaction with others ( $M = 4.38$ ,  $SD = .67$ ), and leisure ( $M = 4.18$ ,  $SD = .63$ ; see Table 20). Ratings of control over important areas of life can also be seen in Table 20. Residents were rated by staff as having a little to some control (ratings 2.00 to 3.00) over all of these areas. Out of the four most frequently

Table 20

*Staff Responses to the Question "What three things contribute most to a younger resident's overall quality of life?" (N = 65)*

Response	N of responses (n = 194)	% of responses	N who endorsed response	% who endorsed response	Importance rating		Control rating	
					Mean	SD	Mean	SD
<b>Leisure activity</b>	<b>34</b>	<b>18</b>	<b>34</b>	<b>52.3</b>	<b>4.18</b>	<b>.63</b>	<b>2.68</b>	<b>1.34</b>
<b>Independence</b>	<b>23</b>	<b>12.2</b>	<b>23</b>	<b>35.4</b>	<b>4.57</b>	<b>.51</b>	<b>3.09</b>	<b>.90</b>
<b>Interaction with others</b>	<b>21</b>	<b>11.1</b>	<b>19</b>	<b>30.8</b>	<b>4.38</b>	<b>.67</b>	<b>2.86</b>	<b>1.32</b>
<b>Nursing care</b>	<b>19</b>	<b>10.1</b>	<b>19</b>	<b>29.2</b>	<b>4.74</b>	<b>.45</b>	<b>2.53</b>	<b>1.07</b>
Family	17	9.0	17	26.2	4.76	.44	2.71	1.40
Community involvement*	13	6.9	13	20	3.85	.80	2.69	1.25
Diet	9	4.8	9	13.8	4.22	.83	1.78	.44
Psychological attitude	6	3.2	6	9.2	3.67	.82	3.00	1.27
Being treated with respect*	6	3.2	6	9.2	4.83	.41	2.83	1.17
Physical residence	5	2.6	5	7.7	4.60	.55	2.40	1.14
Privacy*	5	2.6	5	7.7	3.60	.55	2.20	1.10
Personal hygiene*	5	2.6	5	7.7	4.00	1.00	4.00	1.00
Physical health	4	2.1	4	6.2	4.00	1.16	1.50	.58
Friendships	3	1.6	3	4.6	4.67	.58	3.00	1.00
Self-esteem*	3	1.6	3	4.6	4.33	1.16	2.67	2.08
Work/Volunteerism	3	1.6	3	4.6	3.33	1.16	3.00	1.00
Communication with others	3	1.6	3	4.6	4.67	.58	3.67	.58
Exercise	2	1.1	2	3.1	4.50	.71	4.00	.00
Personal Safety	2	1.1	2	3.1	5.00	.000	4.00	.00
Helping/caring for others*	2	1.1	2	3.1	5.00	.000	3.00	.00
Spirituality	1	.5	1	1.5	-	-	-	-
Shopping*	1	.5	1	1.5	-	-	-	-
Maintaining a routine*	1	.5	1	1.5	-	-	-	-
Having a romantic partner*	1	.5	1	1.5	-	-	-	-

\* indicates those areas of life that were identified by staff as important to a younger resident's QOL but not identified by residents as being important.

Table 21

*Younger Resident and Staff Responses to Open-ended Questions Regarding QOL*

	Most frequent responses to what contributes to a younger resident's QOL	Mean importance ratings for contributing factors		Control ratings for contributing factors	
		<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Younger Residents (n = 42)	Family	4.81	.40	2.67	1.28
	Leisure Activity	4.13	.62	1.35	2.50
	Friends	4.13	.92	3.75	1.43
	Nursing Care	3.90	.57	.93	3.67
Staff (N = 65)	Nursing Care	4.74	.45	.90	2.71
	Independence	4.57	.51	1.34	2.53
	Interaction w/ others	4.38	.67	3.09	1.07
	Leisure Activity	4.18	.63	2.68	1.32

mentioned contributing factors, staff rated resident control for independence/control over decision making highest ( $M = 3.00$ ,  $SD = .90$ ), followed by their control over their interaction with others ( $M = 2.86$ ,  $SD = 1.31$ ), leisure ( $M = 2.68$ ,  $SD = 1.34$ ), and nursing care ( $M = 2.53$ ,  $SD = 1.07$ ). The multiple response nature of this question precluded further statistical analyses to determine significant differences in mean importance and control ratings between the factors.

*Ratings of importance for the nine domains of the QOLP:PD-CC.*

Another way of assessing what factors staff view as being important to a younger residents quality of life was to have staff rate the importance of the nine subscales of the QOLP: PD-CC. Mean importance ratings for all nine subscales were in the “somewhat” to “very important” range (3 – 4.99) and are presented in Table 22. To determine which if any subscales were rated as significantly more or less important, a repeated measures ANOVA was performed with all nine subscales entered. As inter-correlation between the subscales existed, the assumption of sphericity was violated and the Greenhouse-Geisser statistic will be reported. Significant differences between importance ratings were found ( $F(6.3, 397.9) = 53.81$ ,  $p = .000$ ) and so post-hoc tests were conducted. To prevent running all possible post-hoc comparisons (i.e., 32), the graphical presentation of means was examined (see Figure 3 in Appendix M) to guide which comparisons would be made. Results from the paired comparisons are reported in Table 23. Results indicated that Physical Belonging was rated as significantly more important than the remaining eight subscales. Physical Being, Psychological Being, Spiritual Being, and Social Belonging were rated next most important, with a repeated measures ANOVA showing no significant differences between these four subscales ( $F(3, 189) = 1.629$ ,  $p = .184$ ). Leisure Becoming



Table 22

*Group Differences for Importance Ratings of QOLP:PD-CC Contributors to Quality of Life Between Young Continuing Care Residents and Continuing Care Staff*

QOLP:PD contributing variables	<u>Staff (N = 65)</u>		<u>Young Residents (n = 42)</u>		<u>df</u>	<u>t</u>
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>		
Physical being	4.12	.48	3.91	.68	105	-1.795
Psychological being	4.21	.50	4.04	.63	105	-1.469
Spiritual being	4.08	.58	3.98	.61	104	-.814
Physical belonging	4.37	.46	4.03	.60	104	- 3.272**
Social belonging	4.18	.50	3.60	.68	104	- 5.067**
Community belonging	4.00	.46	3.44	.65	104	-
Practical becoming	3.23	.63	3.03	.63	104	5.242**
Leisure becoming	4.00	.57	3.35	.65	104	-1.550
Growth becoming	3.85	.56	3.75	.61	104	- 5.489**
						-.891

\*\*  $p \leq .001$

Table 23

*Differences in Staff Importance Ratings of Subscales of QOLP:PD-CC (N = 65)*

QOLP:PD-CC contributing variables	<u>M</u>	<u>SD</u>	<u>df</u>	<u>t</u>
Physical Belonging	4.37	.46	63	3.564**
Social Belonging	4.18	.50		
Community Belonging	3.89	.50	63	2.630*
Spiritual Being	4.08	.58		
Community Belonging	3.89	.50	63	10.888**
Practical Becoming	3.23	.63		
Leisure Becoming	4.00	.57	63	2.591*
Growth Becoming	3.85	.56		

\*  $p \leq .01$

\*\*  $p \leq .001$

was rated third in importance, followed by Community Belonging and Growth Becoming (no significant differences in importance between these two subscales). Practical Becoming was rated as significantly less important in comparison to all of the other scales.

To determine if importance ratings given to each of the nine subscales of the QOLP:PD-CC differed between staff and residents, independent t-tests were conducted. Results of this comparison are shown in Table 22. Four of the nine subscales on the instrument were rated significantly more important to QOL by staff than by younger residents. These scales include Physical Belonging ( $t(104) = 3.27, p \geq .001$ ), Social Belonging ( $t(104) = 5.07, p \geq .001$ ), Community Belonging ( $t(104) = 5.10, p \geq .001$ ), as well as the Leisure Becoming scale ( $t(104) = 5.49, p \geq .001$ ). There were no differences between staff and residents in the amount of importance they assigned to the remaining subscales.

#### *Recommendations for Changes to the Continuing Care Facility*

The last goal of the study was to determine what changes could be made in the continuing care facility to improve QOL for younger residents. Residents were able to generate 23 different recommendations, which can be seen in Appendix L's Table 3. The four most frequently mentioned recommendations in descending order of frequency include: (1) staff should be more compassionate in the care that they provide (endorsed by 21.4% of residents), (2) residents should have more independence in decisions that impact their lives (19% of residents) (3) the continuing care facility should offer more opportunities for day trips into the community (16.7% of residents), and (4) more social activities targeted toward younger residents should be offered at the continuing care facility (14.3% of residents).

Staff participants were also asked to recommend changes to the continuing care center that might help improve the QOL of younger residents. Staff were able generate 31 different recommendations, which are presented in Appendix L's Table 4. The four most frequent recommendations from staff in descending order of frequency include: (1) more nursing staff should be hired to work shifts (endorsed by 36.9% of staff), (2) more social activities targeted toward younger residents should be offered at the continuing care facility (35.4% of staff), (3) more companionship should be provided for residents by means of volunteers (30.8% of staff), and (4) more day trips into the community should be made available (24.6% of staff).

### *Discussion*

#### *Description of Younger Residents*

The first goal of the study was to provide a description of younger continuing care residents, including information about their work and leisure activities and their social support. Previous studies have focused primarily on older continuing care residents and we currently know very little about the characteristics of younger residents and their day-to-day lives. Due to the dearth of extant literature on this population, it is difficult to make comparisons between the results of this study and those of similar studies. Despite this limitation, this study provides an initial first step in achieving a greater awareness and understanding of younger residents. This information is clearly needed, in light of the projected increase of younger adults with physical disabilities that will need to live in continuing care facilities in the coming years (Family Economic Review, 1993).

Although it was thought that some younger residents would continue to work in the community, none of the participants were currently employed and only a small

minority volunteered. Many expressed to the researcher that, although they would like to help out in the facility or engage in some form of meaningful work, they did not believe it was possible due to their physical limitations and a lack of opportunity to do so.

Given the lack of involvement with employment and volunteer pursuits, residents occupied their time primarily with leisure activities. As many had limited contact with the larger community (37.2% left the facility less than once a month), leisure involvement centred mostly on activities offered at the continuing care site. Although the facility did offer a number of activity programs, the recreation department had suffered significant financial cuts three months prior to data collection. During the time that the interviews took place, the most popular activities identified by residents involved creating something (e.g., woodworking) and maintaining and improving their body and mind (e.g., physiotherapy, trivia program). However, it should be noted that due to reduced recreational funding, some programs that had been popular in the past (e.g., ceramics, cooking classes) were no longer offered. Scheduled outings into the community were most missed. Many residents reported that since this program had been removed approximately three to four months prior, they had not left the continuing care facility.

Due to the reduction in funding, only one recreational therapist and one volunteer coordinator remained to provide activities for approximately 300 younger and older residents at the facility. In addition, there was an observable shortage of available volunteers to act as porters for the activity programs that remained. The lack of available personnel to help transport residents to activities posed a problem for residents with mobility challenges. Perhaps as a result, watching television was the only activity that

some residents (14%) engaged in. As the trivia program had volunteers to porter residents, this might have contributed to its popularity.

In addition to leisure activities, the social support of younger residents was also examined. While maintaining social ties is pivotal for well-being and good QOL, institutionalization has been found to disrupt social relationships in older residents (Bitzan & Kruzich, 1990). Although family members of older residents tend to maintain similar patterns of contact (York & Calsyn, 1977), ties with neighbours and friends may be broken after relocation (Bitzan & Kruzich, 1990). Consistent with the literature on older residents (Bitzan & Kruzich, 1990), the visitors of this sample of younger residents were primarily family. Many participants reported regular visits from friends when they first relocated to the facility, but as their length of stay in the facility increased, contact with their friends had diminished. This report is congruent with studies showing a negative relationship between length of residence and frequency of visits (Hook, Sobal, & Oak, 1982; Port et al., 2001).

The majority of younger residents reported having weekly visitors, with only 11.6% reporting visitors everyday. In comparison to the number of older residents who had daily visitors (25%) in Brinker's (1999) study, it appears that younger residents have less frequent contact with family and friends. They also seem less likely to have confidant relationships. Comparing the percentage of younger residents that had a confidant (65.1%) with the percentage of residents with a confidant (86%) in Dyck's (1994) older resident sample, younger residents appear to have fewer people with whom they can self-disclose and experience intimacy and reciprocity with (Cantor, 1979; Powers & Bultena, 1976; Strain & Chappell, 1982). Due to the vast research showing that having a confidant

positively impacts such things as depression (e.g., Murphy, 1982), loneliness (e.g., Simons, 1983-84), and life satisfaction (e.g., Chappell & Badger, 1989), it is troubling that one third of the younger residents did not consider themselves to have someone to confide in.

Of those younger residents who did have someone to confide in, half identified a friend or a sibling. This is contrary to Wenger and Jerrome's (1999) finding that people generally choose someone that is closer in genealogical terms as a confidant. They reported that spouses were most likely to be named as confidants, followed by children, then siblings and friends. However, as the majority of younger residents had never married or were no longer married, this may account for this discrepant finding.

In summary, leisure and social support are important aspects of a younger resident's daily life. Leisure and social support may be related, in that family members and friends can facilitate a resident's access to leisure. Results in Table 14 indicate that residents with confidants are more frequently involved in activities, and residents with more frequent visitors get out into the community more. In addition, leisure and social support may be related in that family members and friends can act as advocates in helping residents access the leisure resources that they need.

### *Quality of Life of Younger Residents*

#### *The use of the BBB model to assess QOL in younger residents.*

The second goal of this study was to provide information about QOL in this population. There are numerous different definitions of QOL and an equally large number of instruments for its measurement. A major problem with many previous attempts to study QOL is that more attention is given to providing operational definitions of the

construct, rather than providing a conceptual basis for the measures used (Raphael et al., 1994). Without a theory, important domains can be missed. One of the advantages of the BBB model is that it provides one of the few conceptual frameworks of QOL. The model is influenced by the humanistic-existential tradition that recognizes that individuals have physical, psychological, and spiritual dimensions. It also recognizes that individuals need to belong, in both a physical and social sense, and to distinguish themselves as individuals by pursuing their own goals (Renwick & Friefeld, 1996). As such, a theoretical rationale exists for the inclusion of each of the subcomponents in the model.

Based on the content analyses in Study 1, it appears that the subcomponents of the BBB model are all relevant to the QOL of younger residents, and that the model excluded no important factors. Further support for the model's application with younger residents can be found in the significant relationship each subscale of the QOLP: PD-CC had with both outcome measures of QOL (e.g., LSI-A, SWLS). Moreover, internal consistency estimates were high, both for the overall QOLP: PD-CC and its sub-components, indicating homogeneity of items.

Although all of the subcomponents of the BBB model were related with QOL, they were also highly related to each other. Significant correlations between the subscales of the QOLP:PD-CC were expected (see Table 15), as all of the factors are supposed to influence QOL. However, some of the subcomponents were correlated to such a high degree (i.e., Psychological Being and Spiritual Being) that it is unclear whether some of the subscales are actually measuring separate constructs. Problems in adequately defining the different constructs might be at issue.



Another concern is that inconsistent responses about what is most important to QOL were found between the open-ended questions and the QOLP:PD-CC. Although there are many reasons why this might have occurred, a possibility is that some of the important factors identified through open-ended questioning (i.e., family, friends, nursing care) were not adequately assessed in the QOLP: PD-CC. For example, although nursing care was often identified as important in the open-ended format, using the QOLP:PD-CC nursing care was measured by only one item subsumed within a larger scale assessing other services offered in the community.

Also of interest was the researcher's observation that some residents tended to rate the items of the QOLP:PD-CC as unimportant because they were not available. So, when responding to the QOLP:PD-CC, a small subset of respondents replied that family were not important, but, on further questioning, replied that they had no family and were dissatisfied about this. Thus there was a tendency to minimize the importance of those factors that were unavailable, a strategy that may be used to cope with a difficult life circumstance. Using a combined score that reflects, in part, judgements of importance may be misleading for those engaging in this coping strategy.

It appears that more research on the psychometric properties, construct validity, and factor structure of the QOLP: PD-CC is needed before judgments can be made about the appropriateness of this tool for use with younger residents with physical disabilities. At the very least, investigation into other appropriate models of QOL for this population should continue. One model that does appear promising is Lindstrom's QOL model (1992). In this holistic model the four spheres that are examined include: (1) Personal sphere (e.g., physical, mental, spiritual resources), (2) Interpersonal sphere (e.g., family

structure and function, intimate friends, extended social networks), (3) External sphere (e.g., work, income, and housing), and (4) Global sphere (e.g., societal macro environment, specific cultural aspects, human rights and social welfare policies). The last sphere in Lindstrom's model has not been included in other models of quality of life, but is likely relevant when assessing the QOL of younger continuing care residents. Adults with physical disabilities are often impacted by social welfare policies. In addition, the way that adults with disabilities view themselves is likely influenced by cultural perspectives on disability. As such, it seems likely that this area of life is important to examine when assessing the QOL of younger residents.

*Overall quality of life.*

In facing a life of extended disability and institutionalization, characterized by less control over the environment and daily routines, it was thought that younger residents would experience a poorer QOL in comparison to community-dwelling adults that were not living with a disability. The present findings are consistent with this assumption. While there is no relevant comparison data using the SWLS as an outcome measure of QOL, the mean LSI-A score of 8.19 for this sample is notably lower than the mean of 13.2 obtained from adults in the general population (Harris & Associates, 1975).

To determine how the overall QOL of younger residents compares to the QOL of community-residing adults with disabilities, PsycINFO (1974-present) was searched using the keywords 'satisfaction with life scale,' 'life satisfaction index,' and 'quality of life profile.' From this search, studies that had used these instruments with SCI and TBI populations were located. No studies were found that had used these QOL measures with individuals with MS, as it appears that health-related or disease-specific quality of life

instruments are commonly used with this population. Due to the fact that only a small number of younger residents with SCI and TBI were included in the study, a detailed presentation of mean differences between the samples on QOL will not be presented. In general, it appears that younger residents have similar levels or somewhat lower levels of QOL than community-residing adults with TBI and SCI (Corrigan et al., 2001; Dijkers, 1999; Manns, 1999; Putze & Richard, 2001; Rintala et al., 1992; Smith et al., 1989). However, differences between the populations could be due to a number of factors other than residency, such as differences in health-related symptoms like pain or severity of physical disability.

What is most important to keep in mind is that there are wide individual differences in QOL and, in this sample, it was not related to functional health. Despite poor health and living in an institutional environment, many residents rated their QOL better than expected. It appears that some residents are able to adapt to circumstances many would consider undesirable, and continue to view themselves as living a good life. Literature has found that “resilient” individuals construe life events in ways that maintain and even promote happiness (Lyubornirsky, 2001). Wide individual differences in overall QOL may be related to social comparison, optimism, and the strategic use of coping strategies.

Comparisons with how one’s peers are doing can influence evaluations of QOL (Diener & Fujita, 1997; Wheeler & Miyake, 1992). By reflecting on the situations of others who are less fortunate, people can be comforted with the thought that things could be worse (Michalos, 1985). Although residents in the sample were experiencing poor health, compared to those who could not participate in the study, they were doing well.

With limited contact with friends outside the facility, it may be that residents were engaging in social comparison with lower functioning residents, thereby preserving their perceived QOL.

Optimism has also been found to be related to life satisfaction (Lyubornirsky, 2001) and is especially important in situations of long-term commitment or difficult to reverse circumstances (Schneider, 2001). Realistic optimism involves focusing on the favourable aspects of the situation, otherwise known as “making the best of it.” This “making the best of it” attitude was reported in an ethnographic study of older residents in continuing care (Kahn, 1999) and may be an attitude that is adopted by younger residents as well.

In addition, coping responses can influence overall QOL appraisals. According to Lazarus and Folkman (1984), when internal and external demands are taxing or exceeding resources, people employ a coping process. In Groomes and Leahy’s (2002) study of adults with a variety of different disabilities, they reported that avoidance was the most common coping strategy used and was associated with the lowest stress appraisals. Using this type of coping, participants in Groomes and Leahy’s study cognitively altered the perception of the stressor (e.g., breaking down overwhelming aspects into small, manageable components), employed cognitive restructuring (e.g., saying things like “there are people worse off than I”), and minimized or denied serious aspects of the disability to preserve psychological strength and maintain a positive outlook.

Finally, contextual factors must be taken into account when explaining why younger residents reported a higher QOL than would be expected. It is unlikely that after only meeting with the researcher, who is essentially a stranger, for a short period of time,

residents would feel completely comfortable in confiding the negative aspects of their lives. In addition, residents are a vulnerable group that are highly dependent on staff for care. Despite assurances of confidentiality, residents may have felt that by being completely candid, their care would be in jeopardy.

*Important factors to quality of life.*

Responses to what is most important to QOL differed depending on whether the question was asked in an open-ended format or in having the resident rate the importance of items on the QOLP: PD-CC. In the open-ended format, family, friends, leisure, and nursing care were most commonly reported as important to QOL. On the QOLP: PD-CC, however, the scales that measure these factors (e.g., Social Belonging, Community Belonging, Leisure Becoming) were not rated the highest in importance. Instead, residents rated their feelings and evaluations about themselves (Psychological Being), their beliefs and values (Spiritual Being), their physical health/mobility (Physical Being), and their physical surroundings (Physical Belonging) as more important than the other scales on the measure. These responses indicate that what is most important to QOL are the most basic aspects of who a person is, or “sense of self,” and the person’s environment. This is consistent with theories of person-environment interaction that state that a person’s well-being is a product of the interaction between perception of self and perception of the environment (Kahana, 1982; Lawton & Nahemow, 1973). Although it should be noted that the most important factors from the QOLP:PD-CC were mentioned during open-ended questioning (see Table 7), the frequency that these factors were endorsed was not high.

The reason for this discrepancy in ratings may be a methodological one. Different responses may be obtained depending on how one poses the question. Although there is an assumption that whatever comes to mind first must be the most salient to the individual, it may be instead that these answers are more “accessible” than others. For example, individuals may be more likely to spontaneously describe things like family and friends when asked an open-ended question. However, when probed, they may list more psychological and spiritual domains, as represented on the Psychological Being and Spiritual Being subscales. Results of this study indicate that while external factors like social support and leisure are still important, areas that are more intrinsically tied to the self are most important when provided with a range of options. The finding that the different methodologies yield different results is important for future research in this area.

The subscale of the QOLP:PD-CC that was rated as less important in comparison to the remaining scales was Practical Becoming. The lower importance assigned to items on this scale may be related to opportunities available in the continuing care facility. For example, some of the items ask about how important it is for residents to do volunteer work, do schoolwork or course work, and look after a pet. Although these may be important, the opportunity to pursue these avenues was not offered at the continuing care site. By lowering the importance assigned to this scale, residents may have been realistic about what they could and could not hope to achieve.

*Factors related to quality of life in younger residents.*

The following factors were significantly correlated with the LS I-A and the SWLS: (1) Physical Being, (2) Psychological Being, (3) Spiritual Being, (4) Physical Belonging, (5) Social Belonging, (6) Community Belonging, (7) Practical Becoming, (8) Leisure

Becoming, and (9) Growth Becoming. In addition, mean control ratings for open-ended responses, perceived physical health, pain, frequency of visitors, and the presence of a confidant were significantly correlated with the LSI-A. Of all the related factors, residents' perceptions of their physical health (Physical Being), physical environment (Physical Belonging), and leisure activities (Leisure Becoming) were most highly correlated with QOL ratings. As the relationship between QOL and the nine subscales of the QOLP: PD-CC were discussed previously and the factors most highly related to QOL are discussed in the following section, this section will focus on the relationships found between QOL and those measures not included on the QOLP: PD-CC.

*Functional abilities and quality of life.*

A common perception is that the more functionally dependent one is on others for daily care, the more quality of life must suffer. Based on this assumption, QOL is frequently assessed in the context of rehabilitation research by measuring functional status in one or more areas (Renwick & Friefeld, 1999). Results from this study do not support this assumption, as no relationship between self-reported functional health and QOL was found. Instead, it was residents' perceptions of their physical health and self-rated pain that were related to scores on the LSI-A measure of QOL. This finding is consistent with literature on adults with SCI, where perceived health is consistently related to QOL (Boschen; 1996; Fuhrer et al., 1992; Kinney & Coyle, 1992; Richards et al., 1999). It also is consistent with studies in the MS literature, where relationships between QOL and pain ratings, but not functional abilities have been found (Coyle et al., 2000; Gulick, 1997). Although it may seem reasonable to believe that an individual's perception of his/her health is directly related to his/her functional ability, results from this study indicated that

the two concepts are unrelated, as no significant relationship between perceived and functional health was found.

*Sense of control and quality of life.*

Literature confirms the prevailing assumption that residents of continuing care facilities often have limited control over their everyday activities (Cox, Kaeser, Montgomery, & Marion, 1991). In addition, many residents are dependent on others or mechanical devices in their daily lives and experience difficulties attending social and other events because of transportation difficulties and health (Frytak, 2000). As this issue of empowerment and personal control has also been a focus in the rehabilitation literature (Renwick & Friefeld, 1996) it seemed necessary to examine sense of control in this population of younger continuing care residents. By responding to an open-ended question that asked about sense of control over self-identified important areas of life, residents as a whole reported having 'a little to moderate' control (e.g., mean rating of 2.76 out of a scale of 1 (no control) to 5 (a lot of control)) over the important areas they listed. Residents that had higher perceptions of control also reported experiencing a better QOL. This finding is consistent with research with older residents that showed that having choice within an institution and feeling a sense of control contributed to higher morale (Pohl & Fuller, 1980; Ryden, 1984).

Although we could not determine, in a statistical sense, if there were significant differences between what residents felt they had control over, it appears that there were individual differences. Residents indicated that they had the highest amount of control over leisure. This is surprising considering the significant environmental change in the range of options available. However, residents still had the ability to decide whether or not



they would participate in these activities, and it is possible that this is what they were basing their ratings on. In comparison with leisure, residents reported that they had relatively less control over family and friends. In retrospect, the meaning of this is unclear, as control over family and friends may mean a variety of things (e.g., frequency of visitation, having errands done). As one participant put it, “do you really ever have control over another person?” Out of the four most frequently mentioned categories that were examined, residents indicated that they had the least amount of control over the nursing care they received. Many residents (18.6%) reported that by having more control over the nursing care that they received, their QOL would be improved. This is consistent with the literature that suggests that congruence between the level of control a person wants and what the environment is able to offer is important for satisfaction (Kahana, 1982; Langer, 1985).

*Social support and quality of life.* Social support, as defined by Cobb (1976), is information leading to: (1) the belief that one is loved, esteemed, and valued, (2) a feeling of being cared for, and (3) a sense of belonging to a reciprocal network. In this study two indices of social support were examined. The first, frequency of visitors, was a more objective measure of social support. The finding that frequency of visitation is positively related to QOL is consistent with Thompson and Heller’s (1990) reports that fewer visits and lower perceived social support in a sample of elderly continuing care residents was related to poorer mental and physical health outcomes.

The second, presence of a confidant, was a measure of emotional support. Results indicated that younger residents with a confidant reported significantly higher life satisfaction. This finding is congruent with research indicating that a confidant

relationship is related to higher life satisfaction in the general population (Chappel & Bedger, 1989). It is also similar to reports that older continuing care residents who had someone to talk to about themselves and their problems reported higher levels of life satisfaction than those that did not (e.g., Strain & Chappell, 1982).

In summary, perceived physical health, pain, control, having a confidant, and frequency of visitors were found to be significantly related to QOL. While control was related to both the LSI-A and SWLS, the remaining factors were related only to the LSI-A. This discrepancy is likely explained by the differences in the two outcome measures of QOL. While SWLS is a single-factor measure of QOL based on a cognitive assessment of satisfaction, the LSI-A is composed of three factors (e.g., cognitive assessments of satisfaction; happiness or a positive affect; an optimistic and positive outlook of life at present and in the future). Thus, because the two outcome measures varied in their factor structure, it is logical to assume that they may be differentially related to the variables examined in this study.

#### *Differences and Similarities in the QOL of Younger and Older Residents*

The third goal of this study was to examine whether differences exist between the QOL of younger and older residents. It was hypothesized that younger residents would experience a poorer QOL. It was assumed that relocation to a continuing care facility would be more normative for older versus younger adults, leading younger adults to feel out of sync with their age peers. In addition, older residents are in a stage of their lives where they have completed many life tasks like raising a family or establishing a career, whereas younger residents may not have been able to accomplish many of the goals that they set out to achieve. Results of this study, however, did not support this hypothesis. No

significant differences were found between younger and older residents' QOL using the LSI-A, SWLS, and total QOLP: SV as outcome measures.

The only difference found between the two populations was the importance placed on purposeful activities. Examples of these purposeful activities include cleaning and tidying the living space, caring for other adults, and helping people who live nearby. Younger residents rated the scale that measured this construct on the QOLP:PD-CC (Practical Becoming) significantly lower in importance. Differences in functional abilities may account for the differential rating between the two groups. Buchanan and colleagues (2002) found that residents with multiple sclerosis were significantly more dependent in self-rated functional health than older residents that did not have multiple sclerosis. As such, younger residents may have been less able to perform some of the practical tasks included in the scale. For example, as 63% of the sample was unable to hold a pencil in order to answer items on the MMSE, items on the Practical Becoming scale like "looking after a pet" and "doing course/schoolwork" may have seemed like impossible goals. According to Spranger and Schwartz's (1999) theory of response shift, significant life changes (e.g., declines in health) prompt behavioural, cognitive, and affective processes with the potential to create a shift in an individual's standards of what is important to achieving a good QOL. If younger residents are less physically able to perform these practical tasks, by assigning this area of their lives as less important they can adapt to their situations and maintain a stable evaluation of themselves and their lives.

Another possible reason for differences between the two groups on the value assigned to this scale relates to self identity. In a study of older women's identity perceptions, MacRae (1990) found that older women described themselves primarily in

terms of how they relate to others. These elderly women had been socialized to be other-oriented through their roles of mother and homemaker and their identity came from helping others. As many of the items on the Practical Becoming relate to “doing for others,” differences between the groups may instead be due to the primarily female sample of older residents rating these items as more important and, as such, an artifact of the sample composition.

#### *Differences and Similarities in Staff and Younger Resident Perspectives*

The fourth goal of this study was to determine whether there were differences and similarities between younger residents and staff perspectives on what is important for QOL. Open-ended questions and the QOLP: PD-CC were used to examine this question. Although previous studies have reported significant differences in the perspectives held by staff and older continuing care residents (Berlowitz, Du, Kazis, & Lewis, 1995), the answers that staff provided in the open-ended question were very similar to those of younger residents. Where the groups differed was that staff considered nursing care as most important to a younger resident’s QOL, whereas younger residents felt that family was most important. Although the holistic care approach that continuing care facilities ascribe to recognizes the importance of the emotional, social, and spiritual needs of the resident, in addition to needs for nursing and personal assistance (Hill & Honeyman, 1992), faced with staff shortages it is reasonable that staff would emphasize the importance of providing basic care needs over other areas. In addition, while holistic care approaches are espoused, often the medical model prevails in continuing care, resulting in an emphasis on physical/medial functioning. This is particularly true when resources are scarce, as financial cutbacks are most often targeted at psychosocial resources.

In addition to similar responses on the open-ended questions, ratings provided by staff and residents on the QOLP: PD-CC were also similar. Where differences occurred, it was staff not residents who assigned more importance to certain areas of life. Social desirability effects occur in many self-report inventories and this may account, in part, for these results. Staff obviously want to present themselves as caring and compassionate individuals and, in doing so, may have endorsed almost everything as important.

#### *Recommendations for Continuing Care Facilities*

The last goal of the study was to elicit from residents and staff the changes that could be made in the continuing care facility to improve younger residents' QOL. Recommendations provided by younger residents are similar to those made by older residents in previous QOL research (Logsdon, 2000). These commonly identified recommendations are for a friendly and compassionate direct care staff, the availability of enjoyable and meaningful activities, the ability to make decisions and choices, and to function as independently as possible (Logsdon, 2000).

Although most of the recommendations were comparable between the groups, the most frequently endorsed recommendation from staff was for more staff to be hired whereas the most frequent recommendation from residents was for staff to be more compassionate in providing care. These recommendations may be related. The aforementioned funding cutbacks at the continuing care facility had caused a reduction in staff, leading to an even more rigid care routine and, perhaps, lower morale among staff. These pressures may result in a situation whereby care becomes more task-oriented than person-oriented. This may be perceived by residents as a loss of compassion. While this is

speculative, staff shortages have clear implications for the quality of care that can be provided, and staff-resident interactions.

### *Implications for Clinical Practice*

Improved QOL is seen as a desirable outcome of service provision (Raphael, Renwick, Brown, & Rootman, 1996) and research on QOL can serve to guide resource allocations and interventions. On the basis of this study's results, it appears that physical health/mobility, leisure activities, and the physical environment are most highly correlated with life satisfaction and should be targeted in order to improve the QOL of younger continuing care residents. These three areas are quite inter-related. An individual's involvement in recreational activities is facilitated to a great extent by his/her level of mobility, which depends on the person's physical health and the accessibility of the environment in which he/she lives. Person-environment congruence models (Kahana, 1982; Moos & Lemke, 1994) emphasize the importance of "fit" between an individual's competencies and his/her environment. As such, environments need to be designed so that they sustain existing competencies, and provide adequate support where needed.

Ensuring that residents are able to maintain or improve their physical abilities is an important step to their achieving a good QOL. Offering rehabilitative programs, such as physiotherapy and occupational therapy, should be a priority in continuing care facilities. Not only will these programs influence physical health and functioning, but they will also provide a sense of empowerment, that is, the sense that residents are 'doing something' to improve their situation. With proper programs in place, supported by adequate levels of staff, it may be possible for some residents to improve their current situations so that potentially they can return to community living with support.

As half of the items on the Physical Being scale relate to a resident's mobility, providing the opportunity for residents to access their environment is an important goal. Ensuring physical accessibility in the facility (e.g., large rooms to accommodate wheel chairs, elevators, hand rails) and around the immediate neighbourhood (e.g., secure sidewalks, easy exit and entrance to buildings) are important determinants as to whether a resident is able to remain active. The availability of a reliable handi-bus service is also crucial, as this is the only means many residents have to access the community. However, identifying ways to facilitate getting around in the facility and the community are moot points if, due to physical limitations, the resident is unable to even leave his/her room. Many younger residents, despite being functionally dependent, are capable of accessing their environment with the use of electronic wheelchairs. However, this option is not available to some residents because of financial limitations. In efforts to improve QOL for this population, advocating for improved funding is a priority.

Modification to the physical structure of the environment may also lead to better perceptions of QOL in younger residents. Having enough living space and living in a home-like rather than hospital-like environment is important to younger residents, as it would be for most people. While having private rooms for residents may be an idealistic goal with respect to available resources, it appears to be important to QOL.

Setting policies that encourage independence are necessary to improving QOL of younger residents. It seems clear that residents who want to take more control of their daily care should be allowed to do so. Unfortunately, the practicality of this suggestion in a highly structured, resource-scarce environment seems questionable. Institutional environments generally run counter to the idea of autonomy, or the ability of an individual

to control decision-making and other activities. Stringent regulations and routines, as well as the physical and cognitive limitations of the resident can create obstacles for resident decision-making (Frytak, 2000).

Another area that should be attended to is the amount and type of leisure activities that are available (e.g., day trips, meaningful/productive activities). Like all people, residents need to maintain a meaningful existence and continue to interact with the world outside the continuing care facility. Leisure activities should not be offered only to younger residents with high levels of physical and cognitive ability, but also to younger residents with cognitive impairments, severe physical limitations, and communication loss.

Younger residents identified family as an important contributor to their QOL. As such, getting family more involved in the continuing care facility is a worthy goal, recognizing that families will vary significantly in the amount of involvement they desire. This might be accomplished by educating the family on their role in a younger resident's well-being, providing families with a schedule of activities offered in the continuing care facility, and implementing regular conference meetings to improve communication between staff and family members. In addition, some younger residents are unable to dial a telephone because of their physical disability. Providing these residents information on new technological advances (e.g., voice activated dialling systems) may foster more independence in the contact residents have with family and friends in the community.

It is recognized that the above recommendations are dependent on resources. As was evident in the study, the amount of funding that is available to continuing care settings is in decline. Some consequences of reduced funding are staff shortages and fewer



programs, both of which impact residents' QOL. In addition to the effects government funding has on continuing care facilities, provincial funding is the sole form of income for many adults with physical disabilities. This usually covers only the basic level of care (e.g., nursing care, medications, and food) leaving residents with little money to spend on additional things to improve their QOL (e.g., electric wheelchair, leisure activities in the facility and the community). Societal attitudes and government policies must change if the amount of resources available to continuing care facilities and to younger residents is to improve. While it is necessary that residents themselves advocate for change, it is also important for their families and friends, health care professionals, and society in general to adopt this advocate role.

#### *Limitations of the Research*

The present study has several limitations. The first limitation is the small sample size, which precluded regression and factor analyses. Furthermore, it is recognized that a number of different medical conditions affect younger continuing care residents. By grouping all young continuing care residents into one category, information may be missed. As such, different important factors to QOL may exist for different conditions. While this is possible, due to sample size concerns, this question could not be examined.

In general, sample sizes were small due to the challenging aspects of conducting research in a continuing care facility. Although the researcher pursued all 147 residents included on the young adult units at the continuing care site, many were unable to participate because they exceeded the age of 65, had cognitive impairments, or were unable to communicate with the researcher. Another challenge to sample size was obtaining consent from legal guardians, as many guardians did not feel that the resident

would be able to communicate with the researcher or would be able to provide responses that were useful. A few guardians did not consent because they were anxious about what their loved one would say about the facility. They were afraid that if negative comments were to reach staff, the care that would be subsequently provided to the resident would suffer. This again reinforces the vulnerability of this population and the challenges of obtaining reliable self-report data.

There were also challenges associated with interviewing staff. The number of staff at the continuing care site had recently been downsized and work-load expectations had increased. Many staff members felt that the time constraints they were under made it such that they could not participate and others were clearly apprehensive about participating in the study. It seems possible that despite reassurances of confidentiality, job-security was an issue.

A second limitation is the generalizability of the study. Only residents who were able to communicate and were without severe cognitive impairments were included in this study. It is likely that those who were unable to take part may have had a more compromised QOL. Although exclusionary criteria were adopted for practical purposes, it should be recognized that the sample does not provide a representation of all younger residents.

The issue of generalizability to other continuing care sites is also of concern. The continuing care facility where the study took place had a large number of younger residents, with a total of 128 out of 147 residents that lived on the young adult units under the age of 65. However, most continuing care facilities are populated primarily with elderly persons, with only a few younger adults as residents. Whether the QOL of this

sample represents the QOL of younger continuing care residents that live in this type of setting is unclear.

A third limitation relates to the comparisons made between younger and older residents. Although no significant findings in regard to overall QOL ratings were found, these groups differed on many factors in addition to age. In the younger resident sample both genders were equally represented and residents were primarily divorced or separated, while the comparison sample of older residents were mostly female and widowed. Furthermore, the majority of younger participants had a diagnosis of Multiple Sclerosis, whereas research on older continuing care residents has found that congestive heart failure, cerebrovascular accident or disease, and emphysema/chronic obstructive pulmonary disease are the most common conditions that precipitate continuing care placement (Buchanan, Wang, & Ju, 2002). So while an attempt was made to look at age differences, the two samples were quite different on other characteristics. Future research needs to keep these issues in mind if further comparisons between younger and older residents are to be pursued.

The final limitation is the time period in which data was collected at the continuing care facility. Funding cuts had resulted in a dramatic change in staffing. Most of the funding to the recreation department had been cut leaving few recreation staff and reduced program options. In addition, many nursing positions had been eliminated. More casual and part-time staff were responsible for providing care, which diminishes the degree to which relationships between residents and staff can be established, as well as staff's knowledge of residents' unique care needs (Bitzan & Kruzich, 1990). With heavier workloads and the change in staff composition, less attention to

psychosocial/rehabilitation efforts was paid. These significant changes most certainly influenced staff and resident perceptions about QOL.

#### *Directions for Future Research*

The present study is an important first step in studying the QOL of young continuing care residents. Future research with this population might examine Spranger and Schwartz's (1999) theory of response shift. The response shift theory proposes that significant life changes (e.g., declines in health) prompt behavioural, cognitive, and affective processes with the potential to create a shift in an individual's standards of what is important to achieving a good QOL. This line of research may shed light on why some residents are able to maintain a high QOL in the face of relocation and chronic illness. In addition, this "resilience" may be related to personality and "sense of self." Examining personality variables like "optimism" may provide further information about resilience and QOL in this population. Clearly, sustaining one's sense of self-identity and ego integrity in the face of declining health is important for QOL. Phenomenological approaches may provide valuable information about the ways in which residents sustain "sense of self" in the face of adversity.

Clearly, sample size will be an issue in studying this population. Future research will need to target many different continuing care sites in order to get a large enough overall sample size composed of adequate numbers of residents with different physical disabilities (e.g., MS, SCI, TBI). Related, many of the younger residents could not complete the quality of life measures either because they had cognitive impairments and/or communication disorders. Future research needs to examine the QOL of these residents, as it is precisely this population for whom information on quality of life is most

important. In order to assess QOL in a broader range of residents, in particular those with cognitive impairment and communicative disorders, researchers will need to utilize methods other than self-report.

The utility of using a QOL instrument that obtains both importance and satisfaction ratings is another avenue of future research. Although continuing the practice of weighting by importance has intuitive appeal, weighted and un-weighted summary scores usually correlate very highly (Trauer & Mackinnon, 2001), as was the case in this study. By using the most parsimonious instrument to measure QOL, administration time is reduced. This is a valuable goal when conducting research with a population where interruptions and fatigue are common obstacles in the interviewing process.

Many challenges face researchers examining the quality of life of young continuing care residents. With more research into understanding this population, more progress can be made into potentially improving their life quality. Considering the projected rise of younger adults in continuing care settings, it is crucial that this important population is no longer ignored.

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## Appendix A

## Relevancy Ratings for all Items on the Long Version of the QOLP:PD

Items	Mean Relevancy Rating	Standard Deviation
<b>Physical Being:</b>		
1. Being physically able to get around the residence.*	3.42	.90
2. Being physically able to get around the neighbourhood.	2.92	1.16
3. Being physically able to use public transportation.*	3.17	.72
4. Being physically active and keeping fit.	3.17	.83
5. Getting enough sleep and rest.	3.00	.95
6. Good nutrition and eating the right foods.	3.08	.90
7. Having enough energy to do the things they want to.*	3.58	.67
8. Maintaining their personal hygiene and caring for themselves, by THEMSELVES.*	2.83	1.19
9. Maintaining their personal hygiene and caring for themselves, WITH THE ASSISTANCE OF OTHERS.	3.25	.75
10. Personal appearance.	3.08	.67
11. How they are able to manage the pain that they have.	2.92	1.31
12. Overall physical health.*	3.08	.90
<b>Psychological Being:</b>		
1. Accepting the way that they are.*	3.00	1.28
2. Making their own decisions.*	3.42	.79
3. Acting independently, on their own.*	3.17	1.19
4. Being able to remember things.	2.92	1.08
5. Their level of stress.	2.83	.72
6. The mood they are usually in.*	2.83	1.19
7. Coping with what life brings.	3.17	.58
8. Feeling good about themselves.*	2.92	1.00
9. Having a positive attitude towards life.*	2.83	1.27
10. Having a sense of humour.	2.92	1.08
11. Their mental health.	3.25	.87
<b>Spiritual Being:</b>		
1. Being caring towards other people.	2.25	.97
2. Celebrating birthdays or special events.	2.83	.94
3. Feeling peace within themselves.*	2.67	1.15
4. Feeling that their life has purpose.*	2.75	1.22
5. Sharing love with other people.*	2.58	1.24
6. Having their own ideas of right and wrong.*	2.92	.90
7. Having religious or spiritual beliefs.*	2.25	1.29
8. Having things to look forward to.*	3.08	.67
9. Participating in religious or spiritual activities.	2.00	1.35

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Physical Belonging

1. Where they live.*	2.92	1.00
2. Living in a safe place.*	3.50	.67
3. Having a space for privacy.*	3.42	.79
4. Having their own personal things.	3.42	.67
5. Living in a comfortable place.*	3.42	.67
6. Living in a place with enough space.*	3.08	.100
7. Living in a place that is physically accessible.*	3.33	.89
8. What part of Canada they live in.	2.17	1.40
9. What neighbourhood they live in.	1.92	1.16
10. Living in a safe neighbourhood.	2.75	1.22

## Social Belonging

1. Having a spouse, partner, or special person.*	2.42	1.44
2. Having friends.*	2.92	.900
3. Being close to some members of their family.	3.42	.79
4. Having acquaintances.	2.92	1.00
5. Having neighbours they can turn to.*	2.08	1.38
6. Being able to count on family members for help.	3.25	.87
7. Having people nearby who they can communicate with.*	2.67	1.15
8. Meeting in social/cultural/interest groups.	2.42	1.16
9. The degree to which they depend on people in their family.	3.08	.90
10. Having social events to attend.*	2.33	1.15
11. Being accepted by people they see regularly.*	2.75	1.14
12. Sexual intimacy.	1.83	1.53
13. Being respected by people around them.	2.83	1.11

## Community Belonging

1. Being able to get health services (from doctors, therapists, nurses, dentists, etc.).	3.25	.75
2. Being able to get social services (vocational services, social worker, etc.).*	2.92	1.24
3. Being able to get other special services (attendant care, etc.).*	3.00	.95
4. Being able to live in affordable housing.	3.25	.75
5. Going to places in their neighbourhood (stores, etc.).*	2.83	.72
6. Feeling the government understands their needs.	3.08	1.24
7. Having access to meaningful work.*	2.17	1.47
8. Having courses, classes, or programs that they can take.	3.00	.85
9. Having enough money to live comfortably.	3.42	.67
10. Having events in the community to go to (movies, etc.).*	2.92	1.00
11. Having programs/services in a language they understand	3.33	.78
12. Having transportation that allows them to get where they want to be.*	3.33	.89
13. Having adaptive equipment or resources (wheelchair, telephone adaptations, etc.)	3.42	1.00

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**Practical Becoming:**

1. The everyday things they do for a spouse or other adult (laundry, cleaning, etc.).*	1.25**	1.36
2. Looking after a pet.	1.58	1.31
3. Doing volunteer work through an organization.*	2.25	1.29
4. Doing work around their residence (cooking, repairs, tidying).	1.50**	1.17
5. Doing work they get paid for.*	1.25**	1.48
6. Going to appointments (doctor, dentist, therapist, etc.).	2.75	.75
7. Looking after their children or other children.*	1.17**	1.47
8. Shopping for themselves or others.	2.17	1.03
9. Helping family, friends, or neighbours in practical ways.*	2.25	1.06
10. Doing schoolwork or coursework.*	2.00	1.13

**Leisure Becoming:**

1. Having vacation and holiday activities.	2.33	.89
2. Getting out with others (shopping, lunch, etc.).*	2.50	1.17
3. Going to community events like fairs or sales.	2.25	1.06
4. Going to movies or shows.	2.42	1.08
5. Doing hobbies (painting, gardening, knitting, etc.).	2.58	1.31
6. Doing indoor activities (TV, reading, etc.).	3.17	.83
7. Doing outdoor activities (walks, driving, etc.).*	2.33	1.30
8. Participating in holiday activities (Christmas, Hanukkah, Thanksgiving, etc.).*	3.17	.72
9. Participating in organized recreation activities (cards, sports, bingo, etc.).*	2.58	1.16
10. Visiting and socializing with friends and neighbours.*	3.00	.95
11. Visiting and socializing with people in their family.	3.08	1.00
12. Taking breaks from their usual routines.*	2.17	1.34

**Growth Becoming:**

1. Adjusting to changes in their personal life.*	3.33	.65
2. Creating new challenges and/or projects in life.	2.67	1.15
3. Improving or maintaining their skills (mental, manual, communication, etc.).*	3.17	1.03
4. Improving or maintaining their mental health.	3.08	1.24
5. Improving or maintaining their physical health.	3.58	.51
6. Learning about new things.	2.92	1.08
7. Learning to get along better with others.*	2.33	1.23
8. Solving their own problems.*	3.08	.90
9. Trying things they haven't tried before.*	2.50	1.17
10. Sharing ideas with other people.	2.33	1.07
11. Working towards goals they set for themselves.*	2.92	1.08

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Note. Relevancy ratings ranged from 0 (not at all relevant) to 4 (extremely relevant)

\* items included only on the short form of the QOLP:PD

\*\* items whose mean relevancy rating were 2 SD below the mean.

## Appendix B

## Informed Consent Forms

INFORMED CONSENT  
(Study 1: Residents)

Research Project Title: Quality of Life in Younger Continuing Care Residents  
Investigators:

- Dr. Candace Konnert, 220-4976, [konnert@ucalgary.ca](mailto:konnert@ucalgary.ca)
- Ashli Watt, B.Sc., 220-4977, [adwatt@ucalgary.ca](mailto:adwatt@ucalgary.ca)

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read and listen to this form carefully and to understand any accompanying information.

The goal of this study is to determine how appropriate the Quality of Life Profile: Version for Persons with Physical and Sensory Disabilities (QOLP:PD) is for assessing the quality of life of young continuing care residents. This measure has been used to assess quality of life of adults with physical disabilities that live in the community, but has not been used with young continuing care residents.

To achieve this goal we would like to interview you. An individual interview session will be held lasting no longer than one hour. During this interview, we will ask you to rate the degree to which elements of the QOLP:PD are relevant to and representative of the QOL of young continuing care residents. You will also be asked whether you feel changes should be made to the QOLP:PD instrument, such as additions or deletions.

If there are questions you would prefer not to answer that will be fine. You should know, as well, that the information you give us will be kept confidential. After you complete the interview, the questionnaire will be kept in a locked file at the University of Calgary. This file will only be accessible to staff involved in this research study. You will be given a number code and will not be identified by name. If you find the interview is too long please let me know and we can stop and perhaps continue at a later time. You are free to withdraw from the study at any time without jeopardizing your health care.

In the event that you suffer injury as a result of participating in this research no compensation will be provided for you by the University of Calgary, the Calgary Health Region, or the researchers. You still have your legal rights. Nothing said here about treatment or compensation in any way alters your right to recover damages. Your participation may benefit other people residing in continuing care settings by improving our ability to assess and potentially improve quality of life. If you like, we will provide you with a summary of our results at the end of the study so that you can see how this research might help others.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a participant. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact Ashli Watt at 220-4977, or Dr. Candace Konnert at 220-4976.

If you have any questions concerning your rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

Participant's Signature: \_\_\_\_\_ Date \_\_\_\_\_

Participant's Name (printed): \_\_\_\_\_ Date \_\_\_\_\_

Legal Guardian: \_\_\_\_\_ Date \_\_\_\_\_  
(if appropriate)

Investigator and/or Delegate: \_\_\_\_\_ Date \_\_\_\_\_

Witness' Signature: \_\_\_\_\_ Date \_\_\_\_\_

A copy of this consent form has been given to you to keep for your records and reference.

☐ Please check here if you would like to receive a summary of the results of this study when we are finished, in about one years time.

INFORMED CONSENT  
(Experts: Assessment – Study 1)

Research Project Title: Quality of Life in Younger Continuing Care Residents

Investigators:

- Dr. Candace Konnert, 220-4976, [konnert@ucalgary.ca](mailto:konnert@ucalgary.ca)
- Ashli Watt, B.Sc., 220-4977, [adwatt@ucalgary.ca](mailto:adwatt@ucalgary.ca)

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read and listen to this form carefully and to understand any accompanying information.

The goal of this study is to determine how appropriate the Quality of Life Profile: Version for Persons with Physical and Sensory Disabilities (QOLP:PD) is for assessing the quality of life of young continuing care residents. This measure has been used to assess quality of life of adults with physical disabilities that live in the community, but has not been used with young continuing care residents.

To achieve this goal we would like to interview you. An individual interview session will be held lasting no longer than one hour. During this interview, we will ask you to rate the degree to which elements of the QOLP:PD are relevant to and representative of the QOL of young continuing care residents. You will also be asked whether you feel changes should be made to the QOLP:PD instrument, such as additions or deletions.

If there are questions you would prefer not to answer that will be fine. You should know, as well, that the information you give us will be kept confidential. After you complete the interview, the questionnaire will be kept in a locked file at the University of Calgary. This file will only be accessible to staff involved in this research study. You will be given a number code and will not be identified by name. If you find the interview is too long please let me know and we can stop and perhaps continue at a later time. Or, if you like, you can withdraw from the study completely.

In the event that you suffer injury as a result of participating in this research no compensation will be provided for you by the University of Calgary, the Calgary Health Region, or the researchers. You still have your legal rights. Nothing said here about treatment or compensation in any way alters your right to recover damages. Your participation may benefit other people residing in continuing care settings by improving our ability to assess and potentially improve quality of life. If you like, we will provide you with a summary of our results at the end of the study so that you can see how this research might help others.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a participant. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact Ashli Watt at 220-4977, or Dr. Candace Konnert at 220-4976.

If you have any questions concerning your rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

Participant's  
Signature: \_\_\_\_\_ Date \_\_\_\_\_

Participant's  
Name (printed): \_\_\_\_\_ Date \_\_\_\_\_

Legal  
Guardian: \_\_\_\_\_ Date \_\_\_\_\_  
(if appropriate)

Investigator and/or Delegate: \_\_\_\_\_ Date \_\_\_\_\_

Witness'  
Signature: \_\_\_\_\_ Date \_\_\_\_\_

A copy of this consent form has been given to you to keep for your records and reference.

☐ Please check here if you would like to receive a summary of the results of this study when we are finished, in about one years time.

INFORMED CONSENT  
(Residents: Assessment – Study 2)

Research Project Title: Quality of Life in Younger Continuing Care Residents  
Investigators:

- Dr. Candace Konnert, 220-4976, [konnert@ucalgary.ca](mailto:konnert@ucalgary.ca)
- Ashli Watt, B.Sc., 220-4977, [adwatt@ucalgary.ca](mailto:adwatt@ucalgary.ca)

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read and listen to this form carefully and to understand any accompanying information.

This study will assist in improving the quality of life of younger continuing care residents by fulfilling three goals. First, this study will determine the factors that are most important to the quality of life of younger residents. Second, this study will compare younger and older residents' life quality and determine if there are any similarities or differences in the factors that contribute to the quality of life of these groups. Third, this study will compare resident and staff views on quality of life in a continuing care facility, and will also compare resident and staff views on the changes that could be made to improve younger residents' quality of life.

To achieve these goals we would like to interview you. This interview should take no longer than 60 to 90 minutes and will take place over one or two sessions. Initially, we will ask you about your background, such as your birth date, your marital status, and your level of education. We will then ask you about your views on your own quality of life and things that could be done in the continuing care facility to improve your quality of life. We will also ask you about your memory and physical health. These interview sessions will take place at your convenience.

If there are questions you would prefer not to answer that will be fine. You should know, as well, that the information you give us will be kept confidential. Only persons working on this research project will have access to the information you provide in the assessment. We would also like to look at your medical chart to obtain your birth date, the date you relocated to this continuing care facility, and what types of health conditions you are experiencing. We will ask you to indicate on this form whether we have your permission to do so.

After you complete the interview, the questionnaire will be kept in a locked file at the University of Calgary. This file will only be accessible to staff involved in this research study. You will be given a number code and will not be identified by name. Further more, all the information will be treated as group data and pooled across many respondents. If you find the interview is too long please let me know and we can stop and perhaps continue at a later time. Or, if you like, you can withdraw from the study completely at any point in time. Whether or not you choose to participate or continue in the study will have no effect on the care you receive or on the attitudes of other people towards you.

In the event that you suffer injury as a result of participating in this research no compensation will be provided for you by the University of Calgary, the Calgary Health Region, or the researchers. You still have your legal rights. Nothing said here about treatment or compensation in any way alters your right to recover damages. Participation in this study does not involve risk or discomfort other than the sensitivity and personal nature of some of the questions. It has the potential to detect any emotional difficulties you might be experiencing. In addition, your participation may benefit other people residing in continuing care settings by improving our ability to assess and potentially improve quality of life. If you like, we will provide you with a summary of our results at the end of the study so that you can see how this research might help others.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a participant. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact Ashli Watt at 220-4977, or Dr. Candace Konnert at 220-4976.

If you have any questions concerning your rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

Participant's

Signature: \_\_\_\_\_ Date \_\_\_\_\_

Participant's Name (printed): \_\_\_\_\_ Date \_\_\_\_\_

Legal Guardian: \_\_\_\_\_ Date \_\_\_\_\_  
(if appropriate)

Investigator and/or Delegate: \_\_\_\_\_ Date \_\_\_\_\_

Witness' Signature: \_\_\_\_\_ Date \_\_\_\_\_

A copy of this consent form has been given to you to keep for your records and reference.

- ☐ Please check here if you would like to receive a summary of the results of this study when we are finished, in about one years time.
- ☐ Please check here if you give permission for the principle investigator and co-investigator to view your medical chart.



INFORMED CONSENT  
(Staff: Assessment – Study 2)

Research Project Title: Quality of Life in Younger Continuing Care Residents  
Investigators:

- Dr. Candace Konnert, 220-4976, [konnert@ucalgary.ca](mailto:konnert@ucalgary.ca)
- Ashli Watt, B.Sc., 220-4977, [adwatt@ucalgary.ca](mailto:adwatt@ucalgary.ca)

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read and listen to this form carefully and to understand any accompanying information.

This study will assist in improving the quality of life of younger continuing care residents by fulfilling three goals. First, this study will determine the factors that are most important to the quality of life of younger residents. Second, this study will compare younger and older residents' life quality and determine if there are any similarities or differences in the factors that contribute to the quality of life of these groups. Third, this study will compare resident and staff views on quality of life in a continuing care facility, and will also compare resident and staff views on the changes that could be made to improve younger resident's quality of life. You have been asked to participate in order to fulfill the third goal of this study.

In order to fulfill goal three, we will compare staff and resident responses to questions on what factors are related to residents' quality of life, the importance of certain factors to residents' quality of life, and what can be done to improve quality of life in a continuing care facility. Thus, we would like to interview you for about 5 to 10 minutes to get your perspective on the quality of life of continuing care residents. We would then like to give you a short questionnaire that will take approximately 10 minutes. You can return this questionnaire at your convenience.

If there are questions you would prefer not to answer that will be fine. You should know, as well, that the information you give us will be kept confidential. After you complete the interview, the questionnaire will be kept in a locked file at the University of Calgary. This file will only be accessible to staff involved in this research study. You will be given a number code and will not be identified by name. Further more, all the information will be treated as group data and pooled across many respondents.

In the event that you suffer injury as a result of participating in this research no compensation will be provided for you by the University of Calgary, the Calgary Health Region, or the researchers. You still have your legal rights. Nothing said here about treatment or compensation in any way alters your right to recover damages. Your participation may benefit people residing in continuing care settings by improving our ability to assess and potentially improve quality of life of younger residents. We will

provide you with a summary of our results at the end of the study so that you can see how this research might help others.

We can stop the interview at any time and perhaps continue at a later time. Or, if you like, you can withdraw from the study completely. Whether or not you choose to participate or continue answering questions will have no effect on any aspect of your employment with Carewest, including your performance evaluations.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a participant. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have further questions concerning matters related to this research, please contact Ashli Watt at 220-4977, or Dr. Candace Konnert at 220-4976.

If you have any questions concerning your rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Services, University of Calgary, at 220-3782.

Participant's  
Signature \_\_\_\_\_ Date \_\_\_\_\_

Participant's Name (printed): \_\_\_\_\_ Date \_\_\_\_\_

Investigator and/or Delegate's Signature \_\_\_\_\_ Date \_\_\_\_\_

Witness' Signature \_\_\_\_\_ Date \_\_\_\_\_

A copy of this consent form has been given to you for your records and reference.

If you would like to receive a summary of the results of this study when we are finished, in about two years time, please fill out the information below:

Name: \_\_\_\_\_

Mailing Address: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

## Appendix C

## Item Modifications for the QOLP:PD-CC

Item on the QOLP:PD	Item on the QOLP:PD-CC
<p><b>Physical Being Item 1:</b> Being physically able to get around your <i>home</i></p> <p><b>Physical Being Item 3:</b> Being physically able to use public transportation</p> <p><b>Social Belonging Item 3:</b> Having other <i>neighbours</i> you can turn to</p> <p><b>Community Belonging Item 2:</b> Being able to get other special services (<i>attendant care, etc.</i>)</p>	<p>Being physically able to get around your <i>residence</i></p> <p>Being physically able to use public transportation and <i>handibus</i></p> <p>Having other <i>residents</i> you can turn to</p> <p>Being able to get other special services (<i>laundry, housekeeping</i>)</p>

## Appendix D

## Demographic Measures

Gender:

Participant's gender:

- 1 Male
- 2 Female

Ethnicity:

Participant's ethnicity (clarify if necessary):

- 1 Caucasian
- 2 Asian (please specify): \_\_\_\_\_
- 3 Native Canadian
- 4 East Indian
- 5 Black
- 6 Other (please specify): \_\_\_\_\_

Age:

What is your age? \_\_\_\_\_ years

What is your date of birth? (confirm from medical chart) Day \_\_\_\_ Month \_\_\_\_ Year \_\_\_\_

Marital Status:

What is your current marital status?

- 1 Single
- 2 Involved in a relationship
- 3 Married
- 4 Widowed
- 5 Divorced
- 6 Separated

Education:

How far did you go in school? (Please indicate the highest level completed.)

- 1 0-4 years
- 2 5-8 years
- 3 high school incomplete
- 4 high school completed (grade 12 \_\_\_\_\_ grade 13 \_\_\_\_\_)
- 5 post high school - business or trade school
- 6 1-3 years college/university
- 7 4 years college/university completed
- 8 post-graduate college/university

Occupational Information:

What kind of work have you done most of your life? (Circle the most appropriate.)

- 1      never employed
- 2      homemaker
- 3      paid work (state the specific occupation in detail) \_\_\_\_\_
- 4      volunteer work (state the specific volunteer work done) \_\_\_\_\_

Do you currently work?

- 1      yes
- 2      no

**If yes:**

Is this work:

- 1      volunteer                      2      paid

What specific work are you involved in? \_\_\_\_\_

Does this work take place:

- 1      inside the facility
- 2      outside the facility

How often do you work?

- 1      everyday
- 2      5-6 times a week
- 3      3-4 times a week
- 4      1-2 times a week
- 5      once every couple weeks
- 6      once a month
- 7      less than once a month

**If no:**

When did you quit working and why? \_\_\_\_\_

Primary Medical Condition

What medical conditions do you currently have? (Give most importance to condition related to physical disability) \_\_\_\_\_

Duration of Residence

Date of initial interview – Date of relocation to continuing care facility

## Appendix E

## Leisure and Social Support Questions

Leisure Activities:

What activities/hobbies are you currently involved with?

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How often are you involved in these activities?

- 1      everyday
- 2      5-6 times a week
- 3      3-4 times a week
- 4      1-2 times a week
- 5      once every couple weeks
- 6      once a month
- 7      less than once a month

On average, how often do you leave your residence? (Circle the most appropriate)

- 1      everyday
- 2      5-6 times a week
- 3      3-4 times a week
- 4      1-2 times a week
- 5      once every couple weeks
- 6      once a month
- 7      less than once a month

Where do you usually go when you leave the continuing care facility?

---

Social Support

Who visits you?

- 1      spouse
- 2      children
- 3      parents
- 4      other family members
- 5      friend
- 6      staff

How frequently do you have visitors?

- 1 everyday
- 2 5-6 times a week
- 3 3-4 times a week
- 4 1-2 times a week
- 5 once every couple weeks
- 6 once a month
- 7 less than once a month

Do you have a special person that you can confide in regarding personal issues or things that are important to you?

- 1 yes
- 2 no

**If yes:**

How is this person related to you?

- 1 son
- 2 daughter
- 3 father
- 4 mother
- 5 spouse
- 6 other

Does this person live here at the Fanning Centre (ask only if not immediately apparent)?

- 1 yes
- 2 no

## Appendix F

## Cognitive Status Measure

**Mini-Mental State**  
by M.F. Folstein, S.E. Folstein  
and P.R. McHugh

Patient's Name \_\_\_\_\_  
Test Date \_\_\_\_\_  
                    month                      day                      year  
Testor Name \_\_\_\_\_

I. Orientation

"I am going to ask you some questions and give you some problems to solve. Please try to answer as best as you can."

Allow 10 seconds for each reply.

Year(exact answer only) ..... 1 \_\_\_\_\_  
Season ..... 2 \_\_\_\_\_  
Month ..... 3 \_\_\_\_\_  
Date ..... 4 \_\_\_\_\_  
Day (exact answer only) ..... 5 \_\_\_\_\_

Country (exact answer only) ..... 6 \_\_\_\_\_  
Province ..... 7 \_\_\_\_\_  
City ..... 8 \_\_\_\_\_  
Residence ..... 9 \_\_\_\_\_  
Floor ..... 10 \_\_\_\_\_

II. Registration

"I am going to name 3 objects. After I have said all three objects, I want you to repeat them. Remember what they are because I am going to ask you to name them again in a few minutes."

"Ball" ..... 11 \_\_\_\_\_  
"Car" ..... 12 \_\_\_\_\_  
"Man" ..... 13 \_\_\_\_\_  
Number of Trials ..... ( )

Say them slowly at approximately 1 second intervals.

Score 1 point for each correct reply on the first attempt. Allow 20 seconds for reply. If participant did not repeat all three, repeat until they are learned or up to a maximum of 5 times.

III. Attention and Calculation

Spell the word "world" correctly.

"Now spell it backwards, please."

Number of letters in  
correct order (out of 5) ..... 14-18 \_\_\_\_\_

Allow 30 seconds to spell backwards.  
If cannot spell "world" even with assistance, score 0.

Record how subject spelled "world"  
backwards \_\_\_\_\_  
                    d l r o w



## IV. Recall

"Now what were the three objects that I asked you to remember?"

"Ball" ..... 19 \_\_\_\_  
 "Car" ..... 20 \_\_\_\_  
 "Man" ..... 21 \_\_\_\_

## V. Language

**naming:** Show the participant a wrist watch and ask him/her what it is. Repeat for pencil. ("What is this called?"). Allow 10 seconds.

Watch ..... 22 \_\_\_\_  
 Pencil ..... 23 \_\_\_\_

**repetition:** "I'd like you to repeat a phrase after me: No ifs, ands, or buts." Allow 10 seconds.

Repetition (exact answer only) .... 24 \_\_\_\_

**reading:** "Read the words on this page, and then do what it says."

Closes eyes ..... 25 \_\_\_\_

Allow 10 seconds. Maximum of three times.

**3-stage command:** Give the participant a piece of plain blank paper and say, (if left-handed) "Take this paper in your right hand, fold it in half once with both hands, and put the paper down on the floor."

Takes paper in correct hand ..... 26 \_\_\_\_  
 Folds paper in half ..... 27 \_\_\_\_  
 Puts paper on floor ..... 28 \_\_\_\_

**writing:** Hand participant a pencil and paper. "Write any complete sentence on that piece of paper."

Writes sentence ..... 29 \_\_\_\_

Allow 30 seconds.

**copying:** Place design, pencil, eraser, and paper in front of participant. "Copy this design, please."

Draws pentagons ..... 30 \_\_\_\_

Allow multiple tries within 1 minute. Participant must draw a 4-sided figure between the two 5-sided figures.

TOTAL (out of 30) ..... \_\_\_\_

## Appendix G

## Open-Ended Quality of Life Questions

I would like you to think about your overall quality of life. Quality of life, in simple terms, means: "How good is your life for you?" Every person's life is different, and there are many different aspects of living that may contribute to the overall quality of a person's life.

Now that I have explained what I mean by quality of life, I am going to ask you about your personal quality of life.

1. What things contribute most to your overall quality of life?

i. \_\_\_\_\_ ii. \_\_\_\_\_ ii. \_\_\_\_\_

PROBE: What individual areas are most important to your quality of life?

PROBE: Is there anything else?

(If resident cannot generate 3 responses after both statement probes, proceed on to question 1.b).

2. You have identified a number of things that are important to your quality of life (repeat the responses). Now, for each response that you have provided, I would like you to rate how important it is to your quality of life. You will use the following choices in responding:

- |   |                     |
|---|---------------------|
| 5 | Extremely important |
| 4 | Very important      |
| 3 | Important           |
| 2 | Somewhat important  |
| 1 | Not very important  |

So for (say response i. here). How important is it to your quality of life? i. \_\_\_\_\_

How important is (response ii) to your quality of life? ii. \_\_\_\_\_

How important is (response iii) to your quality of life? iii. \_\_\_\_\_

3. Please tell me how satisfied you are with those things you have identified as being important contributors to your quality of life. I would like you to rate your satisfaction level by using the following alternatives:

- 5       Extremely satisfied
- 4       Very satisfied
- 3       Somewhat satisfied
- 2       Not very satisfied
- 1       Not at all satisfied

How satisfied are you with (response i. here)?   i. \_\_\_\_\_

How satisfied are you with (response ii)       ii. \_\_\_\_\_

How satisfied are you with (response iii)       iii. \_\_\_\_\_

4. Let's begin with (insert what they have said for response i), how much control do you feel you have over this?

- 5       a lot of control
- 4       quite a bit control
- 3       some control
- 2       a little control
- 1       no control

PROBE: How much are you in charge of this part of your life?

- i.       \_\_\_\_\_
- ii.      \_\_\_\_\_
- iii.     \_\_\_\_\_

5.       Think now about the setting in which you live. What things could be done in the continuing care facility to improve your overall quality of life?
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## Appendix H

## Quality of Life Profile Measures

Quality of Life Profile: Version for Persons with Physical and Sensory Disabilities in Continuing Care (QOLP:PD-CC)

\*\* indicates items added to the short form of the QOLP:PD based on content validation results

I'd now like to return to the topic of quality of life, or how good your life is for you. We have talked a bit about areas that you have identified as being important to quality of life. Now I would like to obtain your opinion about the importance of a variety of areas. Some of these areas you might have already brought up, while others haven't been discussed yet. After you finish telling me how important each of these areas are, I will ask you to tell me your level of satisfaction with each of these particular areas.

To begin then, I am going to name a number of areas and I want you to tell me how important they are to the quality of your life.

## Importance Rating Scale:

- 1 = Not at all important
- 2 = Not very important
- 3 = Somewhat important
- 4 = Very important
- 5 = Extremely important

## Physical Being:

Importance

How important to you is..?

1. Being physically able to get around your residence. \_\_\_\_\_
2. Being physically able to get around your neighbourhood. \_\_\_\_\_
3. Being physically able to use public transportation and handi-bus. \_\_\_\_\_
4. Having enough energy to do the things you want to. \_\_\_\_\_
5. Maintaining your personal hygiene and caring for yourself, by YOURSELF. \_\_\_\_\_
6. Your overall physical health. \_\_\_\_\_

## Psychological Being:

How important to you is...?

1. Accepting the way you are \_\_\_\_\_
2. Making your own decisions. \_\_\_\_\_
3. Acting independently, on your own \_\_\_\_\_
4. The mood you are usually in. \_\_\_\_\_
5. Feeling good about yourself \_\_\_\_\_
6. Having a positive attitude towards life. \_\_\_\_\_

### Spiritual Being:

How important to you is..?

1. Feeling peace within yourself.
2. Feeling that your life has purpose.
3. Sharing love with other people.
4. Having your own ideas of right and wrong.
5. Having religious or spiritual beliefs.
6. Having things to look forward to

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### Physical Belonging

How important to you is..?

1. Where you live.
2. Living in a safe place.
3. Having a space for privacy.
4. Living in a comfortable place.
5. Living in a place with enough space.
6. Living in a place that is physically accessible to you.

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### Social Belonging

How important to you is..?

1. Having a spouse, partner, or special person.
2. Having friends.
3. Having other residents you can turn to.
4. Having people nearby who you can communicate with.
5. Having social events to attend.
6. Being accepted by people you see regularly.

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### Community Belonging

How important to you is..?

1. Being able to get social services  
(vocational services, social worker, etc.).
2. Being able to get other special services (attendant care, etc).
3. Going to places in your neighbourhood (stores, etc.).
4. Having access to meaningful work.
5. Having events in the community to go to (movies, etc.).
6. Having transportation that allows you to get where you want to be.
7. Being able to get quality nursing care.\*\*

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### Practical Becoming:

How important to you is..?

1. Doing volunteer work through an organization.
2. Helping family, friends, or neighbours in practical ways.
3. Doing schoolwork or coursework.
4. Shopping for yourself or others.
5. Going to appointments (doctor, dentist, therapist, etc.).
6. Looking after a pet.

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**Leisure Becoming:**

How important to you is..?

1. Getting out with others (shopping, lunch, etc.)
2. Doing outdoor activities (walks, driving, etc.).
3. Participating in holiday activities  
(Christmas, Hanukkah, Thanksgiving, etc).
4. Participating in organized recreation activities  
(cards, sports, bingo, etc).
5. Visiting and socializing with friends and residents.
6. Taking breaks from your usual routines.

\_\_\_\_

\_\_\_\_

\_\_\_\_

\_\_\_\_

\_\_\_\_

\_\_\_\_

**Growth Becoming:**

How important to you is..?

1. Adjusting to changes in your personal life.
2. Improving or maintaining your skills.  
(mental, manual, communication, etc).
3. Learning to get along better with others.
4. Solving your own problems.
5. Trying things you haven't tried before.
6. Working towards goals you set for yourself.

\_\_\_\_

\_\_\_\_

\_\_\_\_

\_\_\_\_

\_\_\_\_

\_\_\_\_

**Now, instead of giving importance ratings, I want you to tell me how satisfied you currently are with the areas that we just went through.**

**Satisfaction Rating Scale:**

- 1 = Not at all satisfied
- 2 = Not very satisfied
- 3 = Somewhat satisfied
- 4 = Very satisfied
- 5 = Extremely satisfied

**Physical Being:****Satisfaction**

How satisfied are you with..?

1. Being physically able to get around your residence.
2. Being physically able to get around your neighbourhood.
3. Being physically able to use public transportation and handi-bus.
4. Having enough energy to do the things you want to.
5. Maintaining your personal hygiene and caring for yourself, by YOURSELF.
6. Your overall physical health.

\_\_\_\_

\_\_\_\_

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\_\_\_\_

\_\_\_\_

### Psychological Being:

How satisfied are you with...?

1. Accepting the way you are
2. Making your own decisions:
3. Acting independently, on your own
4. The mood you are usually in.
5. Feeling good about yourself
6. Having a positive attitude towards life.

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### Spiritual Being:

How satisfied are you with..?

1. Feeling peace within yourself.
2. Feeling that your life has purpose.
3. Sharing love with other people.
4. Having your own ideas of right and wrong.
5. Having religious or spiritual beliefs.
6. Having things to look forward to

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### Physical Belonging

How satisfied are you with..?

1. Where you live.
2. Living in a safe place.
3. Having a space for privacy.
4. Living in a comfortable place.
5. Living in a place with enough space.
6. Living in a place that is physically accessible to you.

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### Social Belonging

How satisfied are you with..?

1. Having a spouse, partner, or special person.
2. Having friends.
3. Having other residents you can turn to.
4. Having people nearby who you can communicate with.
5. Having social events to attend.
6. Being accepted by people you see regularly.

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### Community Belonging

How satisfied are you with..?

1. Being able to get social services  
(vocational services, social worker, etc.).
2. Being able to get other special services (attendant care, etc.).
3. Going to places in your neighbourhood (stores, etc.).
4. Having access to meaningful work.
5. Having events in the community to go to (movies, etc.).
6. Having transportation that allows you to get where you want to be.
7. Being able to get quality nursing care.\*\*

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### Practical Becoming:

How satisfied are you with..?

1. Doing volunteer work through an organization. \_\_\_\_\_
2. Helping family, friends, or neighbours in practical ways. \_\_\_\_\_
3. Doing schoolwork or coursework. \_\_\_\_\_
4. Shopping for yourself or others. \_\_\_\_\_
5. Going to appointments (doctor, dentist, therapist, etc.). \_\_\_\_\_
6. Looking after a pet. \_\_\_\_\_

### Leisure Becoming:

How satisfied are you with..?

1. Getting out with others (shopping, lunch, etc.) \_\_\_\_\_
2. Doing outdoor activities (walks, driving, etc.). \_\_\_\_\_
3. Participating in holiday activities  
(Christmas, Hanukkah, Thanksgiving, etc). \_\_\_\_\_
4. Participating in organized recreation activities  
(cards, sports, bingo, etc). \_\_\_\_\_
5. Visiting and socializing with friends and neighbours. \_\_\_\_\_
6. Taking breaks from your usual routines. \_\_\_\_\_

### Growth Becoming:

How satisfied are you with..?

1. Adjusting to changes in your personal life. \_\_\_\_\_
2. Improving or maintaining your skills.  
(mental, manual, communication, etc). \_\_\_\_\_
3. Learning to get along better with others. \_\_\_\_\_
4. Solving your own problems. \_\_\_\_\_
5. Trying things you haven't tried before. \_\_\_\_\_
6. Working towards goals you set for yourself. \_\_\_\_\_



Quality of Life Profile: Seniors Version (QOLP:SV)

(Raphael, Renwick, & Brown, 1996)

\* indicates items included in the short form of the QOLP:PD-CC

Importance Rating Scale:

- 1 = Not at all important
- 2 = Not very important
- 3 = Somewhat important
- 4 = Very important
- 5 = Extremely important

Satisfaction Rating Scale:

- 1 = Not at all satisfied
- 2 = Not very satisfied
- 3 = Somewhat satisfied
- 4 = Very satisfied
- 5 = Extremely satisfied

Physical Being:

Importance/Satisfaction

- 1. Being physically able to get around your residence. \*
- 2. Having enough energy to do the things you want to. \*
- 3. Your overall physical health. \*
- 4. Good nutrition and eating the right foods.
- 5. Exercising and keeping fit.
- 6. Maintaining your personal hygiene.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Psychological Being:

- 1. Making your own decisions.\*
- 2. Feeling good about yourself.\*
- 3. Having a positive attitude towards life.\*
- 4. Being able to remember things.
- 5. Coping with what life brings.
- 6. Being free of worry, stress, and sadness.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Spiritual Being:

- 1. Feeling peace within yourself.\*
- 2. Feeling that your life has purpose.\*
- 3. Having religious or spiritual beliefs.\*
- 4. Having things to look forward to.\*
- 5. Being caring towards other people.
- 6. Having hope.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Physical Belonging

How important to you is..?

- 1. Living in a safe place.\*
- 2. Having a space for privacy. \*
- 3. Living in a comfortable place.\*
- 4. Being able to make my own decisions.
- 5. Living near family and friends.
- 6. Having your own personal things.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

### Social Belonging

How important to you is..?

1. Having friends.\*
2. Having people nearby who you can communicate with.\*
3. Being able to count on family members for help.
4. Meeting in social/cultural/interest/faith groups.
5. Not being a burden to people in your family.
6. Spending time with adult members of your family.

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### Community Belonging

How important to you is..?

1. Going to places in your neighbourhood (stores, etc.).\*
2. Having transportation that allows you to get where you want to be.\*
3. Feeling the government understands your needs.
4. Being able to live in affordable housing.
5. Having enough money to live comfortably.
6. Being able to get medical services.

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### Practical Becoming:

How important to you is..?

1. Shopping for yourself or others.\*
2. Going to appointments (doctor, dentist, therapist, etc.).\*
3. Doing work around your room (cleaning, tidying, etc).
4. The caring you do for other adults.
5. Doing things to take care of yourself.
6. How you help other people who live nearby.

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### Leisure Becoming:

How important to you is..?

1. Getting out with others (shopping, lunch, etc.).\*
2. Doing outdoor activities (walks, driving, etc.).\*
3. Visiting and socializing with friends and residents.\*
4. Having hobbies (painting, gardening, knitting, etc.).
5. Having indoor activities (TV, reading, etc.).
6. Visiting and socializing with people in your family.

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### Growth Becoming:

How important to you is..?

1. Adjusting to changes in your personal life.\*
2. Improving or maintaining your skills.\*  
(mental, manual, communication, etc).\*
3. Solving your own problems.\*
4. Creating new challenges/projects in your life.
5. Improving or maintaining your physical health.
6. Learning about new things.

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## Appendix I

Formula to Calculate Basic Scores on the QOLP:PD-CC

$$\text{Basic Score} = X = 3 [ (\text{Importance Score}/3) \times (\text{Satisfaction Score}-3)]$$

Importance Rating	Satisfaction Rating	Basic Score
5	5	10
	4	5
	3	0
	2	- 5
	1	10
4	5	8
	4	4
	3	0
	2	- 4
	1	- 8
3	5	6
	4	3
	3	0
	2	- 3
	1	- 6
2	5	4
	4	2
	3	0
	2	- 2
	1	- 4
1	5	2
	4	1
	3	0
	2	- 1
	1	- 2

## Appendix J

## Quality of Life Outcome Measures

Life Satisfaction Index-A

(LSI-A, Adams, 1969)

0 = Disagree

1 = Agree

? = Don't know

1. \_\_\_\_\_ As I grow older, things seem better than I thought they would be.
2. \_\_\_\_\_ I have gotten more of the breaks in life than most of the people I know.
3. \_\_\_\_\_ This is the dreariest time of my life. (Reverse)
4. \_\_\_\_\_ I am just as happy as when I was younger.
5. \_\_\_\_\_ My life could be happier than it is now. (Reverse)
6. \_\_\_\_\_ These are the best years of my life.
7. \_\_\_\_\_ Most of the things I do are boring or monotonous. (Reverse)
8. \_\_\_\_\_ I expect some interesting and pleasant things to happen to me in the future.
9. \_\_\_\_\_ The things I do are as interesting to me as they ever were.
10. \_\_\_\_\_ I feel old and somewhat tired. (Reverse)
11. \_\_\_\_\_ As I look back on my life, I am fairly well satisfied.
12. \_\_\_\_\_ I would not change my past life even if I could.
13. \_\_\_\_\_ Compared to other people my age, I make a good appearance.
14. \_\_\_\_\_ I have made plans for things I'll be doing a month or a year from now.
15. \_\_\_\_\_ When I think back over my life, I didn't get most of the important things I wanted. (Reverse)
16. \_\_\_\_\_ Compared to other people, I get down in the dumps too often. (Reverse)
17. \_\_\_\_\_ I've gotten pretty much what I expected out of life.
18. \_\_\_\_\_ In spite of what people say, the lot of the average man is getting worse, not better. (Reverse)

Total \_\_\_\_\_

Satisfaction with Life Scale

(SWLS, Diener, Emmons, Larsen, & Griffin, 1985)

- 1 = Strongly disagree
- 2 = Disagree
- 3 = Slightly disagree
- 4 = Neither agree nor disagree
- 5 = Slightly agree
- 6 = Agree
- 7 = Strongly agree

- 1. \_\_\_\_\_ In most ways my life is close to my ideal.
- 2. \_\_\_\_\_ The conditions of my life are excellent.
- 3. \_\_\_\_\_ I am satisfied with my life.
- 4. \_\_\_\_\_ So far I have gotten the important things I want in life.
- 5. \_\_\_\_\_ If I could live my life over, I would change almost nothing.

Total \_\_\_\_\_

## Appendix K

## Physical Health Measures

Perceived Physical Health

(Center for the Study of Aging and Human Development, 1978)

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

- 1      excellent
- 2      good
- 3      fair
- 4      poor

Activities of Daily Living (ADL)

(Modified MDS, Morris et al., 1990)

I'd like to ask you about some of the activities of daily living, things that we all need to do as part of our daily lives. I would like to know how much help you need with the following activities: no help, a little help, moderate help, a lot of help, or total help, that is, you can't do it at all on your own.

Code for performance during last month:

- 0 = no help required (independent or no assistance)
- 1 = a little help (some assistance, mostly supervision/oversight)
- 2 = moderate help (limited/intermittent supervision)
- 3 = a lot of help (extensive/constant supervision)
- 4 = total help/can't do at all (total dependence/assistance)

NOTE: Do not read bracketed material. Use only for determining rating if the resident provides relevant information spontaneously.

How much help do you need with:

- a) \_\_\_\_\_ eating and drinking (regardless of skill)?
- b) \_\_\_\_\_ using the washroom facilities (or commode, bedpan, urinal; transfers on/off toilet; cleanses, changes pad, manages ostomy or catheter; adjusts clothes)?
- c) \_\_\_\_\_ moving from, for example, your bed to a chair (or wheelchair) or standing up? (Excludes to/from bath/toilet.)

d) \_\_\_\_\_ moving around your room or around the unit, for example, up and down the hallways and to and from common areas? (If in wheelchair, self-sufficiency once in chair.)

e) \_\_\_\_\_ taking a full-body bath or sponge bath? (Make it clear to the resident that tub transfer should not be included. Rating should be done only on the amount of help needed, once in the tub.)

f) \_\_\_\_\_ dressing, undressing, and grooming yourself, including things like fastening your clothes, combing your hair, brushing your teeth, shaving, and applying make-up? (Including donning/removing prosthesis, if applicable).

Total \_\_\_\_\_

#### Numerical Rating Scale – 11 for Pain

Next I would like you to tell me about any pain that you might be experiencing.

On a scale of 0 to 10, where 0 is no pain at all and 10 is the worst pain imaginable, how do you rate your current pain? \_\_\_\_\_

## Appendix L

## Frequency Information on All Responses to Open-Ended QOL Questions

Table 1

*Responses to Question “What hobbies/activities are you currently involved with?”*

	Frequency of response (n = 104)	Percentage of residents (n = 43)
Activities involved in		
Advocating for resident rights	2	4.7
Billiards	1	2.3
Bingo	3	7.0
Bowling	1	2.3
Bridge	1	2.3
Cards	1	2.3
Ceramics	2	4.7
Choir	1	2.3
Cooking classes	1	2.3
Computer	1	2.3
Crafts	2	4.7
Day trips	1	2.3
Entertainment at Fanning	1	2.3
Exercising	1	2.3
Gardening	3	7.0
Group meetings	1	2.3
Jigsaw Puzzles	1	2.3
Listen to radio	4	9.3
Movies	1	2.3
Painting	6	14.0
Physiotherapy	10	10
Occupational therapy	1	2.3
Reading	4	9.3
Smoking	3	7.0
Stamp Collecting	1	2.3
SUDS	1	2.3
Swimming	1	2.3
Teas	3	7.0
Travel	1	2.3
Trivia	15	34.9
TV	11	25.6
Visit family in community	1	2.3
Volunteering	1	2.3
Wood shop	8	18.6
Word find/Crossword	2	4.7



Table 2

*Responses to Question "Where do you usually go when you leave the continuing care facility?"*

Response	Frequency of response (n = 51)	Percentage of residents (n = 43)
Church	1	2.3
Day trips organized through the continuing care facility	3	7.0
Dentists	2	4.7
Professional hockey game	1	2.3
Gambling	2	4.7
Ice Cream	1	2.3
Immunologist	1	2.3
Lunch	3	7.0
Movies	1	2.3
Visiting other continuing care homes	1	2.3
R and B	1	2.3
Shopping	8	18.6
Swimming pool	1	2.3
University gym	3	7.0
Visit family members	21	48.8
Visit friends	1	2.3

Table 3.

*Resident Responses to Survey Question "What Things Could be Done in the Continuing Care Facility to Improve Your Overall Quality of Life?"*

Response	Frequency of response (n = 78)	Percentage of residents (n = 43)
More companionship visits	2	4.7
More social activities for younger residents	6	7.7
Reinstate ceramics program at continuing care facility	3	7.0
Independence over smoking	3	7.0
Independence over decision making/schedule	8	18.6
Allowance for more input into diet/menu	8	18.6
Evening/weekend activities offered at the facility	2	2.3
Improve cleanliness of the continuing care facility	1	2.3
Offer computer courses	1	2.3
More physiotherapy offered	3	7.0
More compassion from staff in care	9	20.9
More regular staff	4	9.3
More than one bath a week	3	7.0
Day trips into the community	7	16.3
More staff should be hired to provide care and recreation	4	9.3
Meaningful work to do	2	4.7
Improve physical accessibility in the facility	2	4.7
More privacy	2	4.7
Hire porters to take residents to and from activities	1	2.3
Hire better trained staff	4	9.3
Integrate residents of different ages more	1	2.3
Offer occupational therapy	1	2.3
Offer speech therapy	1	2.3

Table 4.

*Staff Responses to Survey Question "What Things Could be Done in the Continuing Care Facility to Improve the Overall Quality of Life of Younger Residents?"*

Response	Number of responses (n = 206 )	Percentage of staff (n = 65)
More companionship visits	20	30.8
More social activities for younger residents	23	35.4
Reinstate ceramics program at continuing care facility	1	1.5
Independence over decision making/schedule	16	24.6
Allowance for more input into diet/menu	7	10.8
Evening/weekend activities offered at the facility	6	9.2
Offer computer courses	5	7.7
More physiotherapy offered	2	3.1
More compassion from staff in care	11	16.9
More regular staff	2	3.1
More than one bath a week	5	7.7
Day trips into the community	16	24.6
More staff should be hired to provide care	24	36.9
More staff should be hired to provide recreation	15	23.1
Meaningful work to do	2	3.1
Improve physical accessibility in the facility	1	1.5
Hire porters to take residents to and from activities	2	3.1
Hire better trained staff	6	9.2
Integrate residents of different ages more	1	1.5
More home-like environment	4	6.2
More financial support from the government	11	16.9
Have access to gym equipment	1	1.5
Keep residents of same cognitive level, physical ability, and age on the same unit on the continuing care facility	5	7.7
Private/bigger rooms	7	10.8
Educational programs should be offered to residents	2	3.1
Have resident's family more involved	5	7.7
Offer psychological help for residents	3	4.6
Provide easier access to handi-bus bookings	1	1.5
Provide recreational programs for residents with cognitive impairments	1	1.5
Offer recreation programs at the facility in sessions so more residents can participate	1	1.5
Strive to rehabilitate residents so they can live in community	1	1.5

## Appendix M

## Mean Ratings for Subcomponents of the QOLP: PD-CC

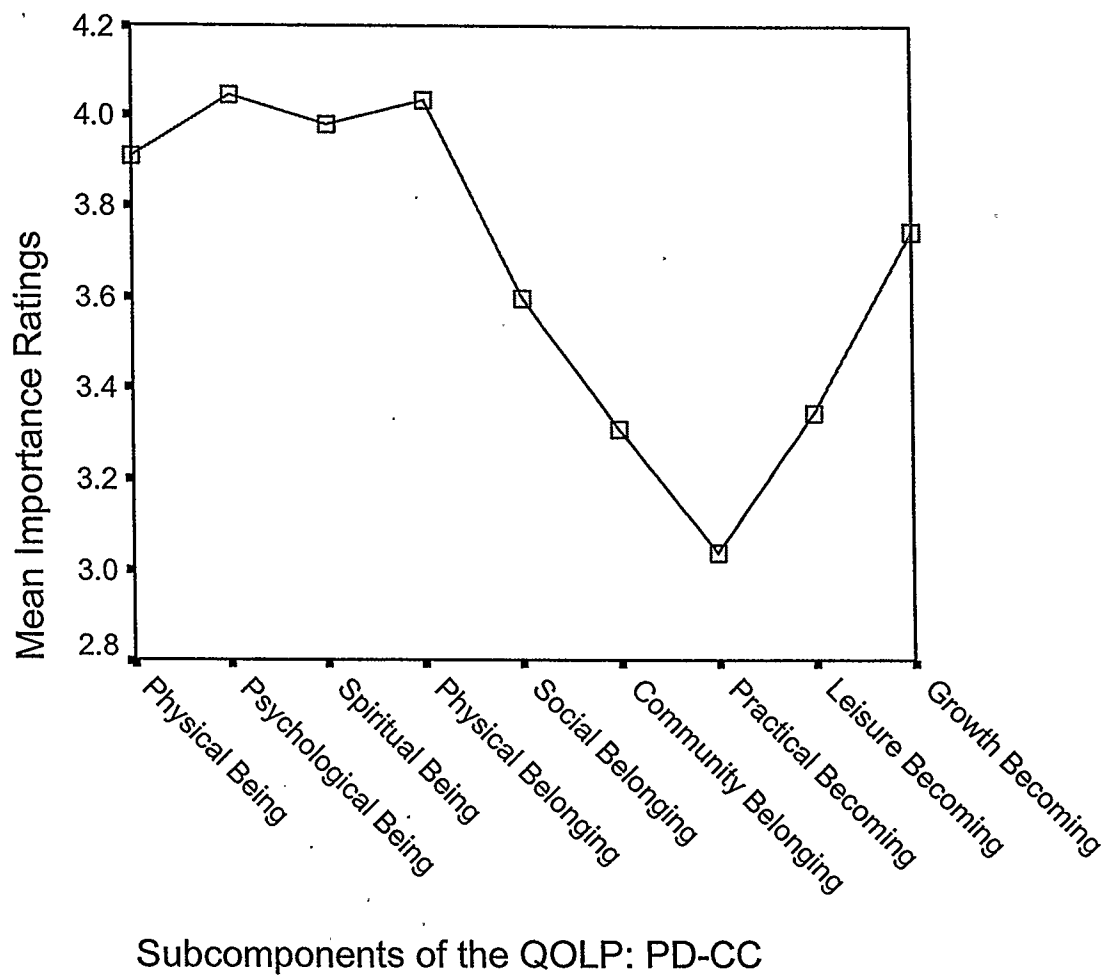


Figure 1. Residents' Mean Importance Ratings for Subcomponents of the QOLP: PD-CC

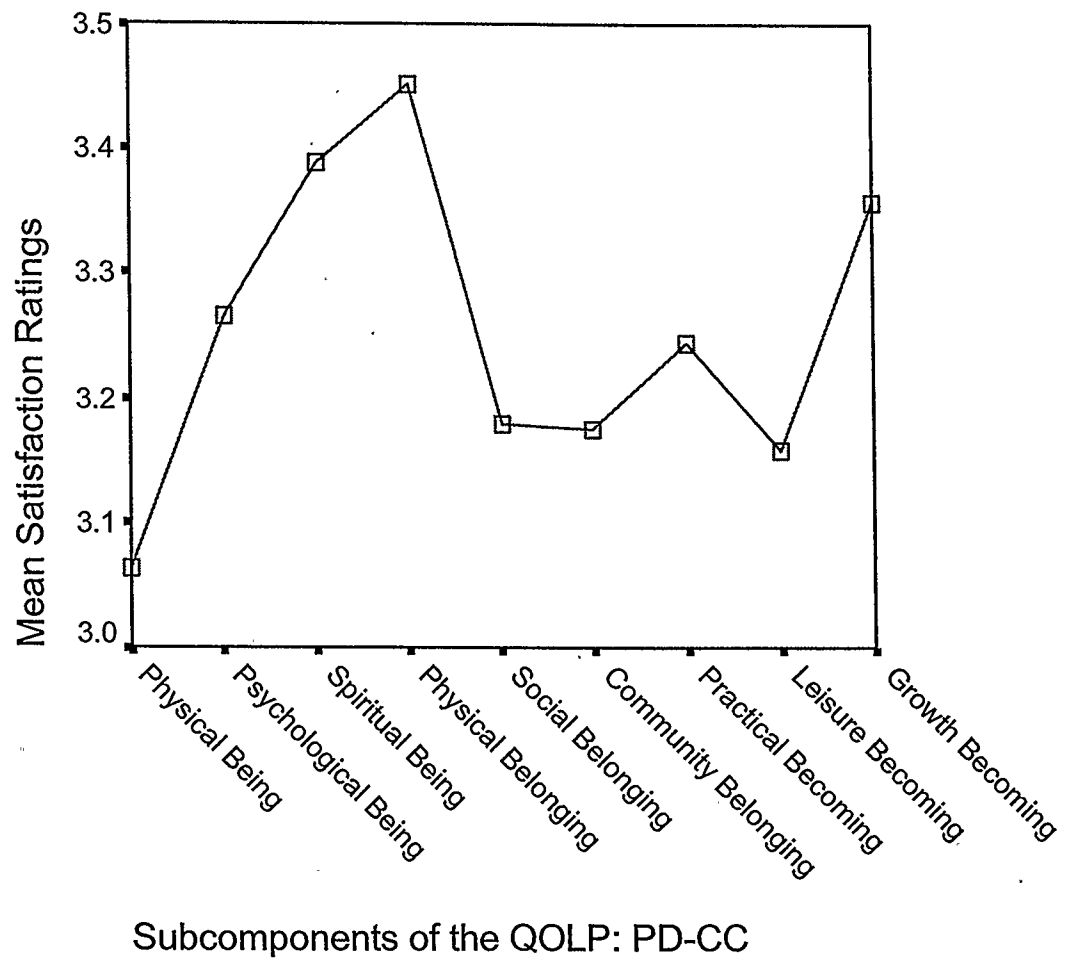


Figure 2. Residents' Mean Satisfaction Ratings for Subcomponents of the QOLP: PD-CC

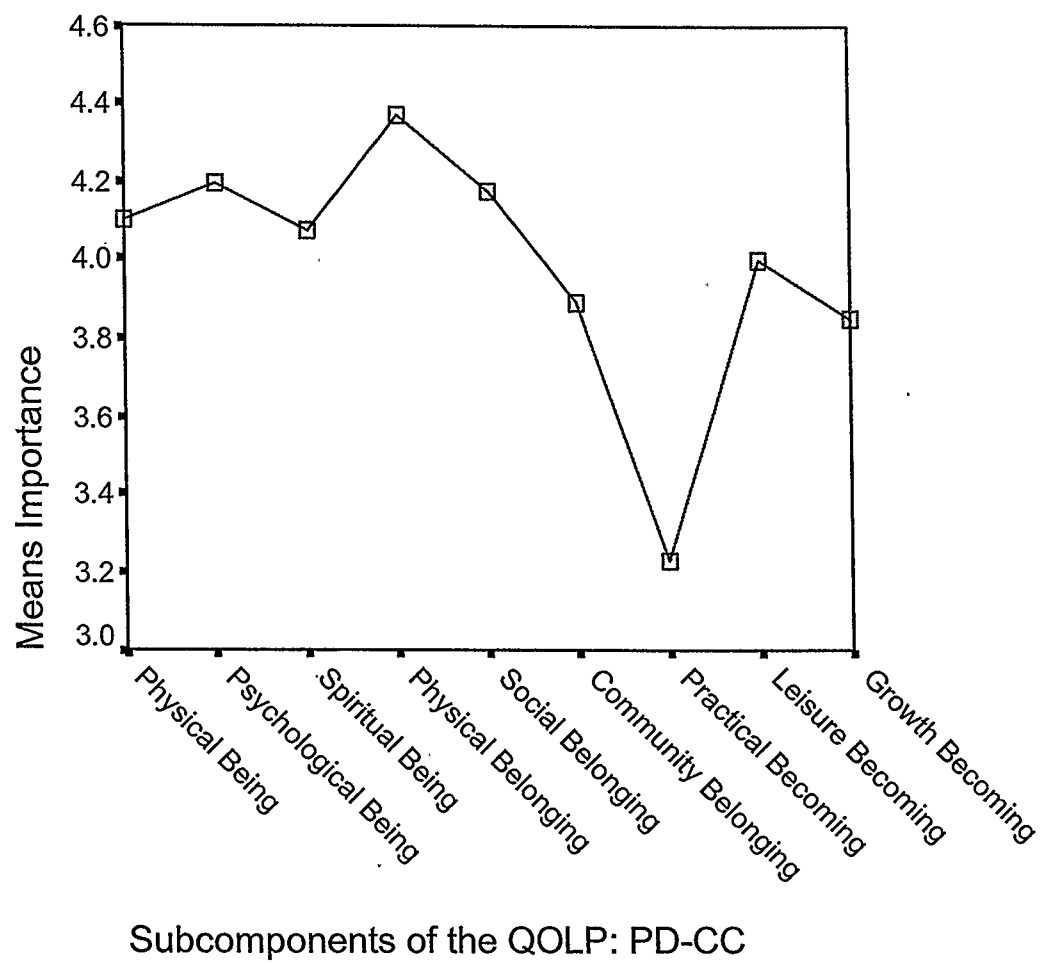


Figure 3. Staffs' Mean Importance Ratings for Subcomponents of the QOLP: PD-CC