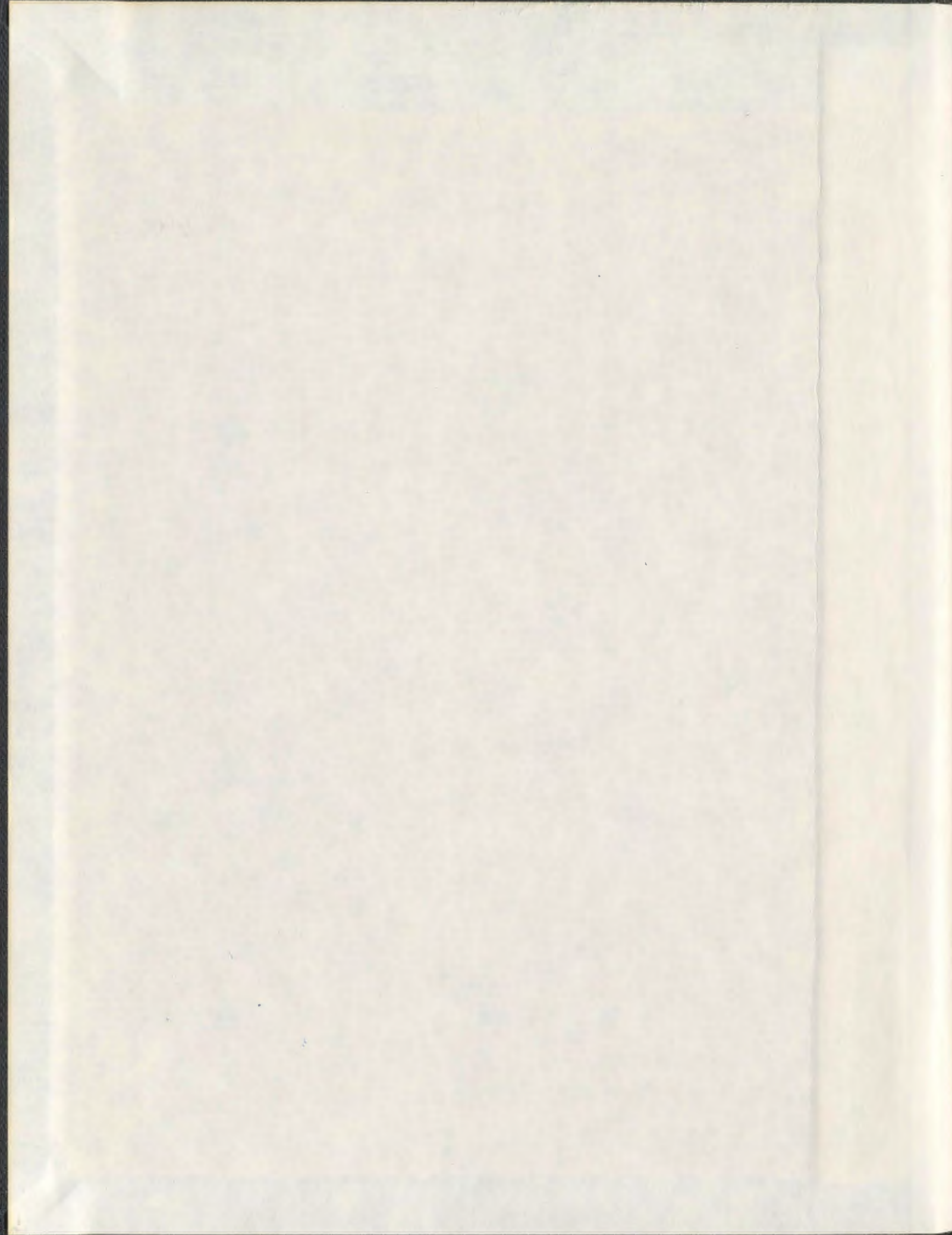


ASSESSING THE CARE REQUIREMENTS AND
PERCEPTIONS OF ELDERLY APPLYING TO LONG-TERM
CARE - THE NEED FOR ALTERNATIVES TO
INSTITUTIONALIZATION ALONG THE CONTINUUM

MEGHAN WALSH



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OF ELDERLY APPLYING TO LONG-TERM CARE – THE
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ALONG THE CONTINUUM**

by

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ABSTRACT

Despite changes in the 1990's to the long-term care system in the Eastern Health region of Newfoundland and Labrador problems persisted. The system continued to be plagued by inappropriate use of nursing home beds, unnecessary acute care use, a discrepancy between the supply and demand of nursing home beds and a deficit of housing and alternatives to institutional care. Research suggested that a portion of applicants to the single-entry system with modest care needs might be better suited to an alternative housing arrangement rather than the two existing options: personal care homes and nursing homes. With the high cost of nursing home beds, lengthy wait times for placement, and a lack of interest in personal care homes, these issues demanded further investigation. The purpose of the study was therefore to gain an in-depth understanding of the system from a segment of applicants with modest care needs that could be extrapolated to a larger population of applicants with similar needs. Consequently, a chart review of an incident cohort of elderly applicants for long-term care placement was conducted to determine disability levels and support requirements. Data collected included care requirements and functional status, acute and chronic care usage, stated preferences for facilities and reasons for application, presence and use of formal and informal support, wait times, and outcomes of applications. In the second phase of the study, twenty individuals from the incident cohort were interviewed using *grounded theory* to explore experiences of the elderly with long-term care and the meanings of their decisions in relation to their personal experiences of aging and more specifically, the application process. Additionally, the objectives were to determine participants' perceptions of their needs; reasons for and causes of the decision to apply for long-term

care placement; the role of applicants' support networks; attitudes regarding existing options; and, finally, opinions regarding a theoretical alternative housing option.

The quantitative findings confirmed: that, firstly, many applicants with modest care needs would be better suited to an alternative housing arrangement (such as a supportive housing) rather than present options; that there are significant problems regarding both informal and formal supports of many applicants; and, lastly, emphasized the important role of critical episodes in many applications. The qualitative research found study participants made continual adjustments and readjustments to all facets of their lives including their environment, support and social networks, expectations and self-identities to avoid moving to a home as their needs increased. It was found that a "*weighing of support*" occurred between participants' existing circumstances and the expectation of support they viewed they would receive in a home. The inconsistencies in their support network and growing difficulties maintaining independence were measured against the perceived consistent care a nursing home or personal care home could provide. A gradual reconciliation to the move occurred, making the decision increasingly easier, while one or more critical episodes - such as a loss of a spouse or sudden decline in health - commonly acted as a trigger in the decision to apply for long-term care. It was found, however, that the decision-making process occurred in stages and that it extended beyond the application to the time of placement, which signified the actual final decision to applicants. The findings suggest that a comprehensive integrated system of long-term care services combined with a range of accessible, alternative housing options designed to avoid or delay placement would reduce demand on the system from the elderly without professional care requirements.

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LIST OF ABBREVIATIONS AND SYMBOLS

ARCS	Alberta Resident Classification System
AHCCC	Alberta Home Care Client Classification
RUGS III	Resource Utilization Grouping System III
HCS	Health and Community Services
SES	Single-entry system
IADLs	Instrumental Activities of Daily Living
ADLs	Activities of Daily Living
ALFs	Assisted Living Facilities
CCRCs	Continuing Care Retirement Communities
TIAs	Transient Ischemic Attacks

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Chapter 1

Introduction

According to the World Health Organization, the aging population is one of the most significant issues facing the health care systems of first world nations. As with many countries, decreasing fertility rates and increasing life expectancy have contributed to the modification of the population pyramid of Canada. In 1971, seniors made up 8% of the population. However, projections are that by 2021 seniors will represent 19% of the total Canadian population and increase to 25% by 2041 (Statistics Canada 2001). The proportion of the oldest segment of seniors is also increasing. Today 1 in 10 Canadians are 85 years of age or older compared to 1 in 20 in 1921 (Statistics Canada 2001). Consequently, the national and provincial governments must remodel their healthcare systems to respond to these changes.

1.1 Background of the Study

While all of the Canadian population is aging, Newfoundland and Labrador's population is aging more rapidly than most (Newfoundland and Labrador Statistics Agency 2005). The province has had a dramatic decline in fertility rates over the past generation and, with the collapse of the cod fishery in the 1990's, has experienced one of the highest rates of outmigration in the country. Consequently, in 2004, the death rate began to surpass the birth rate in the province. These low fertility rates and high rate of outmigration combined with increasing life expectancy has increased the median age of the province to 40 years of age and is expected to increase to 48 years of age by the year 2020 (Newfoundland and

Labrador Statistics Agency 2005). These changes are even more profound in the rural areas where the greatest level of outmigration has occurred.

Traditionally, Newfoundland has had strong family support systems for the elderly. The impact of recent demographic and societal shifts on the social fabric of communities cannot be understated. With the high levels of outmigration of those of childbearing age and many women unable and/or unwilling to provide the traditional support to the elderly, it is reasonable to expect these changes will affect this informal support system. Consequently, the expectation that the family will continue to fulfill the role of primary caregivers for the elderly may be unrealistic.

Undoubtedly, the changes in the present situation present enormous challenges for policymakers regarding the planning of health services. It is expected that the aging population will increase the health care needs of the elderly in the province. Increased resources will be spent on chronic illnesses such as diabetes and cardiovascular and heart disease. Diseases such as Alzheimer's and other forms of dementia will continue to increase as larger proportions of people age further into their eighties and nineties. This is not solely a question of resources but also a policy issue as it requires well-planned policy development in the long-term care sector.

Newfoundland and Labrador is now divided into four Health Regions. Until the change in regional boundaries in 2005, the St. John's Health Region took in the capital city of the province, its neighbouring city and a portion of the surrounding outlying suburban and

rural areas. Now the Eastern Health Regional Health Authority, this region is the most populous in the province encompassing the entire Avalon and Burin Peninsulas and Bonavista Bay area and more than half of the provincial population. Within the city, it now includes several health care organizations including the St. John's Nursing Home Board, St. John's Region Health and Community Services and the Health Care Corporation of St. John's. This region is a significant target for emigration from other areas of the province and therefore has to contend with providing care for many residents within and outside its boundaries.

Newfoundland and Labrador's long-term care model has traditionally relied on expensive institutional care with most elderly being placed in subsidized nursing homes. Over time, it was recognized that this long-term care model was neither sustainable nor desirable for the growing aging population as it contains inefficiencies that cause the system to function at a less than optimal level. Consequently, in 1995 Health and Community Services constructed a single-entry system for individuals seeking placement in the long-term care system (rather than the previous system of applying to particular facilities). The purpose of this gateway was to streamline the process of placement and respond more efficiently to applicants.

Those applying to the single-entry system are categorized from Level I-IV, lowest to highest level of care requirements, respectively. There are two options for applicants. Firstly, there are six nursing homes in the city. The majority of these are operated by

various churches on a not-for-profit basis and are subsidized by the provincial government. The second option is placement in a personal care home, which are privately owned and operated facilities on a for-profit basis. Personal care homes have both subsidized beds and non-subsidized beds and today 46% of personal care home beds in the Region are subsidized (Newfoundland and Labrador Department of Health 2005). Personal care homes do not provide the extensive professional care like nursing homes and consequently, are only able to house Level I and II cognitively well individuals. At present, only nine of the 57 of these personal care homes are located in the urban region (St. John's and Mt. Pearl) and only three were open before 2000, when this research took place.

A third care option is home support subsidized by the St. John's Health and Community Services and provided by private contractors. Application for home support must be done separately from the single-entry system and individuals must meet stringent financial criteria to be eligible.

When an application for long-term care is made to the single-entry system, all applicants are first visited then assessed and categorized at one of four levels of care. Regardless of the determined care needs, clients at one time could choose facilities by preference. For example, one could choose a nursing home over a personal care home. However, several nursing homes no longer have Level I beds (beds for those with modest to low care needs). This has further restricted the applicants' available options. Once assessed and the preference of the available facilities is established, individuals are placed on a waitlist.

Applicants are expected to remit a significant proportion of their monthly income or financial capital when in a nursing home or personal care home. Provision of home support is also based on care needs, but the financial requirements are so restrictive that only those seniors with the lowest incomes may qualify for subsidized home support. As home support application is made separate from long-term care placement, it is difficult to know if Level I and II clients would benefit from or desire home supports rather than long-term care placement. In contrast to the home support program, all seniors can apply for institutional placement regardless of one's financial situation. Consequently, under this present system, it is easier for a client to gain access to a nursing home bed than subsidized home support despite the disparity of cost associated with each option. Because of this system, actual options for seniors with modest health care needs are largely limited to either costly institutionalization in a nursing home or personal home care.

1.2 Significance of Study

An initial study conducted in 1995-1996 in the St. John's Region that coincided with the establishment of the "single-entry system" found inefficiency in institutional long-term care placement. It was found that 22% of a prevalent cohort of those on the single-entry system waitlist who were placed in nursing homes did not need the medical and extensive physical care provided in these institutions and overall only 63% of those accepted for placement required the skilled care provided in a nursing home (O'Reilly et. al 1998).

Since then, several studies have been conducted to examine the long-term care system in health regions throughout the province. Recently, a follow-up study was conducted to investigate changes that have occurred in the St. John's Region between 1997 and 2003. It found that although the appropriateness of placement had improved there continued to be disparities in need of care compared to the level of care available for long-term care applicants (McDonald et al., 2005). From this body of research it is conjectured that a policy of under funding of the home care program and resistance to investment in alternative care models has caused problems of inappropriate use of nursing home care and lengthy wait times for placement in the long-term care system in the province.

1.3 Purpose of the Study

This study was undertaken on behalf of the provincial government of Newfoundland and Labrador. It was suggested that the present system had not been successful in providing appropriate options for seniors in the Region. A combination of high nursing home costs, a deficit of beds for those with modest disability, restrictive access to home supports and the predictions that demands on the system would increase prompted this research. Although several studies were conducted investigating the pattern of resource use and care needs of individuals on the waitlist (O'Reilly et. al 1998; McDonald et al 2005), none had investigated the expressed needs and preferences of an incident cohort of seniors with modest care needs.

Although the need for institutional care like that provided in nursing homes will persist, research findings suggest that a significant proportion of applicants on the waitlist for

nursing home placement in the Eastern Region did not require this level of care. A proportion of clients continue to be inappropriately placed in costly institutional care, waiting long periods for their preferred facility. This is assumed to be due to the absence of alternative care options and limited personal care home beds in the city.

The rationale for the current research was that seniors applying for nursing home care who do not need that level of care could and would choose alternatives to nursing homes if available thus reducing demands on nursing home beds and unnecessary acute care bed use. Consequently, further research was needed to answer several questions: firstly, the level and type of care required of applicants; secondly, reasons why individuals were applying for nursing home care; thirdly, the type and level of informal and formal support that existed in the community and how problems with these supports precipitated seniors' decision to apply for placement; fourthly, their expressed reasons for choosing particular facilities, for example, one nursing home or personal care home over another; and, finally, the general attitudes and expectations of individuals regarding the various options for placement.

To answer the above questions and achieve a greater understanding of the decision-making process this study was undertaken in two phases. In the first phase, a chart review was conducted of an incident cohort of clients assessed as Level I or II and cognitively well by the multi-disciplinary panel applying for nursing home or supervised care, in a fifteen-month period in 1999-2000. The cohort consisted of men and women, sixty-five years and older applying for institutional care and residing in the St. John's Region (now

Eastern Health Region). These chart reviews were intended to provide information regarding applicants' functional and health status, household composition, informal and formal support, preferences of care and reasons for placement.

This incident cohort was also the source of the participants for a qualitative research component, the second phase of the study. In qualitative phase, open-ended interviews were conducted with twenty individuals from the incident cohort with modest disability recommended for placement. The purpose of the study was to delve into issues regarding the decision-making processes of those applying for long-term care. As chart reviews were conducted of individuals meeting the specified criteria, a letter of invitation to participate was sent and a follow-up phone conversation was made to determine participation. Once each participant agreed, a semi-structured, audiotaped interview was conducted. It was hoped that a rich and comprehensive data set would be generated to gain insight into the decision-making process that could not be obtained through quantitative and clinical assessment methods. Beyond the more specific questions relating to the research, it was hoped that a better understanding of the aging process would unfold that exhibited the complex nature of self-identity and independence in the aging process in addition to how the elderly make decisions regarding long-term care. This understanding would allow for a clearer picture of the issues and could be used to respond appropriately to both the demands of patients and the needs of policy makers.

Chapter 2

Literature Review

This literature review researches several areas relevant to this study. Firstly, the substantial literature examining the characteristics or predictors of institutionalization of the elderly is reviewed. The second section discusses various theoretical perspectives on the decision-making process of institutionalization. This discussion includes studies related to migration and mobility patterns of the elderly, the connection between the meaning of home and self-identity, and theoretical models describing individuals' decision-making about institutionalization and decisional control over the process. In the last section of the chapter, the discussion shifts to alternative models of housing and support systems, including service-enriched housing models and integrated care models, that have been touted as effective responses to inappropriate institutionalization.

2.1 Introduction

Institutionalization is the most costly option for governments funding long-term care services. Research suggests that anywhere from 5-50% of people over 65 years become institutionalized at some point in their later years (Klein, 1996). Institutionalization is associated with lower quality of life and is the most unpopular option for the elderly and their families (Friedman et al., 2005). Institutionalization can also be an unnecessary response to meeting the needs of the elderly depending on their health, social and housing circumstances. For example, the literature suggests there is a proportion of the elderly who do not require the professional and medical skilled care provided in nursing homes

but are nonetheless placed in institutions (McDonald et al., 2005; O'Reilly et al., 1998).

As it is desirable to avoid such unnecessary institutionalization, a thorough understanding of the conditions that instigate this process is essential.

2.2 Predictors of Institutionalization

A substantial body of research has examined factors or characteristics associated with institutionalization. The literature suggests that many nursing home placements are due to diverse physical, emotional, social and psychological factors.

2.2.1 Socio-demographic Characteristics

Not surprisingly, age is one of the main factors demonstrated to be positively associated with institutionalization (Carriere & Pelletier, 1995; Lagergren, 1996; Lo Sasso & Johnson, 2002; Mustard et al., 1999; Woo et al., 1994). The literature suggests that risk of nursing home placement increases with increasing age (Hays, Pieper & Purser, 2003). Even when controlling for additional factors such as declining health and widowhood status, one's chance for institutionalization increases for every year of age (Klein, 1996).

Study findings conflict on how gender affects the risk of institutionalization. One study finds that men are at increased risk for nursing home placement (Mustard et al., 1999). This can be explained, in part, by a tendency for men to have weaker informal support networks than women. Alternatively, most studies find that women have an increased chance of institutionalization (Klein, 1996; Lo Sasso & Johnson, 2002; Rockwood, Stolee

& McDowell, 1996). Women's risk is thought to be higher due to their greater life expectancy and the resulting increased probability of developing chronic illnesses or becoming widowed (Klein, 1996).

In addition to age and gender differences, the elderly who are unmarried are at increased risk for institutionalization (Carriere & Pelletier, 1995; Hays, Pieper & Purser, 2003; Lo Sasso & Johnson 2002; Mustard et al., 1999; Rockwood, Stolee & McDowell, 1996; Woo et al., 1994). There are a number of explanations why married individuals may be at lower risk. Firstly, household incomes may be higher for couples than individuals living alone resulting in more resources to purchase necessary support services. Secondly, spouses routinely fulfill the role of on-site primary caregivers allowing couples to live longer in the community (Carriere & Pelletier, 1995). For example, Dwyer (1994) finds that spouses provide more care on an hourly basis and more personal care than other caregivers.

Socio-economic status has been linked to nursing home placement. Several studies find low household income to be a predictor of institutionalization (Carriere & Pelletier, 1995; Lo Sasso & Johnson, 2002; Mustard et al., 1999; MacLennan et al., 1984; Silverstone & Burack-Weiss, 1983; Woo et al., 1994). Higher income (Hays, Pieper & Purser, 2003), home ownership (MacLennan et al., 1984) and higher education attainment have all been shown to decrease one's risk for institutionalization (Mustard et al., 1999). In contrast, Carriere and Pelletier (1995) found individuals with less education tend to have larger informal support networks that may reduce one's chances of institutional placement.

2.2.2 Health Status Characteristics

Health status is found to be a significant predictor of nursing home entry (Carriere & Pelletier, 1995; Lo Sasso & Johnson, 2002). A decline in functional ability is consistently attributed to nursing home placement (Aguero-Torres et al., 2001; Chan, Wong & Yoong, 1998; Glazebrook & Rockwood, 1994; Lagergren, 1996; Woo et al., 1993). Functional dependence resulting from poor health status decreases one's ability to perform instrumental activities of daily living (IADLs), a key predictor of nursing home admission (Friedman et al., 2005; Lo Sasso & Johnson, 2002).

In addition, health problems and chronic illness predispose individuals to institutionalization (Hays, Pieper & Purser, 2003). Diabetes (Rockwood, Stolee & McDowell, 1996; Tsuji, Whalen & Finnucane, 1995), bowel incontinence (Friedman et al., 2005; Tsuji, Whalen & Finnucane, 1995), Parkinson's disease (Rockwood, Stolee & McDowell, 1996; Woo et al., 1993), poor vision (Woo et al., 1993), stroke (Rockwood, Stolee, & McDowell, 1996; Woo et al., 1993) and fractures (Aguero-Torres et al., 2001; Woo et al., 1993) were all found to be significant risk factors for institutionalization.

Declining cognitive function due to dementia was found to predict institutionalization (Glazebrook & Rockwood, 1994; Hays, Pieper & Purser, 2003; Lagergren, 1996; Mustard et al., 1999; Rockwood, Stolee & McDowell, 1996; Woo et al., 1993). Individuals with dementia are institutionalized at much higher rates with up to 50% of those with cognitive impairment reportedly institutionalized (Waltrowicz et al., 1997). In fact, one study finds

cognitive impairment to be the main cause of institutionalization regardless of one's social support network or functional status (Aguero-Torres et al., 2001).

Finally, psychosocial factors such as poor self-rated health are associated with increased risk of nursing home placement (Glazebrook & Rockwood, 1994; Mustard et al., 1999). It is conjectured that depression may be responsible for this risk (Roos & Havens, 1991). Social isolation was found to increase the risk of placement (Hays, Pieper & Purser, 2003; Silverstone & Burack-Weiss, 1983). Loneliness, which has a high prevalence in elderly populations, is not surprisingly a factor in institutionalization (Mavundia, 1996). Regardless of the root cause, an individual's psychosocial health seems to influence their risk of institutionalization.

2.2.3 Social Support Characteristics

The quality and accessibility of informal support networks can also influence the risk for institutionalization. Several studies find that the presence of caregivers reduces institutionalization (Glazebrook & Rockwood, 1994; Silverstone & Burrack-Weiss, 1983; Rockwood, Stolee & McDowell, 1996). Lo Sasso and Johnson (2002) find that elderly individuals who receive regular help from their children are at lower risk of nursing home entry compared with those who received less or no support. In another study, the unavailability of a caregiver was found to be one of the primary reasons for nursing home application (Chan, Wong & Yoong, 1998). Hays (2003) found that children decreased one's chances of institutionalization and further decreased with every living child. In a comparative analysis of women living independently in the community or residential

care, MacLennan (1984) discovered that both the presence of support and proximity to available supports were important differentiating factors. For example, living close to one's support network was particularly effective in responding to a crisis.

Although access to informal and formal supports has been shown to influence institutionalization, the evidence conflicts on whether formal support decreases or increases risk. One study in Sweden identified the level of home support services as a key factor reducing institutionalization rates (Lagergren, 1996), whereas other studies found that paid help could actually increase the probability of nursing home admission due to increased contact and from increased knowledge of options within the system (Bauer, 1996; Dwyer, Barton & Vogel, 1994). Moreover, prior hospitalization and nursing home admission are found to increase placement (Akamigbo & Wolinsky, 2006; Cheek & Ballantyne, 2001; Glazebrook & Rockwood, 1994). Pinguart and Sorensen (2002) suggested that because the elderly are under pressure to make decisions during acute health episodes, once these individuals are in the system they are on track to institutionalization.

2.2.4 Conclusion

The contributory role of the predictive factors reported in the literature taken together can prove more complex than what might be first supposed. A cumulative effect has been found for many of these factors. For example, an unmarried elderly person over the age of 85 in poor health with a low household income is obviously at greater risk (Carriere & Pelletier, 1995). As well, the effect of individual factors cannot be assumed. One might

expect that the elderly with lower education could be at increased risk of institutionalization. However, some research findings indicate that those with lower education tend to have larger family networks to provide support (Carriere & Pelletier, 1995). Akamigbo and Wolinsky (2006) find that even one's expectation regarding placement in a nursing home can be a risk factor for institutionalization. In addition, place or region of residence (Dwyer, 1994) and in some countries such as the U.S., being Caucasian may increase one's chances of nursing home placement (Bauer, 1996; Friedman et al., 2005; Hays, Pieper & Purser, 2003). The literature reports that African American elderly, for example, are institutionalized half as often as their Caucasian counterparts (Dwyer, Barton & Vogel, 1994). This is attributed to stronger familial ties and less access to formal resources (Bauer, 1996).

The studies reviewed here make a significant contribution to our understanding of institutional risk factors for the elderly. Specifically, this body of research examined the complexities of cause and effect among multiple characteristics believed to influence institutional placement. Importantly, it underscores the difficulties involved in predicting need and, ultimately, in developing effective policy for those who are seemingly at greatest risk. However, the findings are limited because of the many unknowns concerning the importance of the interplay of environment and personal circumstances with psycho-emotional factors during the decision-making process. In general, investigations focussed on the significance poor health status, mental and cognitive deficiencies and the adequacy of support networks do not encapsulate the actual decision-making process involved in institutionalization. With the evidence weak on the why, how

and by whom the decision is made and the unique experiences of the elderly person, it is difficult to understand why two people in similar circumstances make disparate decisions about moving to a nursing home.

2.3 Theoretical Models of Decision Making

Over the past few decades the expanding research base has added considerably to the discourse on the decision-making process involved in institutionalization. Some of this research has focussed on the importance of the psycho-emotional meaning of home for individuals (Angus, 2005; Kontos, 1998; Rubenstein, 1989). Migration theorists, such as Wiseman and Roseman (1979), view the elderly as distinct subgroups who determine their residence based on particular stages of old age following retirement. Still other researchers argue that decisions about institutional placement lie with select individuals within the elderly person's support network who actually hold decisional control (Cheek & Ballantyne, 2001; McAuley & Travis, 2000).

2.3.1 The Meaning of "Home"

The concept of home is an integral part of the human psyche. The aging process not only challenges a person's independence and autonomy but also one's ability to cope with the home environment in the face of declining health and incapacity. Kontos (1998) argues that to the elderly 'home' is the geographical space where the individual expresses his/her interests and independence while fostering and facilitating control over their lives. In an ethnographic study of elderly subjects, Rubenstein (1989) theorizes that life and home

become so “intertwined” that home objects and personal attachment to the physical space are ways to express or maintain the individual self. The author contends that the elderly transform their environment through “environmental centralization.” That is, the living space comprising the home environment is altered as the person adjusts to physical and mental decline that accompanies aging. Similarly, Kontos (1998) asserts that ‘home’ is valued as a resource that facilitates the elderly’s adjustment to physical decline and in maintaining independence and self-identity throughout old age.

If the meaning of ‘home’ is rooted in an individual’s identity then it is no wonder the literature consistently states that the elderly desire to remain at home. From interviews of recently admitted nursing home residents, Scocco et al. (2006) find that only 6% of participants had chosen to go to a nursing home. Another study investigating care preferences finds that most people preferred care in the home or community setting with either kin or non-kin, versus *any* type of institutional care (Eckert, Morgan & Swamy, 2004). Similarly, Angus (2005) finds that many elderly did not care how bad their circumstances were as long as they could remain at home. In a study of the elderly in a supportive housing facility, Kontos (1998) finds that while residents accepted their decline, they simultaneously resisted any change that signified institutionalization. If home provides an outlet for constructing and maintaining self-identity and maintenance of home is linked to autonomy and control over one’s life, then what precipitates an elderly person to relinquish such an integral facet of their lives and move to an institution?

2.3.2 Migration Patterns of the Elderly

Several researchers who investigated the migration paths of the elderly propose that following retirement individuals share distinct migration and mobility patterns that are based on acquiring resources to fulfill their needs (Wiseman and Roseman, 1979; Wiseman, 1980; Serow, 1987; Litwak and Longino, 1987; Cutchin, 2001). The appropriateness of the environment for fulfilling need requirements determines whether the individual migrates to another locale in search of additional supportive resources such as family, housing or health services. It is conjectured that any moves are a function of age and needs that surface at different stages of the aging process.

Using Andersen's behavioural model (1968) as a base, in their classic work Wiseman and Roseman (1979) propose a framework describing elderly migration in later life. The framework suggests that the elderly inevitably experience disruptive events that can be either abrupt, like the loss of a spouse, or subtle, such as gradually declining health. The cumulative effect of several disruptive events triggers the need for adjustment that may increase one's desire to move closer to kin, possibly in another community. These authors argued that a move to an institution is an extreme case and is usually brought on by a period of rapid health decline that may include hospitalization.

In a subsequent elaboration upon the migration theory, Wiseman (1980) asserts that migration is characterized by "push and pull factors" such as the pull of support and amenities and the push of environmental stress including "triggering mechanisms" like declining health. Within this framework, the decision to move is seen as a process

whereby people continually or periodically evaluate their circumstances. "Involuntary movers" are those who move unwillingly when certain push factors outweigh the pull factors to remain in their homes.

In a comparative cross-national study of the elderly, Serow (1987) finds significant similarities in both the characteristics and needs causing migration. Using Wiseman's theory of push and pull factors, the "pull" of family proximity was found to be considerable in most nations with a high proportion of the elderly identifying support network proximity as reasons for moving with increasing age. Serow identified two distinct types of migration labelled "transnational phenomenon": the post-retirement move of the younger elderly and the older elderly's search for care needs and support. This author concluded that these two subgroups differ considerably in needs and support service requirements.

In contrast to Wiseman and Roseman (1979), Litwak and Longino (1987) propose a theory of migration that encompassed three types of moves made by the elderly in old age. Findings from a longitudinal study suggested that the first move, or "amenity migration," occurs post-retirement and is due to a desire for lifestyle change. The second move or "intermediate move" precedes institutionalization and is precipitated by early stage chronic disability, inability to perform instrumental activities of daily living or sudden changes in circumstances such as a decline in health or loss of a spouse. The authors claim that intermediate moves are precipitated by the need to be in close proximity to support networks due to an inadequate environment. The third and final

move to institutional care occurs when chronic illness becomes more severe and informal support networks can no longer meet care needs.

In a participant observation study of the elderly in a small Appalachian community, Rowles (1983) puts forth a humanistic model to capture the migration process of decision-making. This model proposes that there are diverse subgroups of elderly who have numerous motives for moves but the motivation to remain in ones home is a function of attachment to place. The final move is usually triggered by a "health crisis." Rowles claimed that the preceding phase of "accommodation," where tactics are introduced to offset chronic illness and declining health, serves to prepare the elderly for the eventual move.

In a more recent study, Cutchin (2001) uses "place integration" to theorize about elderly migration. This theory proposes that aging-in-place and migration reflect a dynamic relationship between person and place. In response to change, the meaning of place is modified for the elderly as they become "reintegrated" into their environment. Cutchin argued that although the possibility for moving is continually present, successful on-going place integration reduces such chances.¹

¹ An example of successful reintegration would be an effective home adaptation to accommodate disability following a fall to keep the person in their home.

2.3.3 Additional Theories of Decision Making

Similar to Rowles (1983), several authors (Forbes and Hoffart, 1998; Rockwood, 1996; Mavundia, 1996; Wielink, 1997) have provided insight into the decision-making process used by elderly individuals in response to changing circumstances and the environment. The consensus among the various theoretical perspectives is that this decision involves the careful balancing of needs against available resources. Consideration is given to such psycho-emotional experiences as feelings of being a burden and loss of identity.

In a qualitative study, Forbes and Hoffart (1998) identify a complex system of formal and informal service, or a “precarious balance” of service, used by community dwelling elderly. Using semi-structured interviews, highly functional elderly in nursing homes and the community were interviewed to determine why some moved to an institution while others remained in the community. The findings suggest that decision-making is initiated when the balance of support is interrupted or tipped. These authors noted that the presence of competing emotions, between a sense of an independent self and feelings of being a burden, initiates the decision-making process to move to a nursing home.

Similarly, Rockwood (1996) claims that maintenance in the community is mediated by a complex interplay of factors. A careful balancing exists between assets that maintain and deficits that threaten community residence. When deficits outweigh assets, there is a breakdown in the capacity for older persons to remain in the community and institutionalization ensues.

Mavundia (1996) interviewed Black elderly in South Africa who were recently admitted to a nursing home. The findings reveal four types of factors responsible for institutional placement. Placement decision-making was found to be a function of: physical factors, such as declining health and chronic illness; social factors, such as assault and elder abuse; psychological factors, such as guilt; and, finally, psychosocial reasons, such as loneliness.

Finally, Wielink (1997) uses a consumer behaviour model to examine elderly people's preferences for care. The findings suggest that when needs are met the elderly tend to evaluate available options by weighing the advantages and disadvantages of each. When confronted with increased personal care needs, the perceived usefulness of informal care decreases and greater consideration is given to the residential care option, especially for the frail elderly who see themselves as requiring greater support in the longer term.

2.3.4 Decisional Control

For many elderly, the decision to seek placement in a nursing home is often due to circumstances beyond individual control. Wiseman and Roseman (1979) claim that change occurs in the locus of control over decision-making that reflects a shift from the individual to family members. McAuley and Travis (2000) also argue that adult children play a fundamental role in the decision-making process. McAuley and Travis (1997) suggest that the elderly person has limited control over the decision-making process with the hierarchy of influence shifting from spouse to children to family members and health professionals depending on who is available at the time of decision-making. These

authors also note that because institutional moves are often involuntary, the elderly person at risk may have limited say in the decision. Cheek (2001) notes that although the process of institutionalization inevitably leads to negative emotions, actual levels of negativity are determined by such things as the availability of information and the degree to which one feels involved in the decision-making process.

2.3.5 Perceptions of Support

If we assume that the elderly have some autonomy or control over the decision-making process, the weighing of circumstances determines the final decision. Undoubtedly, the extent of care and responsiveness of one's support network play a key role in how the individual evaluates the environment. Almind (1985) suggests that nursing home placement is influenced by such *social conditions* as housing and caregiver issues. Thus, initiatives that strengthen informal social networks and provide twenty-four hour a day care could reduce placement. Bauer (1996) finds that the stronger one's overall support networks, the smaller the chance of institutionalization. In a comparative study of women who lived in the community with those who lived in residential care, MacLennan (1984) found that proximity to support was the most important factor in avoiding institutional placement. This was especially true in crisis situations. This research suggests that while support is an important factor in reducing the chance of nursing home placement, proximity and consistency of one's support network may be just as crucial.

2.3.6 Synthesis

The literature reviewed in this section of the chapter reported on research focusing on the decision-making process of institutionalization. It provides a relevant discussion on individual perspectives of aging and institutionalization in terms of declining health, support networks and autonomy. Most of this research either preceded the decision to apply (Almind, 1985; Angus, 2005; Lee, 1997; MacLennan, 1984; Rowles, 1983; Rubenstein, 1989) or followed admission to a nursing home (Cheek & Ballantyne, 2001; Mavundia, 1996; McAuley & Travis, 1997; McAuley & Travis, 2000; Scocco, 2006). Other researchers investigated both community dwellers and nursing home residents (Jenkins, 2000) or those in an alternative facility such as supportive housing (Kontos, 1998). While vital to this discourse, none of the studies include the point in time when the all-important decision to move was made and followed that decision to actual institutionalization. With none of the research focusing on elderly applicants *per se*, the individual perspective especially on the emotional and tangible circumstances experienced following application is missing. Consequently, a full understanding of the process in its entirety is largely absent from the discourse.

Work on migration patterns of the elderly has helped enlighten our understanding of the aging process by linking migration and health status within specific subgroups. Although it clarifies the role played by important triggers at different stages post-retirement, the personal experience of the elderly person is largely missing from the discussion. For example, Serow (1987) investigated cross-national comparisons of migration and Litwak and Longino (1987) studied post-retirement groups versus later life group migratory

patterns. While the research contributes to our understanding of larger group behaviour, it does not capture the essence of the individual's experience of aging and the transition to institutionalization.

2.4 Alternatives to Institutionalization

Many western countries have attempted to move away from costly institutional care and fragmented community services to community-based long-term care models with integrated systems of support (Friedman, 2005). The research suggests that institutionalization could be avoided for many elderly persons if appropriate social environments were available and greater coordination existed between settings to increase system responsiveness (Bauer, 1996). Two approaches are proposed to reduce the risk for institutionalization of the elderly. The first of these approaches for meeting the long-term needs of the elderly is "service-enriched housing models" and the second is "integrated systems of care," which attempt to successfully merge medical and long-term care delivery. The continuum of services for the elderly under both systems of care will be briefly reviewed in the following section.

2.4.1 Service-enriched Housing Models

The next "best" alternative to remaining in one's own home is to receive community-based care in housing designed specifically to accommodate residents' needs. Although housing models have different names across national and international jurisdictions, they share similar attributes (Baker, 1990) and are designed to avoid the negative effects of institutionalization by simultaneously providing an adaptive housing environment linked

with as-needed support services (Supportive Housing Review, 1999). Pynoos et al. (2005) describe service-enriched housing as “living arrangements that provide health and/or social services in an accessible, supportive environment.” In an international review of supportive housing and care models of the elderly Gnaedinger (1998) states,

“It has become apparent that the term supportive housing overlaps conceptually with “sheltered and very sheltered housing” in England and Wales, “service apartments” in Sweden, “protected senior apartments” in Switzerland, some forms of “assisted living” and “congregate housing” in the USA, “assisted independent living” in Australia and “adapted” and “sheltered housing in Denmark.” (p 1)

The goal of all service-enriched housing models is to provide a combination of housing and social and care needs in a location where support and community services provide seniors with a complete living environment (Wailer, 1988). Several service-enriched housing models are discussed while highlighting the nuances between several of the more prolific models including their philosophy, design characteristics and target population.

2.4.2 Assisted Living

Assisted living is a term used more commonly in the United States to describe a model of service-enriched housing. By 1998 over a million people lived in some form of assisted living environment in the United States (Fonda, Clipp & Maddox, 2002). Its core philosophy is to provide living environments that are responsive to the preferences of elderly residents (Hernandez, 2005). This means providing a “home-like” residence that allows for privacy, control and autonomy in a space that is their own but simultaneously accommodates their changing needs (Wright, 2004).

The physical structure of assisted living facilities (ALFs) ranges from adapted homes to renovated portions of nursing homes or buildings purposely built to accommodate residents. The physical environment of most ALFs includes a private living space with a lockable door and amenities such as a private bathroom as well as food preparation and eating areas. In addition, communal areas for dining and socializing are usually included (Hernandez, 2005). Most of these assisted living facilities include formal support 24-hours a day based on need for nursing care, housekeeping, laundry, maintenance, meal preparation, medication management and coordination of medical needs like doctor visits and management of chronic illnesses. For some ALFs the combined environment and services are meant to be a mechanism to enhance "aging-in-place" to accommodate the changing needs of the residents (Hernandez, 2005).

Assisted living varies from state to state depending on regulations and government definitions (Wright, 2004). In a national survey of assisted living facilities, Hawes et al. (2003) found variations in services available, size and type of facilities and overriding philosophy. In another review of ALFs, Wilson (1994) maintains that over time assisted living has mutated into three types of models. The first model, "housing with services", emphasizes housekeeping services more than intensive personal care. The second, "personal care" model, provides both housekeeping and personal care services. The third type is a response to demands of residents for "aging-in-place" where more skilled care such as nursing services is provided more intensively and readily.

In an overview of assisted living, Wright (2004) asserts that the typical resident in an assisted living facility in the United States is a widowed, white woman in her mid-eighties. In general, most residents of assisted living need more help than those living at home but less than nursing home residents. Overall, assisted living claims to be a beneficial service-enriched housing model for an elderly population not in need of the professionally skilled services provided in nursing homes (Fonda, Clipp & Maddox, 2002).

2.4.3 Supportive Housing

A significant amount of research was conducted in Canada during the 1990's to evaluate "supportive housing", a model of service-enriched housing similar to "sheltered housing" in the United Kingdom (Baker & Prince, 1990). The term "supportive housing" is generally used in the literature to describe types of service-enriched housing models. Supportive housing is different from assisted living because formal support services are typically provided from the community as opposed to on-site as with ALFs (Supportive Housing Review, 1999).

Supportive housing is provided in a supportive environment with the goal to reduce the stress of daily chores. It minimally provides a self-contained private space with private bathroom, 24-hour a day monitoring or alarm systems, a superintendent or caretaker and optional meal provision (Baker & Prince, 1990). The target population of supportive housing is similar to that of ALFs. In a review of relevant literature of supportive housing models, it was found that individuals who could benefit most from this type of housing

are the low-income elderly, over 75 years of age, living alone with moderate disability and inadequate community support (Supportive Housing Review, 1999).

2.4.4 Congregate Housing

Congregate housing, one of the oldest formalized service-enriched housing models in the U.S, was intended to provide supportive communal living to low-income frail elderly. As a United States government initiative in the 1960's, it differs from assisted living in that federal funds cover a portion of the costs (Monk & Kaye, 1991), but it has a similar philosophy to increase individuals' security and involvement in their community while maintaining their autonomy (Fishbein, 1975). Supportive services provided in congregate housing mirror those of supportive housing, which emphasize easing daily tasks (Sheehan & Oakes, 2003). The target population are the elderly who are in good physical health but do not want to live alone and could benefit from greater socialization, elderly persons who have a history of poor physical health and are in need of a supportive environment for recovery, or frail elderly who require both formal and informal supports (Monk & Kaye, 1991).

2.4.5 Additional Service-enriched Housing Models

Continuing Care Retirement Communities (CCRCs) are organizations in the United States that provide housing, health care and support to independent and healthy retired individuals with middle-class incomes (Gupta and Galanos 1996). CCRCs are based on a philosophy of aging-in-place. Consequently, most CCRCs provide different housing

options and a range of health and support services that are planned when residents enter the facility and can be adjusted as needs change (Krout, Oggins & Holmes, 1998)

The term “sheltered housing” has been used in several countries in Europe to describe service-enriched housing models. In Denmark a significant shift in policy to deinstitutionalization and community-based care in the 1980’s allowed for the development of such facilities (Cates, 1994). Some of these models were renovated nursing homes providing private apartments that included private bathrooms and kitchenettes. The philosophy of this model stresses self-care, autonomy and choice (Coleman, 1995). These residences are similar to supportive housing in that the support and nursing services are provided from the community in an integrated system of care.

There are also many sheltered housing projects in Great Britain similar to those in Denmark. Their forms vary slightly to accommodate different residents and their needs. The design varies from flats with communal spaces to bed-sitting spaces connected to facilities that overall resemble supportive housing facilities (Baker & Prince 1990). Services such as laundry and 24 hour monitoring are available and facilities include communal areas including dining rooms or kitchens (Coleman 1995).

2.4.6 Empirical Evidence

Much of the research evidence supports the usefulness of service-enriched housing models. In a Canadian study that investigated the health-related quality of life of the elderly in four different settings, supportive housing residents were found to have higher

health-related quality of life scores than those receiving home care at home (Wodchis, Hirdes & Feeny, 2003).

Fonda et al. (2002) compared the functional patterns of low-income elderly residents in an assisted living facility with their counterparts living in the community. Although both groups were comparable on functional decline and mortality rates, assisted living residents were found to have higher and more stable functioning over the same two-year period, and overall were successful in avoiding institutionalization.

Ball et al. (2004) examined how assisted living residents managed declining health. The findings indicate that despite continuing on a course of declining health, the ability to age-in-place was a function of residents' and facilities' capabilities coupled with assistance from outside sources from the community. The findings also suggest that assisted living facilities can fulfill the psycho-social needs of residents by representing "home" and providing meaning to residents' lives.

The research findings conflict on how well service-enriched models of housing prevent institutionalization. It has been suggested that assisted living facilities may not prevent but only delay institutionalization in the long-term (Ball et al., 2004). Overall, the research findings suggest that these models have been successful in delaying placement for some elderly residents and avoiding institutional placement entirely for others (Golant, 2004; Fonda, Clipp & Maddox, 2002). Service-enriched housing models can be a useful alternative for the frail elderly with chronic illnesses at risk for nursing home

placement (Golant, 2004). As well, these housing models enhance socialization and improve the social support network of residents (Cleak & Howe, 2003).

Furthermore, initiatives that attempt to keep the elderly in the community are only useful if they target the appropriate group. Studies suggest that those not at high risk of institutional placement have taken advantage of these models and, in turn, have created an unintended increased demand for the option in a larger segment of elderly, known as the “woodwork affect” (Supportive Housing Review 1999). For example, it has been suggested that some home care programs initiated in the community had little effect on institutionalization rates because they were not targeting those that were at risk for institutionalization (Johri Beland and Bergman 2003).

These models must also ensure the necessary services are cost-effective and appropriately targeted. Pampel, Levin and Louviere (1984) find that most elderly desire an alternative comparable to their current environment. Moreover, demonstrating cost reductions by using service-enriched housing models versus institutional care has varied results (Johri Beland and Bergman 2003; Supportive Housing Review 1999). While variation exists in these models, differences were largely regarding the private spaces available to residents, support services delivery, either on-site or through an agency, and the financial cost of residence. Wright (2004) found the cost of residency in assisted living facilities was largely unaffordable for low to moderate income elderly. Similarly, others also point to the inaccessibility of assisted living to low and moderate income elderly (Fonda, Clipp and Maddox 2002; Hawes et al. 2003).

2.5 Integrated Health Systems

It is evident that the delivery of long-term care and health care services to the elderly is fragmented (Bauer, 1996). Structural problems exist within and between agencies responsible for support service delivery due to inconsistent policies, different funding mechanisms and lack of coordination between organizations (Kodner, 2002). Inefficient delivery of health and care services is blamed for increasing costs and creating unsuitable outcomes such as inappropriate institutionalization (Beland et al., 2006). Integrated service systems or integrated care models were developed in an attempt to forge more effective links between health and support agencies and to provide fully comprehensive care to the elderly. The following section discusses common characteristics and objectives of integrated systems and their effectiveness, as they exist in many countries.

2.5.1 Overview of Integrated Care Models

Many integrated models of care date back several decades with one of the first the American model “On Lok,” a program created in the 1970’s in San Francisco’s Chinatown to avoid institutionalization of the elderly eligible for nursing home placement (Johri, Beland & Bergman, 2003). Since that time various models have been created in many countries including Canada, United States, Italy and England. The target population has been the frail elderly who are eligible for nursing home care or at risk for institutionalization (Johri, Beland & Bergman). The primary objectives of these models are to improve quality of life and services to the elderly, avoid institutionalization and redirect and coordinate long-term, hospital and community care resources more efficiently (Kodner, 2002).

Based on an international review, Johri (2003) reported that integrated service models share common characteristics. Firstly, the models use a case-management approach to deliver care that is characterized by a multi-disciplinary team approach and comprehensive assessments of enrollees. The multi-disciplinary team usually includes a case manager primarily responsible for linking service agencies with family physicians or geriatricians who are commonly gatekeepers to these programs (Kodner, 2002). The second commonality is a single-entry system where all clients are assessed. Single-entry points are beneficial because they allow stable numbers for planning and financial purposes (Johri, Beland & Bergman, 2003) and consistent client assessments (O'Reilly et al., 1998). Finally, Johri claims that many of the effective models include financial mechanisms to achieve cost-effectiveness such as capitation or in the case of publicly funded systems attached "pseudo-costs" to care plans based on resource use.

2.5.2 Examples of Integrated Care Models and their Effectiveness

The System of Integrated Services for the Frail Elderly (SIPA) in Quebec was developed from a synthesis of existing international models of integrated care. This model delivers coordinated primary health care and services as well as long-term, acute, community and institutional care. Integration is facilitated by a multidisciplinary team that assesses and adapts services to the client. It is meant to be a flexible system that is responsible to the individual regardless of residence or required resources (Beland et al., 2006). An evaluation phase was included at project inception. The findings indicate that SIPA significantly reduced waiting times in acute care hospitals, waiting periods for nursing

home placement and the number of emergency room visits. Comparatively, SIPA clients with fewer chronic illnesses had lower institutionalization rates than their counterparts living in the community, and duration of hospital stay was also less for those with the greatest functional disability (Beland et al. 2006).

The Program of All-inclusive Care for the Elderly (PACE) is an American model of integrated care targeting low-income frail elderly eligible for institutional care but who want to remain in the community. The objectives of PACE are to maintain the independence of elderly clients and reduce costs by delaying institutionalization. PACE is modelled around an adult day center where health, long-term care and home care needs are assessed and delivered by a multi-disciplinary team (Friedman et al., 2005). Several studies commissioned by the U.S. government in the 1990's to evaluate PACE have demonstrated its effectiveness for reducing institutionalization (Kodner, 2002). In a recent multi-centered study, Friedman et al. (2005) investigated the risk of nursing home entry for PACE enrollees and found that while all participants were eligible for institutional placement, their risk was less than 15% over a three-year period.

Two programmes were initiated under the national Silver Network Home Care project in Italy (Johri, Beland & Bergman, 2003). The Roverto and Vittorio Veneto programs operate under a community-based case-management system via a single-entry point that includes a geriatrician, nurses and social workers. The target population of both programs are those over 65 years of age with multiple chronic conditions who are receiving home care. Two studies were designed to evaluate these programs. The first study was a

randomized control trial. The findings indicated that program clients had lower hospital and nursing home admissions and improved physical functioning compared to the control group. A second before-after design study also documented a decrease in hospital admissions and length of stay in the client group compared to rates before program implementation (Kodner, 2003).

Similar models of integrated care were implemented in other European countries. The Darlington model in the United Kingdom targets high-risk elderly and has had significant success in reducing institutional rates (Johri, Beland & Bergman, 2003). In addition, the integrated home care system in Denmark has homecare and nursing staff from institutions working interchangeably. Staffing resources are mobile allowing for greater flexibility in moving resources to meet the greater need. Models are constructed at the municipal level and facilitated by home help workers who provide a range of health and support services over a 24-hour period (Coleman, 1995).

Although integrated models of care demonstrate preliminary successes, they have challenges. Programs such as SIPA and PACE represent a significant shift in long-term care policy. Many models operate on a small scale with limited enrolment at an experimentation level or are referred to as “work in progress” (Kodner, 2002). In the United States in particular there have been enrolment problems for various reasons (Mollica, 2003). For example, many governments are not yet willing to institute the necessary sweeping changes to their models of delivery of care to accommodate such

programs. As a result, these programs have not been implemented or tested on a larger scale (Johri, Beland & Bergman, 2003).

2.6 Synthesis

The provision of care to the frail “oldest old” in our society is difficult at best. The dynamic and unpredictable nature of health and resultant care needs in older age can be a daunting task for those who deliver care. This chapter provided a framework to examine the decision-making of frail elderly surrounding institutional placement. The findings suggest that a range of physical, emotional, psychological, social and economic factors work singularly and cumulatively to increase the risk of institutionalization. Demographic variables such as age, gender, marital status and socio-economic status are important factors, as well as the strength and composition of, and proximity to, informal support networks. Additional factors that are significant predictors of institutionalization include critical health episodes or events such as death of a spouse.

Investigations focused on the migratory patterns of the elderly and their decision-making process reveal that the decision to institutionalize is a complex, multifaceted one linked to self-identity and place attachment. The process is subject to interacting factors that may promote or inhibit maintaining independence depending on one’s circumstances. These circumstances also shape the scope of decisional control and autonomy the elderly have regarding their welfare, and thus impact outcome.

Finally, numerous alternative models were developed over several decades to diminish the traditional system's emphasis on institutionalization and fragmented and disjointed care delivery. Service-enriched housing models focus on fostering independence through an adaptive environmental system comprised of diverse services along the continuum of care that intend to be all-encompassing and flexible enough to accommodate changing needs. Many of these models in various forms exist in Canada and a few in Newfoundland and Labrador. Primarily named assisted living or supportive housing in Canada, these models provide flexible as-needed services to Canadian elderly with varying degrees of support or ability to age-in place.

Alternatively, integrated care models are designed to merge long-term and acute care services by eliminating the traditional fragmented medical model of care. A case management or team approach is used to assess and care for individuals in a holistic manner. The belief is that such an approach provides a more responsive and streamlined care style that can, if appropriately managed, be more cost-effective for governments and improve quality of care.

The literature from this review highlights the complexities of the delivery of support services and care models to a group with such divergent health, social and emotional needs. It suggests that the inevitable decline in health, ability to access resources and the changes in status and position that previously informed one's self-identity erode an individual's ability and determination to maintain existing living circumstances. The consequence of these shared experiences by the elderly can be viewed in common

migration patterns that occur at different points in old age depending on several social, psychological, physical and emotional factors. These experiences or factors ultimately culminate into a decision to move. Where an individual moves depends largely on one's resources and proximity to options. It may be to an institution, but it can be to an alternative model of care meant to avoid institutionalization if that option is accessible and deemed the "right fit" by the individual and one's support network. The scope of the discourse reported here provides for a clearer understanding of the issues and can guide the development of a comprehensive model to respond to the aging population needs.

Chapter 3

Methods and Research Design

3.1 Introduction

The purpose of this study is to assist with future planning of the long-term care sector in the province of Newfoundland and Labrador. Previous research indicated the long-term care sector was lacking alternative care options, problems existed with acute care bed usage, there was inappropriate placement into nursing homes, and a true single-entry system that responded to the individual needs of each client did not exist. Consequently, the study was conducted to investigate the decision-making process of applicants to the single-entry system with modest care needs.

3.2 Research Design

The study was conducted in two stages. The first stage was the quantitative phase whereby chart reviews were conducted of the incident cohort in order to gather the following data:

- Characteristics of applicants such as marital status, age, gender and residence;
- Care requirements as determined by the assessment tools;
- Health and functional status of clients;
- Acute and chronic care usage;
- Stated preferences for facilities;
- Reasons for application;
- Formal support use and presence of informal support;
- Outcome of application; and

- Time to placement.

The participants for the second or qualitative phase of the research also came from the incident cohort. The qualitative research was carried out to understand more clearly the meaning of the quantitative data and to determine how the interplay of one's circumstances may prompt application for placement. The interviews hoped to understand:

- reasons for and causes of the decision to apply for long-term care placement;
- the role of applicants' support network in the decision;
- reasons for preferences of particular facilities and attitudes regarding existing options and finally;
- opinions regarding alternative housing options.

3.3 Study Population

Data were collected over a fifteen-month period between March 1999 and August 2000 of all those who applied for long-term care placement in nursing homes and personal care homes in the St. John's Region. Chart reviews were conducted using the Alberta Resident Classification System (ARCS), Alberta Home Care Client Classification (AHCCC) and the Resource Utilization Grouping System (RUGS III) to determine the objective care requirements of all cognitively well applicants who were categorized as Level I and II by Health and Community Services long-term care, single-entry system. Information was also collected on household composition, recent hospitalizations, presence or absence of

both informal and formal support, preferences of facilities and stated reason for placement.

3.4 Sample Selection

The study included all new clients applying for institutional placement via the single-entry system, between May 1999 and August 2000. All applicants residing in the St. John's Region, ≥ 65 years were eligible.

3.5 Incident Cohort

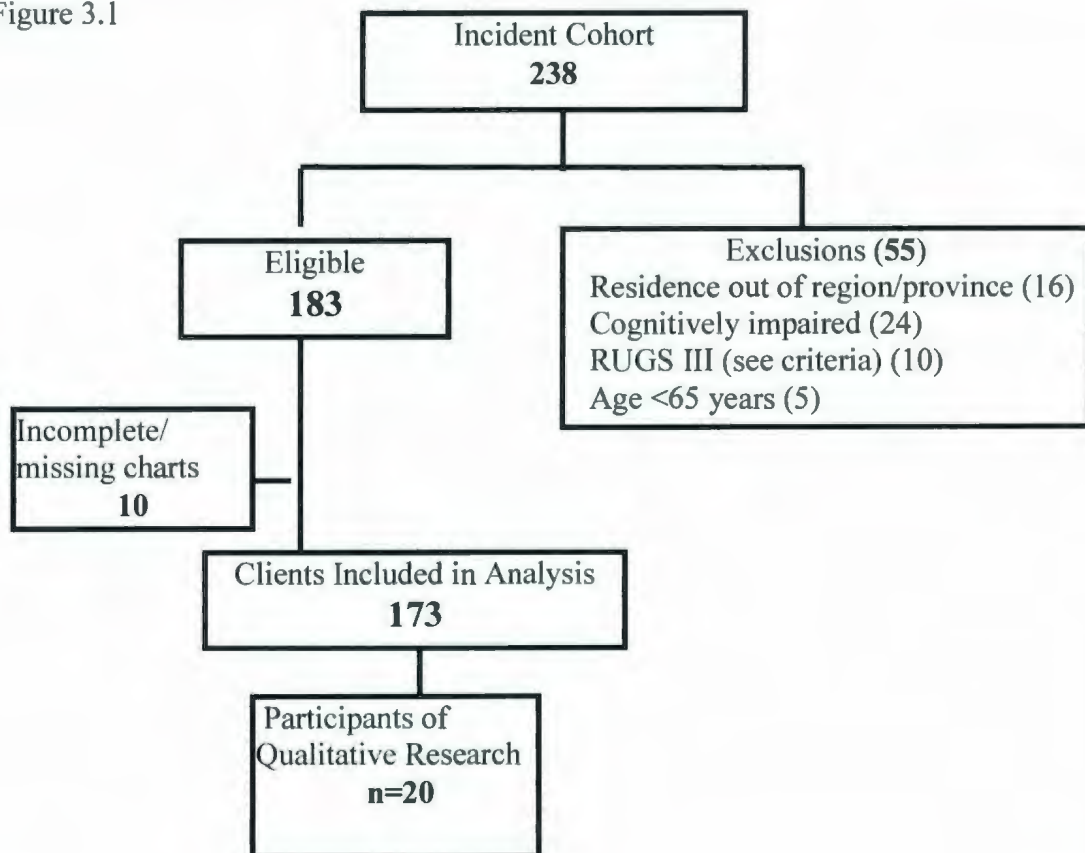
To be included the individual had to be assessed by the single-entry system multi-disciplinary panel either Level I or II, cognitively well, and at least 65 years of age. Excluding those with incomplete or missing charts and using the above stated exclusion criteria, 173 were deemed appropriate for analysis.

3.6 Inclusion/ Exclusion Criteria

To be included in the study all applicants must have been assessed by the St. John's Health Region Health and Community Services (HCS) single-entry system following a request for institutional placement. Details are provided in Figure 3.1. Clients were excluded if their applications were deemed precautionary, if they were applying for placement from another health region, if they were requesting transfer from one facility to another; if their charts were missing significant data or if they were in respite care. In addition, clients were excluded if assessed by the panel as either cognitively impaired, requiring care greater than Level II or requiring complex or significant care that translated

to a RUGS III indicator that would necessitate professional care. Certain indicators such as oxygen therapy, terminal illness and wound dressing did not immediately exclude participants although listed as RUGS III indicator as this would not entirely preclude an individual from residing in the community or alternative housing arrangements. These applicants were included to determine appropriateness of placement to alternative care arrangements other than nursing homes.

Figure 3.1



3.7 Health and Community Services Data Collection Instrument

All individuals applying for placement were assessed by Health and Community Services in the St. John's region using the Newfoundland and Labrador Continuing Care

Assessment for Adult Long-Term Care. This assessment tool gathers information on informal supports, formal and community support information, activities of daily living (ADL's), instrument activities of daily living (IADLs), levels or degree of disability and other medical problems such as chronic illness, and case reports on social issues. From this instrument, a chart review was conducted to determine 1) The RUGS III category for each client as well as their 2) Alberta's HCCC System score and 3) Alberta Resource Utilization score and all other relevant information contained in the chart (See Appendices).

3.8 Classification Systems

The Alberta Resident Classification System (ARCS), Alberta's Home Care Classification – Functional Need Score (HCCC) and RUGS-III system were used in several studies researching long-term care in the province to determine objectively the needs of those in the long-term care sector (McDonald et al 2005; O'Reilley et al 1998). For this study, the assessment tools were incorporated into one data abstraction form and applied to the information provided in the charts (Appendix A). The chart abstraction form's purpose was to determine the functional status and precise care requirements of each individual in the incident cohort.

3.8.1 Resource Utilization Groups III

The Resource Utilization Groups (RUGS-III) was developed as a tool to identify combinations of resident characteristics that would result in different resource use in nursing homes. It was developed using the Minimum Data Set (MDS) for measuring daily

resource use. The RUGS-III classification system was designed to discriminate between and, in turn, classify patients into need and resource use groups by considering their medical conditions and consequent need for treatment, services and psychosocial factors. Patients are assigned to one of seven groups (Rehabilitation, Extensive Services, Special Care, Clinically Complex, Impaired Cognition, Behaviour Problems and Reduced Physical Function) based on clinical characteristics. In addition, the sum of four activities of daily living (ADLs) variables – bed mobility, toilet use, transfer and eating – are scored to determine overall resource needs (Carpenter, Maiw & Turner 1995).

3.8.2 The Alberta Resident Classification System

The Alberta Resident Classification System (ARCS) has been used since 1991 to determine and allocate resources for long-term care facilities in Alberta, Canada (Hirdes 1997). It determines resource needs by levels with each level based on the degree of disability from each category of continence, behaviour and activities of daily living (Armstrong-Esther, 1994).

3.8.3 The Alberta Home Care Classification System

The Alberta Home Care Client Classification – Functional Need Score (FNS) was developed to determine the requirements of clients assessing the long-term care sector. It is made up of 13 key indicators that assess the functional needs of the clients. Levels of independence are assessed based on the type and amount of services one would need to maintain independence. A category of functional need is computed from the sum of

scores of each of the indicators ranging from low (1) to high (5) (Health and Welfare Canada 1992).

3.9 Placement Decision Tree

To determine which option was most appropriate for each applicant, a decision tree was used (Figure 3.2). All applicants deemed eligible in the incident cohort were assessed by the researcher and classified into one of the following long-term care options depending on assessed need: (1) personal care home; (2) nursing home, level I or II; (3) supportive housing; or (4) supportive housing with additional home supports.

The decision tree is based on the assumption that supportive housing and supportive housing with home supports were options for individuals applying for placement via the single-entry system. The algorithm assumes a team, which includes the client, assessment team and family similar to integrated care models discussed in Chapter 2, and initiates an assessment plan.

Alberta Resident Classification Scores (ARCS) were calculated and clients were placed in one of two groups, ARCS of A-B (supportive housing or personal care home) or ARCS of C-E (nursing home or personal care home). There were no clients eligible for analysis that fell into the higher category F-G. The functional need score of the Alberta Home Care Classification was also determined for each applicant. Applicants that scored 3 or above (moderate to high needs) on the FNS were assessed for either a nursing home or

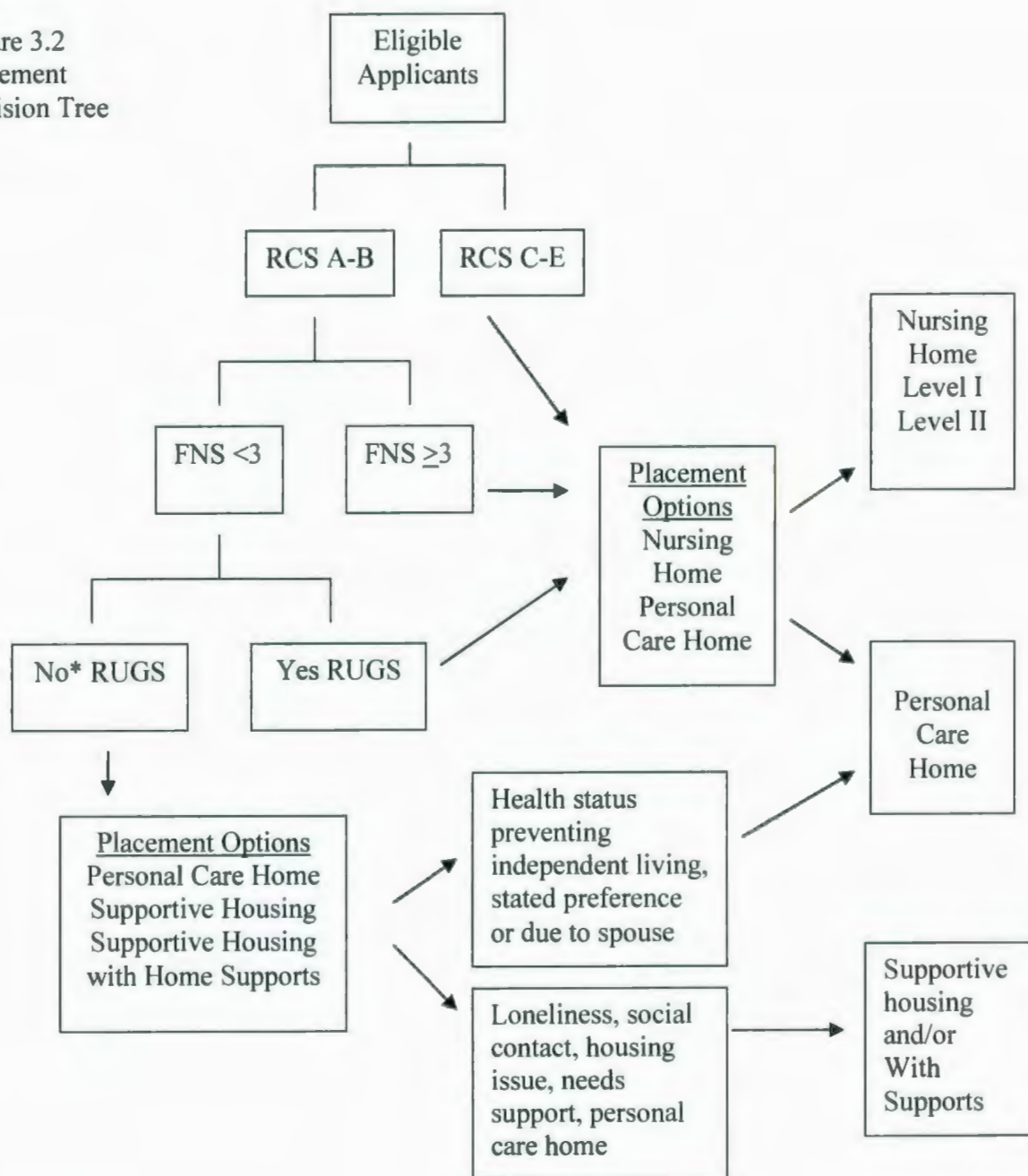
personal care home. Applicants who scored 0 (fully independent) to 2 (low to moderate) were eligible for supportive housing or personal care home placement.

Finally, only those with a RUGS indicator that could be potentially cared for in the community could be a candidate for supportive housing or a personal care home.

Otherwise, those with a RUGS indicator were assessed for a nursing home or personal care home. This decision was based on the applicant's ARCS and FNS score and by the type of indicator they had and the decision about whether these indicators actually required professional nursing care in a nursing home. For example, those recovering from a hospitalization or an illness such as cancer or a fall, or received intermittent oxygen therapy were not automatically deemed indicators that necessitated nursing home care if improvement was expected.

Once scores for each applicant were determined based on the objective criteria of the assessment tool, additional information regarding the applicant was assessed. For example, applicants who have a low FNS and Resident Classification Score (RCS) and have stated "loneliness" for their reason for placement would be a candidate for supportive housing. Alternatively, an applicant with the same FNS and RCS but have stated a preference for a personal care home in their community are assessed for that facility. In other words, options were determined, firstly, by an individual's health and functional status and, secondly, their personal situation and preferences were then considered to determine the optimal placement decision.

Figure 3.2
Placement
Decision Tree



Optimal placement was based on a number of rules:

- When an applicant is applying due to their spouse health needs, the facility is determined by those assessed needs. For example, individuals were assessed for a Level I nursing home bed regardless of individual needs if their spouse required nursing home care and was being placed in a nursing home;
- The category of “supportive housing with home supports” is used when an individual is assessed for supportive housing but requires additional support. For example, an individual who has short-term support needs for services such as rehabilitation due to surgery or a fall, or alternatively, requires a regular amount of personal care but could otherwise live independently would be assessed for this option; and
- Applicants who score appropriately for supportive housing but have a chronic condition or a disability that hampers independently living are instead categorized for a personal care home. For example, vision problems or a physical disability that requires continual supervision would be better suited in a personal care home.

3.10 Qualitative Research Population

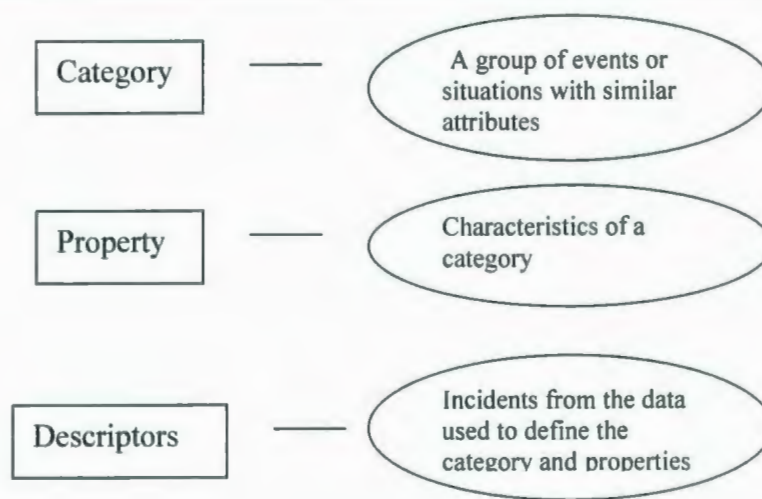
The incident cohort was the source for the qualitative study population. Participants had to be ≥ 65 years old, applying from the St. John’s Region, assessed by the HCS panel as Level I or II and cognitively well, able to understand the interview process and willing to give informed consent to participate. As charts were completed and individuals were

deemed eligible from stated criteria above, letters were sent to individuals via a Health and Community Services placement worker with a corresponding letter from the researcher. This process was continued throughout the chart review phase until an appropriate number of participants were recruited to interview.

3.11 Grounded Theory Background

Grounded Theory was first developed by sociologists Glaser and Strauss in 1967 and was further developed by Chenitz and Swanson (1986) and Strauss and Corbin (1990) to facilitate a greater understanding of human behaviour by generating theories of psychosocial and emotional phenomena. Its theory is rooted in the meanings of events to people in their natural environment, and describes the perspective of individuals' common behaviour (Sheldon 1998). Grounded theory is a widely used research approach whereby the generation of theory, from largely unexplored areas, is investigated from the analysis of semi-structured interviews, observations, and other documentation. Its aim is to establish themes or *categories* from sampling or coding, simultaneously reducing data into units of analysis to understand emerging categories (Figure 3.3.). This process of sampling continues until no new categories emerge and all categories present are fully understood. This is referred to as *saturation* (McCann & Clarke 2003).

Figure 3.3



3.12 Qualitative Method

As participants were identified through chart reviews, a letter was sent by the researcher that explained the study and invited them to participate. A follow-up phone call was conducted to eligible individuals by the investigator approximately a week after the letter was sent to ascertain their willingness to participate. If the individual agreed to participate, an appointment for an at-home interview was scheduled at the participant's convenience.

At the scheduled appointment, the study was explained at length by the investigator, as was the consent procedure. Preceding and throughout the interview, participants were able to ask any questions or receive any further information regarding the study's intent. Interviews were conducted between June 1999 and August 2000. Semi-structured, audiotaped interviews, ranging from 50 to 90 minutes, followed receipt of informed

consent. Interviews were recorded to ensure accuracy of information and participant's responses to the interview schedule and to maintain conversational continuity. As interviews were conducted, transcription and the first stages of analysis began on the transcripts. This process of interviewing and transcribing occurred simultaneously with the chart reviews.

3.13 Interview Schedule

The interview schedule developed for this study was designed to explore the decision-making process of individuals applying for long-term care (Appendix B). Open-ended questions were based on related literature and expectations of need individuals might have in these circumstances. The questions or probes were designed to generate data on participants' entire personal circumstance and environment. For example the tangible aspects of their lives were explored, such as opinions on their housing environment and physical restrictions due to deterioration of health, as well as the intangible aspects such as feelings of loneliness, being a burden to others, and loss of independence and autonomy.

The schedule's purpose was to probe into perceptions of health and well-being and future expectations regarding their decision and the facility chosen. In open-ended interviews the responsiveness of participants' varies, as does the flow or continuity of conversation. Therefore, it was unnecessary to use all questions directly and instead many participants volunteered sought-after information as the interviews took on a life of their own.

There were certain themes that were more difficult to explore. For example, when perceptions regarding facilities were negative, urging participants to verbalize their opinions was sometimes difficult. Some did not feel comfortable clearly stating their opinions but indicated by motions and facial expressions or responded ambiguously. Secondly, it was difficult to get many participants to conceptualize an option such as supportive housing as they were unfamiliar with the concept and thus probes were used many times verbatim with additional prompts that would enable them to better conceptualize supportive housing.

3.14 Qualitative Design

All participants were interviewed in their own home at their own convenience. This proved the most suitable place for interviews given many participants' difficulty with mobility and transportation. It also provided the researcher an opportunity to observe participants in their own environment. The first four interviews were conducted jointly with a researcher trained in the field due to the primary researcher's inexperience with the process. The primary researcher (hereinafter 'the researcher') conducted the remaining sixteen interviews. This training enabled the researcher to understand the nuances associated with the interview process, such as appropriate responses to sensitive topics and how to induce or return the interview to a flow when conversation occasionally stalled.

The interview schedule was used by the researcher to explore the elderly's experiences with long-term care and the meanings of their decision-making process through the

course of the aging process and transfer to institutionalization. This constant comparative method of analysis was pursued to determine and describe the conceptual categories present in the data sets. As possible relationships between major theoretical constructs were tested within the data (i.e.: decision-making, perceptions of care) a substantive theory materialized.

3.15 Data Analysis

As data was collected, the interviews were immediately submitted for verbatim transcription. Once returned to the researcher, interviews were listened to again and checked for accuracy. As the process of data collection and transcription continued, analysis was conducted simultaneously by two coders working independently to identify phrases and words with significant meaning and recurring themes. This coding was done to determine the relationships that generated emerging categories through the identification of properties and descriptors. Throughout this process, meetings took place between the researchers to compare and clarify the emerging categories.

The process of data analysis took several months of intensive meetings and drafts to determine the initial three categories and their corresponding properties and descriptors. It continued until it was agreed by both researchers that no new data was emerging and saturation was achieved. It was originally estimated that saturation would take approximately thirty interviews but only twenty were required. It was thought that this was due to the high degree of homogeneity found in the population. All participants were of the same ethnic and cultural background, between the ages of 74 and 92 years old.

There also did not appear to be significant differences in socio-economic status or education among participants. Many had experienced a critical health episode or life event (for example, death of spouse) and many had previously made their decision to move at least once in response to their needs (living in senior's apartment or facility) in the past. Consequently, the saturation point was achieved earlier than anticipated. Overall, 39 clients were contacted before the desired number of interviews was achieved reaching a participation rate of 50%. Analysis continued for some time with researchers attempting to refine the categories and ensure there was no overlapping of emerging themes.

3.16 Ethics

Approval was sought and received from the Human Investigations Committee of the Faculty of Medicine at Memorial University of Newfoundland, Newfoundland and Labrador. In the initial phase of Health and Community Services chart review and analysis, client participation was not required therefore consent was not sought. However, for the qualitative phase of the study, all participants were required to sign a consent form approved by the Human Investigation Committee immediately prior to commencing the audiotaped phase of the interview.

All appropriate measures were taken to ensure confidentiality. Audiotapes were coded and kept in a secure place. Transcribed interviews were stored in a locked filing cabinet accessible only to the researcher. Participants were informed that they would not directly benefit from participation in the study, nor would the study have any negative

consequences. For example, it would in no way affect their position on the waitlist for placement or hamper their acceptance into their preferred facility. In addition, they were informed they could withdraw from the study at any time. Care was taken so no identifying information would be used in documentation or reporting to ensure that confidentiality was maintained.

Chapter 4

Incident Cohort

4.1 Introduction

The chart review of the incident cohort was conducted between March 1999 and August 2000 as the first stage of the study. This chapter reports on the findings of the chart review and results from the analysis of that cohort. A total of 173 charts met the inclusion criteria and were eligible for review. This incident cohort acted as the source for interviewees in the second or qualitative phase of the research.

The purpose of the chart review was to gather information to provide a picture of applicants with modest care needs (panelled as Level I and II cognitively well) applying to the long-term care system in the province. Information collected includes: demographic characteristics such as age, gender and marital status; health and functional status of applicants; acute and chronic care utilization; reason for application and attitudes and preferences towards facilities; support network information such as formal and community support usage and presence and extent of informal support; and outcome information such as outcome of application and time to placement to a long-term care facility.

4.2 Participant Characteristics

Participant characteristics of the incident cohort are provided in Table 4.1. The mean age of the cohort was 82 with an age range of 65-98. The gender differences were 70% female and 30% male. Twenty percent of the cohort were married. Half of the subjects

were widowed and 5% of applicants were divorced, separated and single. Nearly 14% of applicants were applying as a couple. Approximately half of the cohort lived in his or her own home, 20% in the home of a friend or family member, 4% in a personal care home and almost 20% residing in an institution at the time of assessment.

Table 4.1 Characteristics of Incident Cohort

	Total Cohort (%)
n	173
Age (mean)	82.3
Range	65-98
65-74	23(13.3)
75-84	85(49.1)
85+	65(37.6)
Gender	
female	121(69.9)
male	52(30.1)
Marital status	
married	39(22.5)
widowed	90(52.0)
divorced/separated	8(4.7)
single	9(5.2)
Applying to LTC as a couple	24(13.9)
Residence at time of assessment	
Own home	84(48.6)
home of friend or family member	35(20.2)
Personal Care Home	7(4.0)
Chronic Care Hospital	11(6.4)
Acute Care Hospital	33(19.1)
Other (institution)	2(1.2)
Other(communitiy)	1(0.6)

4.3 Health Status of Participants

Table 4.2 presents information regarding applicants' health and functional status. Over 87% of the cohort scored an A or B on the RCS, scores that indicate the majority of the cohort had moderate to low care needs. Over 12% of the cohort had no Functional Need Score (FNS) or were fully independent. Over half or 52.1% of the cohort scored less than 3 or below "moderate" on the FNS. As expected, nearly 83% of the cohort did not have a RUGS indicator. Nearly 18% of the cohort had one of the RUGS indicators that fell into the "community support" category. However, only six applicants could be considered for community support when the decision tree was applied. The indicators included alcohol abuse, intermittent oxygen therapy, depression, diagnosis of cancer and receipt of dialysis.

More than 62% of the cohort suffered from at least one of the chronic illnesses or disabilities that have been shown to be risk factors for institutionalization (Tsuji, Whalen and Finnucane 1995; Rockwood, Stolee and McDowell 1996; Friedman et al. 2005; Woo et al. 1993; Agüero-Torres et al. 2001). It is noteworthy that 17% percent of the total cohort suffered from reduced cognitive function. The level of cognitive impairment had not progressed to the extent to be assessed as such, however, 17% were in the early stages of dementia.

Table 4.2 Health Characteristics of Incident Cohort

	Incident Cohort (%)
Nursing Home Resident Classification Score (RCS)	
A	102(59.0)
B	49(28.3)
C	14(8.1)
D	7(4.0)
E	0(0)
F	1(0.7)
G	0(0)
RUGS Clinical Indicator	
Special Rehab	3(2.0)
Clinically Complex	1(0.7)
Hemiplegia/Aphasia	2(1.3)
Respiratory/Oxygen therapy	7(4.0)
Terminal Illness	8(4.6)
Dialysis	3(1.7)
Impaired Cognition/ Behaviour Problems	6(3.5)
No Clinical Indicator	143(82.7)
Functional Need Score FNS	
0 fully independent	20(11.6)
1 low	36(20.8)
2 low to moderate	34(19.7)
3 moderate	52(30.1)
>3 moderate-high	31(17.9)
Chronic Illness	
Diabetes	28(16.2)
Bowel incontinence	9(5.2)
Parkinson's	4(2.3)
Poor vision	23(13.3)
Stroke	12(6.9)
Fractures	2(1.2)
Cognitive problems	30(17.3)
Total chronic illness	(108)62.4

4.4 Placement Decisions

Figure 4.2 illustrates the breakdown of the cohort using the decision tree. An explanation of the decision tree is provided in Chapter 3. Table 4.3 provides information regarding the placement decisions of the single-entry system panel compared to the researcher's decisions using the decision tree.

As seen in Table 4.3, there are considerable differences between panel decisions and the decision tree. Thirty percent of applicants were paneled for placement in a personal care home compared to just below 14% when the decision tree was applied. Nearly 32% of applicants were assessed for placement in Level I nursing home care compared with 16% of applicants using the decision tree. Ten or 3.2% of these applicants assessed at Level I nursing home were assessed at this level because of their spouse's need for institutional care rather than their need for care. If an option existed to place individuals in an alternative option in close proximity to their spouse with the high care needs rather than in a nursing home bed, numbers in this category would decrease further.

The fewest differences between the panel decision and criteria using the decision tree were those applicants paneled at a nursing home level II. Only two applicants were not deemed by the decision tree to be appropriate for placement at that level. One applicant was receiving oxygen therapy but due to the low scores on the RCS (B) and FNS (1) were assessed at a supportive housing with home supports option. The second also had low scores on both the FNS (1) and RCS (A) and required care for a colostomy but again when the decision tree was applied was also as a candidate for supportive housing.

In total, there were 59 or over 34% of applicants who could be placed in a supportive housing environment, with or without additional home supports. One applicant had applied for entry into a private nursing home (Chancellor Park).

Table 4.3 Incident cohort placement decisions of panel versus recommended placement decisions of researcher by decision algorithm

Placement Options	Panel Decision (%)	Researcher Decision (%)	Total difference per of n beds (%)
Personal Care Home	53(30.6)	24(13.9)	-29(16.7)
Nursing Home LI	55(31.8)	27(15.6)	-28(16.2)
Nursing Home Level II	64(37.0)	62(35.8)	-2(1.2)
Supportive housing	0(0)	50(28.9)	+50(28.9)
Supportive housing + home care	0(0)	9(5.2)	+9(5.2)
Private nursing home	1(0.6)	1(0.6)	0(0)

Table 4.4 Facility Preferences

At the time of application, applicants are able to specify where they desire placement and to refuse certain facilities. Table 4.4 provides information of specific facility preferences by category, stated reason for choice of facility and proportion of those who refused personal care homes. The information provided is the preferences stated by applicants without the choice of an alternative housing model.

Placement in one of the nursing homes in the city was preferred by over 57% of applicants. More than 26% of applicants stated a personal care home as their first choice.

It should be noted that over 17% of those that preferred placement in a personal care home chose a personal care home in the urban region.

As this was not specific data collected by Community Health and Services, nearly 75% of applicants did not state their reason for their preference of a specific facility or the information was not in the chart. For those whose chart included this information, the cited reasons for choice of facility included; location (8.1%), personal experience with the facility (9.2%), chosen because their spouse resided in the facility (4%), religion affiliation (2.3%), veteran status (1.2%) and one applicant (0.6%) stated the provision of care in the facility of choice.

Table 4.4 Facility preference of cohort by category

Facility preference by category	n (%)
Nursing home	99(57.2)
Personal care home	46(26.6)
Department of Veterans Affairs Pavillion	1(0.6)
No preference	27(15.6)
Refusal of personal care home	
Yes	43(24.9)
No	71(41.0)
No data	59(34.1)
Stated reason for choice	
Location	14(8.1)
Experience	16(9.2)
Religion	4(2.3)
Spouse	7(4.0)
Care Provision	1(0.6)
Veteran	2(1.2)
Unknown	129(74.6)

Almost 25% of applicants refused placement in a personal care home. With 8.1% stating location as their reason for facility preference and 17.4% preferring a personal care home in the urban center, location is found to be an important reason for many refusing personal care homes.

4.6 Reason for Application

Table 4.5 provides information of applicants' reasons for application to the single-entry system. Over 20% of applicants stated problems or issues with their support network as their reason for application. This included those that had family or caregiver problems or were receiving inadequate care from their support network. The second category consisted of psychosocial reasons that also made up over 20% of reasons for applicants decision. These were applicants that stated they were socially isolated or lonely or stated they could no longer cope with their daily lives. Finally, those reasons in the "other" category included additional reasons that did not fit in the previous categories such as: a recent death of their spouse (2.3%); housing issues (8.1%) such as eviction, unhappy living conditions, need to move from present living situation; spouse required more care (6.4%); and 2 (1.2%) applicants were requesting a move from a personal care home.

Despite that only 34% cited health or functional status as their reason for application, more than 68% of applicants were assessed for placement in a nursing home. It is interesting to note that when the decision tree is applied, 34% of applicants could be placed in a supportive housing option if made available.

A majority of applicants, over 55% of the cohort, experienced a critical event before application. These events included hospitalization (22.5%), a sudden decline in health (9.8%), death of a spouse (6.9%), a fall (5.8%) or their spouse experiencing a critical event (5.8%). A small number experienced a sudden caregiver issue (1.2%), death of a family member (1.7%), or marital problems (1.7%) such as a separation or divorce.

Table 4.5 Applicants stated reason for application

Stated reasons for placement	Total (%)
Support Network Reasons	
Burden to family	2(1.2)
Family pressure	4(2.3)
Informal support/caregiver stress	15(8.7)
Requires more support/care	14(8.1)
Psycho-Social Reasons	
Coping	5(2.9)
Loneliness or needs more social contact	30(17.3)
Health Reasons	
Cognitive	7(4.0)
Decline in health	47(27.2)
Safety Issues (cognitive or physical)	2(1.2)
Physical disability	3(1.7)
Other	
Death of spouse	4(2.3)
Housing issues	14(8.1)
Requested move from PCH	2(1.2)
Spouse care needs	11(6.4)
No reason provided	13(7.5)

4.7 Support Network

The information regarding informal support was divided into three categories: those that had informal support; those applicants who had informal support such as family or friends but who were unable to provide the level and extent of support required; and those who had no informal support. Almost half (49%) of applicants had informal caregivers in their lives who provided a range of help to applicants whether it was spouses, children, other family members or friends.

Table 4.6 Frequency of recent critical incidents experienced by applicants

Critical Event	Total (%)
Caregiver issue	2(1.2)
Death of family member	3(1.7)
Death of spouse	12(6.9)
Fall	10(5.8)
Hospitalization	39(22.5)
Marital Problems	3(1.7)
Spouse-critical incident	10(5.8)
Sudden decline in health	17(9.8)
Total:	96(56.1)
No Critical Event:	76(43.9)

Over 36% of applicants had informal support that fell into the second category, those who had informal caregivers but for a variety of reasons were unable or unwilling to provide the level of support and care applicants required. This included: spouses who could no longer cope with the care required due to their own health or applicants' health; children

of applicants who had demands in their lives that made it impossible to provide care as required; and caregivers who were just no longer willing to provide the required care. A total of 14.5% of applicants had no informal support to rely on for any or all their needs.

Nearly 39% of applicants were receiving some type of formal supports in the community at the time of application, either privately funded or subsidized through support from Health and Community Services. Types of formal community support ranged from support for health reasons, such as nursing services and personal care, to home support such as housekeeping services and Meals on Wheels.

Privately paid formal supports accounted for 24.4% of the formal supports applicants were receiving, while Health and Community Services made up 6.2% of the services received by applicants. This is not surprising as the ability to qualify for subsidized home supports is based on stringent financial criteria that many applicants do not meet. 22% of applicants were receiving care in an institutional setting, whether an acute or chronic care hospital or a personal care home.

Overall, the majority of applicants did have some form of a support network that consisted of either informal or formal support or both. However, from the findings in Table 4.5 over 20% of applicants cited problems with their support network as their reason for desired placement. A further 17% cited inadequate social contact or loneliness as their reason for application. This suggests inadequacies in many applicants' support network.

Table 4.7 Type and frequency of support network

Type of Support	n (%)
Informal support	
Yes	85(49.1)
Yes, not willing/able	63(36.4)
No	25(14.5)
Formal support	
Home support/personal care (private)	24(13.9)
Nursing, physiotherapy, other (private)	11(6.4)
Nursing Care (CHS)	10(5.8)
Combination CHS and private support	2(1.2)
Respite Care	1(0.6)
Day Hospital	5(2.9)
Formal Support (undefined)	4(2.3)
Other Services (MOWs, VON, etc.)	5(2.9)
Institutional (PCH, hospital)	38(22.0)
No Formal Support	61(35.3)
No data	7(4.0)
Total with Formal support (%)	67(38.7)

4.8 Outcome information

Outcome information was collected for all applicants several months following the chart review was completed. Table 4.8 provides the outcome data for the cohort. By November 2000, while 6% were still awaiting placement, 65% of applicants had been placed. Just over 5% were deceased and 5.8% had withdrawn their application. One (0.6%) applicant has transferred to the precautionary list; one (0.6%) was still awaiting placement from a personal care home and one (0.6%) awaiting placement to the DVA nursing home. There was no information regarding 16.8% of the applicants.

Table 4.8 Outcome of incident cohort

Outcome	N (%)
Placed	112(64.7)
Deceased	9(5.2)
Withdrawn	10(5.8)
Precautionary	1(0.6)
Awaiting from community	10(5.8)
Awaiting from personal care home	1(0.6)
Awaiting DVA home	1(0.6)
No info	29(16.8)

Table 4.9 provides outcome information regarding time to placement by facility and place of residence. Time to placement in a personal care home was just above one month or 36.6 days. Compared with nursing homes, this placement time was significantly shorter as wait times to placement in a level one nursing home bed were nearly seven months (206 days). Wait times for Level II nursing home beds were shorter at four months (120.9 days) but were still significantly longer than personal care home.

Substantial differences also existed when placement times are compared by place of residence. The shortest time to placement by residence was for those who were living at a friend or family member's home, just over forty days compared to over three times that for those living in their own home 126 days or over four months. Those in acute care were waiting three months to be placed in a facility from hospital and five months if in a chronic care hospital. This results in a significant use of chronic and acute care beds by clients waiting for placement.

Table 4.9 Mean Time to Placement of Cohort by facility and place of residence

Time to Placement	
By Facility	Days (months)
Personal Care Home (n=44)	36.6(1.2)
Nursing Home:	
Level 1 (n=22)	206(6.9)
Level 2 (n=29)	120.9(4.0)
By Place of Residence:	
Own home (n=43)	126.1(4.2)
Home of friend or family member (n=19)	40.5(1.4)
Acute care hospital (n=22)	90.6(3.0)
Chronic care hospital (n=7)	150(5.0)

4.9 Discussion

The findings in this chapter provide an overview of a segment of the elderly applying for nursing home placement via the single-entry system. While applicants required a moderate to low need for care, the data revealed that a need for support exists in this group. Scores on both the FNS and RCS signified low to moderate care needs for most applicants but only 7.8% had no functional need score. Moreover, it was found that over 62% of the incident cohort suffered from a chronic illness or disability that has been shown to be a risk factor for nursing home admission, including the 17% of the cohort who were in the early stages of dementia or Alzheimer's. Many had experienced a critical incident such as a fall or hospitalization and 25.5% were residing in hospital at the time of assessment.

From the analysis of this cohort, many participants were measured as having very low or no physical care needs using the assessment tools. Nearly half of the applicants had a FNS score below 3 or, in other words, were largely independent for most care needs. Similarly, with the exception of one applicant, the remaining scored A-D on the Resident Classification System, again representing moderate to low care needs. And 66% of applicants cited something other than their health as the reason for their application.

At first glance, a lack or inconsistency in one's support network does not seem to be noteworthy as only 14.5% were without informal care and many applicants (45.8%) residing in the community had some form of formal support. However, the findings suggest that there were problems with the quality of informal support with over 20% suggesting problems with their support network as their reason for application. The issue with inadequate support is further highlighted by the 36% of the cohort with informal caregivers who were no longer willing or able to provide adequate care.

A number of applicants also cited psychosocial reasons for their application. Loneliness or the need for social contact and an inability to cope with living alone accounted for 20% of the cohort. Additional domestic reasons, such as a death of a spouse and housing issues, constituted another 10% of applicants. In other words, for a significant proportion of applicants, application was precipitated by circumstances and needs other than health and functional status. Therefore, many applicants who require a modest level of care and support are applying for placement to facilities that provide expensive high-level care for social or psychological reasons.

At the time of assessment, applicants are able to state facility preferences for placement. Again, as with the panel, the type of options available limits applicants. Nearly 25% of applicants refused placement in a personal care home or only listed nursing homes on their preference list. It has been suggested this was because there were few personal care homes in the urban centers of the health region. Indeed, of those whose charts included reason for their choice of facility, nearly 32% stated location as their primary reason for choosing their preference. Furthermore, a majority of those who requested placement in a personal care home had requested a home in the urban region. From the analysis of the cohort, it is unknown whether additional reasons exist as to why so many refused placement in a personal care home.

When the decision tree was applied it was found that 34% of applicants could be placed in supportive housing if it was an available option and 15% of those were panelled for level I nursing home care. It must be noted that the majority of differences between the panel decision and the decision tree is largely due to the existence of the theoretical housing model. When those who refused a personal care home (24.9%), those with low-level care needs applying for nursing home care due to their spouse (3%) are considered and the theoretical model is removed as an option few differences between the panel and the decision tree exist. There are few options for either the applicants or the panel to consider. Consequently, the panel was placing applicants appropriately by need with the options that are presently available for them to consider.

4.10 Limitations

There are several limitations to the research. Firstly, information on applicants was limited by the amount and detail of the information collected by Health and Community Services during the application process. For example, many charts did not include information regarding the reason for applicants' choice of facility. Therefore, a true picture of applicants' preferences regarding facilities is unclear. Secondly, the information available from the charts regarding applicants' informal support is inadequate and consequently, the Alberta Home Care Classification assessment tool could not be used as it was intended and consequently, only the Functional Need Score of the tool is used to measure applicants. Thirdly, applicants' financial situations are unavailable for the chart review process. This is a significant issue for understanding an applicant's ability to pay privately for options such as home supports and community services or alternatively or his or her ability to pay for housing options in the community. Therefore, it is impossible to measure the extent to which the single-entry system is used to obtain resources or support services by those who have inadequate resources to pay privately for the necessary support in the community.

Another limitation of the research is due to the structure of the single-entry system. The objective of a true single-entry system is to function as a gateway to long-term care services to ensure the individual is assessed and provided the most suitable option in their circumstances. However, this single-entry system was designed with the home care option as separate from placement options. Individuals requiring services or placement must apply separately for long-term care placement and/or home supports. Consequently,

it cannot be determined whether there is a proportion of applicants which would and could be better suited with home support rather than in a nursing home or personal care home. Therefore, it can only be assumed, as the system presently exists, that home care is not a suitable option for the applicants even though many are theoretically suitable for home supports in the community when functional and health status are used as the criteria.

4.11 Conclusion

The findings suggest there is a portion of applicants applying for institutional care via the single-entry system who do not require nursing home care. One of the primary reasons for this inappropriate placement is a lack of options to both applicants and those determining placement. It was found that an affordable supportive housing option may be appropriate for 34% of those in this group of individuals applying for placement. Affordable and desirable personal care homes in the urban areas of the health region could also alleviate pressure on nursing homes for those to whom independent living is undesirable due to health or other reasons.

With 17.3% of applicants applying as a couple to nursing homes, a discussion regarding options for this segment of applicants would be a useful exercise. For example, an adjoining supportive housing facility to a nursing home that could enable healthy spouses to live in close proximity to their spouses without using a nursing home bed could further reduce demands for costly nursing home care.

Additionally, over 17% of the cohort was found to be in the early stages of dementia or Alzheimer's. From previous research conducted for the same single-entry system waitlist for 1999-2000 found that 18% were deemed cognitively impaired by the panel. This indicates that a significant percentage of applicants are suffering from some form of cognitive impairment. Alternative models of care and housing should be investigated for these applicants with varying levels of cognitive impairment.

Finally, over 25% of the cohort was in either a chronic or acute care hospital at the time of application. The literature shows that this is a critical point for elderly individuals and that they will likely fall into the nursing home system unless all attempts are made to facilitate a move back to the community. Many times, moving back to one's home is no longer an option but options such as supportive housing with appropriate support to facilitate reintegration back into the community may reduce the numbers of nursing home admissions after hospitalization.

It was understood that limitations exist with the chart review phase of the research. For example, the findings from the chart review suggest a problem regarding applicants' support network that requires further exploration. Applicants' preferences regarding facilities and the high refusal rate for personal care homes and thoughts regarding alternative housing options were impossible to capture from the information provided in the charts. Additionally, a thorough examination of applicants' experiences during critical events that leave individuals vulnerable to institutionalization and a full understanding of the decision-making process that leads individuals with modest care needs to apply for

nursing home care are all issues that can only be captured through qualitative investigation. Chapter 5 presents the data from the qualitative phase of the study.

Chapter 5

Qualitative Results

5.1 Profile of participants

The incident cohort was the source for the participants of the qualitative phase of the study. The objective was to develop a broader understanding of the experiences of the cohort from the findings from interviewees. Therefore, it is important to compare characteristics of the cohort with the interviewees in order to extrapolate those results.

Participant characteristics of the interviewees and the incident cohort excluding interviewees are provided in Table 5.1. There was no significant difference in age between groups. The average age of the twenty participants was eighty-three with 95% of participants over 75 years of age. The average cohort age was 82 with age range of 65-98. Gender was similar in both groups with 70% female and 30% male. A larger number of interviewees (40%) were married compared to 20% of the cohort. The number of those widowed was similar in the two groups however; more interviewees were married compared to the cohort.

A higher number of interviewees, 35% were applying as a couple compared to 11% of the participants excluding interviewees. Couples were discussed as a separate subset in the qualitative data to determine any differences in the decision-making process between married and unmarried participants. More interviewees were living in their own home (70%) compared to 45% of the quantitative group. This difference may be from the fact

that none of the interviewees was residing in a chronic or acute care hospital at the time of data collection.

Table 5.1. Sociodemographic characteristics interviewees and incident cohort – interviewees excluded

	Interviewees (%)	Incident Cohort (%) (interviewees excluded)
N (%)	20	153
Age (mean)	83.1	82.2
Range	71-93	65-98
65-74	2(10)	21(13.7)
75-84	10(50)	75(49.0)
85+	8(40)	57(37.3)
Gender	n (%)	n (%)
female	14(70.0)	107(69.9)
male	6(30.0)	46(30.1)
Marital status		
married	8(40.0)	31(20.3)
widowed	10(50.0)	79(51.6)
divorced/separated	1(5.0)	7(4.6)
single	1(5.0)	10(6.5)
Applying as a couple	7(35.0)	17(11.1)
Residence at time of Assessment		
Own home	14(70.0)	70(45.8)
home of friend or family member	5(25.0)	30(19.6)
Personal Care Home	1(5.0)	6(3.9)
Chronic Care Hospital	0(0)	11(7.2)
Acute Care Hospital	0(0)	33 (21.6)
<i>Other**</i>	<i>0(0)</i>	2(1.3)

Table 5.2. Health status characteristics interviewees and incident cohort – interviewees excluded

	Interviewees (%)	Incident Cohort (%) (interviewees excluded)
Nursing Home Resident Classification Score (RCS)		
A	17(85.0)	85(55.6)
B	3(15.0)	46(30.1)
C	0(0)	14(9.2)
D	0(0)	7(4.6)
E	0(0)	0(0)
F	0(0)	1(0.7)
G	0(0)	0(0)
RUGS Clinical Indicator		
Special Rehab	0(0)	3(2.0)
Clinically Complex	0(0)	1(0.7)
Hemiplegia/Aphasia	0(0)	2(1.3)
Respiratory/Oxygen therapy	2(10.0)	5(3.3)
Terminal Illness	0(0)	8(5.2)
Dialysis	0(0)	3(2.0)
Impaired Cognition/ Behaviour Problems	0(0)	6(3.9)
No Clinical Indicator	18(90.0)	126(81.8)
Functional Need Score FNS		
0 fully independent	8(40.0)	12(7.8)
1 low	5(25.0)	31(20.3)
2 low to moderate	4(20.0)	30(19.6)
3 moderate	2(10.0)	50(32.7)
>3 moderate-high	1(5.0)	30(19.6)
Chronic Illness		
Diabetes	5(25)	23(15.0)
Bowel incontinence	1(5.0)	8(5.2)
Parkinson's	0(0)	4(2.6)
Poor vision	5(25)	18(11.8)
Stroke	0(0)	12(7.8)
Fractures	0(0)	2(1.3)
Cognitive problems	1(5)	29(19.0)
Total chronic illness (%)	60.0	62.7

Table 5.2 includes the health status of interviewees and the cohort. Excluding one applicant who scored an F, a score representing heavy physical care requirements, scores for the cohort (interviewees excluded) ranged from A to D, scores that represent moderate to low care needs and required services. All of the interviewees were scored either an A or B of the RCS. Forty percent of interviewees had no FNS or were fully independent compared to 7.8% of the cohort. Eighty-five percent of interviewees scored below “moderate” on the FNS compared to 48% of the cohort. Only three interviewees had a FNS greater than 3 compared to more than 50% of the cohort.

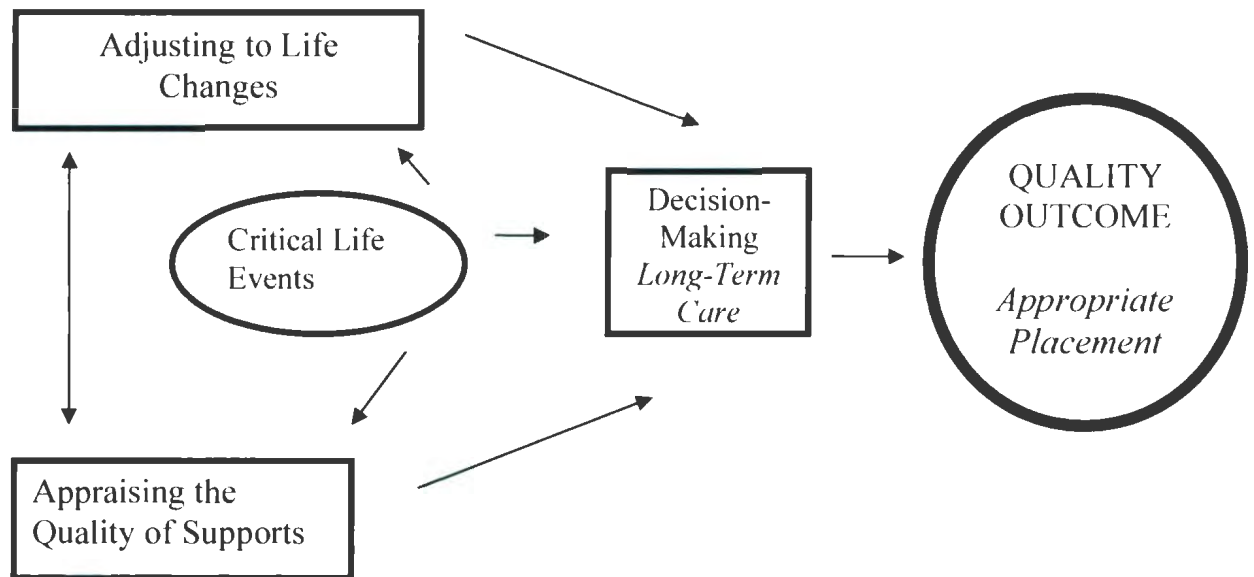
As expected, ninety percent of interviewees and almost 82% of the cohort had no RUGS clinical indicator. Over 15% of the cohort had one of the RUGS indicators that fell into the “community support” category. Three of the interviewees had a RUGS indicator, two of which required oxygen therapy. All three of these interviewees were living at home at the time of the interview and the two receiving oxygen therapy were receiving help from either family or formal home supports with the oxygen therapy. The third participant was recovering from a successful mastectomy at home and was receiving nursing services from HCS. Finally, a similar proportion of interviewees, 60% and 62.7% of the cohort suffered from at least one of the chronic illnesses or disabilities that have been shown to be a risk factor for nursing home admission. Overall, the two groups were similar in social and health characteristics. Consequently, the findings of the qualitative research reported below are relevant to a large proportion of the total cohort with similar characteristics.

5.2 Introduction

For study participants the decision to apply for institutional placement was not an easy one. It was apparent that the decision-making process was ongoing, complex and interwoven with life experiences. As circumstances changed and vulnerabilities became more pronounced due to inadequate family contact, declining health and increasing social isolation, adjustments became necessary. This was achieved by constructing and reconstructing support networks and modifying personal spaces.

Figure 5.1 illustrates the decision-making process. In this model, adjustment to changing circumstances is successful and ongoing until a singular critical event or a succession of events lead the individual to reconsider the manageability of things. It is at this point that confidence in one's ability to maintain independent living is compromised and the decision made to apply for long-term placement. Critical events (i.e., death of a spouse, sudden decline in health or hospitalization) trigger appraisals and re-appraisals of current circumstances. Support networks and coping abilities are critically evaluated and the conclusion reached that resources are insufficient. The combination of critical events, insufficient supports and simultaneous erosion of self-confidence are catalysts that prompt engagement in a decision-making process that leads to an application for institutionalization.

Figure 5.1 Theoretical model of decision-making process to institutionalization.



5.3 Adjusting to Life Changes

Uncertain health status is the key property of the Adjusting to Life Changes category. A certain level of decline is expected in health as part of the normal aging process, but there are also unanticipated critical events that cause sudden declines. The descriptors defining this property capture how participants struggled to balance the expected with the unexpected in the social, emotional and physical realms.

A second property of this category is accepting and resisting change. The core elements attempt to capture the struggle and trade-off between the need for security and consistent support versus what one fears losing most - autonomy and self-identity. In response to changing life events, many participants had downsized from family homes to alternative

housing arrangements (e.g., moving in with family or to a senior's directed facility). As critical events accumulated over time, further adjustments were required until finally consideration was given to long-term care placement. Noteworthy is the fact that participants resisted the perceived finality of moving to a long-term care facility even after applying for placement.

5.3.1 Uncertain Health Status

Study participants were experiencing or had experienced significant declines in overall health. The singular or cumulative effect of one or more critical illness episodes led to a reevaluation of independent living. Increased limitations in social and leisure activities due to declining health necessitated that participants adjust to their "new social reality." When declining physical health was combined with a search for more optimal living arrangements, consideration was given to potential negative repercussions for social health and, ultimately, emotional well-being.

The study sample was comprised of five couples dealing with similar and disparate life circumstances. Two couples were living in their own homes, two had downsized to an apartment, and one lived with a daughter. The final couple was separated when the husband was placed in a nursing home. Significantly, all of the couples were facing changes that they felt necessitated adjustments in current living arrangements. An important motivator was a sudden or gradual decline in the physical health of one or both members of the dyad. When declining physical health was combined with a change in

residence, some participants also experienced diminished social health and emotional well-being.

For one couple the husband's health had deteriorated significantly leaving him almost completely reliant on oxygen therapy while his wife, the healthier one, was also unwell: "I broke my ankle a year ago when I lie down everything would turn bottom up ... I get dizzy and stomach sick." A decline in health status had negative repercussions for leisure activities: "I spent a few years taking part [in church activities] and then this [illness] came on so I had to forget about that."; "I used to knit a lot, but now since I took the bad head, I don't knit at all." Although the burden of household management was solved by moving in with their daughter, socialization was infrequent and restricted to family and friends in close proximity: "We don't have much company at all."

A second couple had experienced a succession of unanticipated events. Following a sudden illness, the husband was admitted to hospital and subsequently a nursing home. A short time later, the wife was physically abused by a close relative, leaving her with permanent disabilities and an immediate loss of independence. She was living with family members while waiting for placement: "Only for my hand broken I would be in my own home. ... I could do everything for myself." At the time of the interview, she was also experiencing mobility restriction due to cardiac disease: "I cannot walk very much. ... I get short of breath."

A third couple was experiencing a gradual decline in the mental health of the wife who was diagnosed with Alzheimer's. Although the husband had minor health problems, he was concerned about his ability to adequately care for his wife. The system of reliance on each other was breaking down under the strain: "If we get to the point where we have great difficulty with one healthier than the other, then you've got to make some changes and no matter what sort of outfit you have [supports] it won't change that." As the husband noted his ability to socialize with friends and family was also compromised due to a shrinking social network: "They're all dead, all the couples that we used to get together with for playing cards and one thing or the other ... [I have friends remaining] but it's not like it used to be."

The fourth couple was in fairly good health and had made several moves since retirement, with the last move to a senior's cottage next to a nursing home. The last two moves were attributed to the wife's illness: "I had angina and there were steps in our house and the doctor said that it would be too much for me ... we moved then to condominiums." The husband was very independent but noticed a decline in his tolerance for routine exercise: "I go [for a walk] almost everyday. Last year now I could go around three or four times but the legs get weaker." Despite declining health, this couple continued to be active socially with cottage tenants and outside friends and family: "There's a clubhouse [on-site recreational centre] and we go over there ...when we can." "We go out everyday, we're going to [hometown] for a holiday. My husband maybe he doesn't like it [driving] now but we manage."

The final couple had experienced noticeable changes in functioning levels. The husband described a recurrent illness: "I had pneumonia twice in the last few months. This one is sticking with me." The wife, although relatively healthy, felt less confident with her personal care: "The last three or four [baths] I told [husband] to stay in case I might not be able to get out." This couple had remained fairly active and pondered their fate if they moved to a nursing home.

The remaining twelve participants were single, and like the couple cohort, had already adjusted their living arrangement (i.e., lived alone in either a senior's directed facility or an apartment complex). Most of these individuals had recently experienced critical life events such a decline in emotional and/or physical health or loss of significant other.

One participant who had experienced a diabetic episode requiring hospitalization spoke about ongoing illness symptoms that were worrisome for herself and her children: "I sometimes stagger to the side, I don't know what's causing it but the children don't want me walking to the mailbox." A second woman voiced some concerns about her physical health and activity level following a recent mastectomy: "I don't feel anything wrong with my body, only I'm just slowed down." A third participant with a history of TIAs was hospitalized following a cardiovascular event. A recent fall heightened her feelings of vulnerability: "I fell the other day getting in the bed I must have put my hand out to touch the walker and I fell between the bed and the walker."

Importantly, whether participants were dealing with the sequel of a critical event or the cumulative effects of a gradual health decline, independent living seemed to be more problematic when they were alone. A couple of participants were especially concerned about becoming unexpectedly ill without others knowledge about their status for an extended period: "If say I get sick here in the night, I could be in this apartment for a day and no one would know about it." "I'm just as content to stay here [in apartment alone] but you never know when you're 88, you might have a seizure or something." Another participant's words echoed similar concerns about increased feelings of vulnerability:

I have a heart condition and I have this problem of giddiness. Now yesterday I went to those couple of places and half the time I wasn't sure where I was. So I can't go out by myself. And then I have bad legs and its so many little things, not just one thing but so many little things

Single participants had varying levels of social activity with some living fully active lives and others relatively inactive and dependent largely on social contact with family or peers. Despite being lonely because of the loss of her spouse, one woman indicated that she continued to do some of the things she enjoyed: "Yeah, I'm always reading. I don't know what I'd do if I couldn't read." Another woman also derived comfort from reading activities but worried about whether they could continue: "I read as much as I can but I'm losing my sight. I have glaucoma so I read what I can. And that's about all I can do."

The presence of illness events or a gradual health decline also resulted in a reassessment of one's ability to engage in social activities outside of the home. In some instances the changes were dramatic, leaving participants feeling socially isolated. One woman voiced her frustrations with health restrictions and a declining social network: "I used to go to

different things There are not too many of the old crowd ... a lot of them moved away or died.” A second participant, the oldest at 92, who had been very healthy and independent until a recent illness episode dramatically altered her social world, echoed similar sentiments: “We [friends] always went out ... on the buses. We’d go to [Store] shopping and all the rest, but I don’t go now. I feel I can’t go with my eyes like this.”

Participants with less severe health restrictions were still trying to maintain an active social life. One woman described how she adjusted her social outings to accommodate her declining health: “I go to the socials at the club, if I go with somebody else. I don’t drive by night because I got diabetes in this eye. I like going around, I’d be gone everyday of my life while I’m able to.” A second woman described taking similar measures in order to maintain social activities: “If I go [out], I have to have someone go with me because I’m not to be trusted. I get giddy, a funny head.” Still another participant felt restricted in what he could do because of unpredictable illness events: “If I could go on a cruise I’d go but ... [my daughter] doesn’t want me to go If I don’t take my needles on time, sometimes I pass out. I had that happen a couple of times.” Another participant compared her life at present to the one she once enjoyed: “I don’t find it [lonely]. I suppose I do compared to the life I was used to because I was never in. Well I know I can’t go [out much]. I’ve consoled myself to that fact.”

Living in senior’s facilities allowed participants to socialize and participate in activities that they would normally be unable to do because of their health. The ease of organized on-site activities and friends living next door increased their socialization. Despite

diminished activity tolerance, one participant continued to socialize in the seniors' facility: "Here at [senior's building] we have a club. I'm a member of it. They have darts, they play cards ... they have bingo. I can't see well enough now to play, but I go out." Participants who resided in such facilities were able to avoid social isolation and loneliness despite mobility problems and illness: "I don't go out but I did, we always went on the buses we'd go shopping. And so many [other tenants] come [to visit], there's nearly always somebody here. I don't have a chance to get lonely."

A contentious issue was the need to sacrifice one's social circle in search of a better or more manageable environment. One participant talked about the sudden changes that occurred when she moved out of her community into a personal care home: "I used to [play cards/socialize] when I was home but I haven't touched it in years now. I wouldn't know the first thing about it I don't think." This reality seemed to play heavily on participants' minds as they pondered another move that could potentially have major implications for their current levels of independence.

5.3.2 Accepting and Resisting Change

Participants struggled to cope with the emotional and psychological impact of multiple life changes. As participants grappled with the aging process and resulting loss of independence, they struggled to redefine the self in terms of what was and how they used to be, and what they were becoming. The difficulties associated with change were compounded by the multiple losses (health, significant others, friends and family) and the growing dependency on others for necessities. Many of them seemed to be wrestling with

accepting an inevitable future while resisting a complete loss of autonomy. For them long-term care placement represented relinquishing total control over their lives and an irrevocable loss of identity. It became the favourable option because it was expected to alleviate the threat of becoming a burden to their families, which seemed more objectionable to them than becoming a resident in a nursing home. Consequently, they resisted this final step until the cost to their dignity of living with family outweighed the loss of autonomy.

One couple reflected on the past and how significantly their lives had changed. The wife mused about their younger years: "I did a lot of painting and papering and stuff like that. When I was home, I was at the fish and we had our own place, our own garden and we used to have our own vegetables." The husband seemed to be more accepting of their current lot than his wife: "Nothing to be done, it [change in activity level] didn't bother me. What's behind is behind, that's it." Nevertheless, the rapid decline in his health promoted him to conceal the truth from his family: "I'll go in my room and I'll put the machine on throughout the night. They [family] don't know anything about it." One of his greatest fears was becoming too much of a burden for his daughter: "Some of the reasons why [seeking placement] is our age and another is that our daughter is working, she's got her family, she is unable to stay at home and we wouldn't want her to do it."

The participant who had given up her home under trying circumstances and was waiting to be placed with her husband reminisced about when she was independent: "I had my own home and I was very comfortable there until I got broke up in my health." "I did it

all myself. I had no one to come and do anything for me that way My two hands were right then." She also described how she was pressured into relinquishing her home: "I didn't understand anything. If I had my time back, I would have stayed in my own home. There is nothing in my home now it has all been given away ... yes I jumped too quickly." She was also clear about not becoming a burden for her family: "No I would just as soon go in the home because I can't manage it at all. I would rather go in the home and be out of everybody's way."

It is a difficult decision to commit to moving from one's home to a long-term care facility. One couple was finding the decision particularly difficult because of the memories: "We've been here now in this home for about 45 years you see, all of them [children] were raised here." Given the wife's diagnosis of Alzheimer's and his gradual health decline, he was finding it difficult just doing daily chores: "I'm to the point when you reach this stage you just can't be bothered with these [daily tasks] things."; "You can't handle it [change] see. I used to see to the bills come in [but] as time goes on you get a bit on the lazy side, the interest is not there." A second couple with both members in good health and managing well in an apartment echoed similar sentiments: "You get tired of living here and we want to relax now."

For those individuals who had lost a spouse, loneliness was a key factor requiring adjustment. The period of time that had lapsed did not seem to lighten the pain. One participant who had lost her husband several years ago was still grieving: "He had an aneurysm. ... He always did my hair for me ... he used to do everything for me, and I cry

almost everyday now.” Another participant spoke about the recent loss of his wife: “It’s not too bad here [senior’s complex] [but] living alone is not so good, she [wife] died in September.” A third participant also lost her husband a few months before the interview: “Yes my dear [we] went everywhere together, Saturday nights we always went to the dance, but now.” She did acknowledge, however, that moving to a nursing home would not alleviate her pain: “Of course no matter where I go I’m going to miss him.”

Other participants did not feel secure living alone. Although one woman initially resisted selling her house, she eventually made the decision because of feeling lonely and frightened: “I just decided that I was going to leave and sell the house. Well I found it a bit lonely. That’s why I said I’m not going to live like this ... being frightened to death of any noise.” A second woman spoke about living alone without anyone to call on: “That’s the one thing that worries me. I don’t want to be in the house alone dead for a day or two. It happened to two of my friends.” A third woman acknowledged that she could not adjust to living alone at this point in her life: “I know for a fact that this place is getting to me these last few months I think I’m lonely and I’m afraid someone is going to come in through the door.” Still another woman indicated that she would feel more content to remain in her home if someone visited to break up the loneliness: “I don’t suppose ... if there was anyway they could visit people like me in their own home for an hour or a half hour or something you know to break the [loneliness] up.”

Despite deteriorations in all aspects of health participants were clearly unhappy about losing their independence and resisted it. One participant had been very independent until

she broke her ankle the year before: "Well I drove a car and I only gave up driving in [last year] I could go when I wanted, didn't have anybody waiting on me. Yes, you really lose your independence ... but I'm reconciled to it now, sometimes with a bad temper." The woman requiring the most care spoke of her life before hospitalization. She would not admit to herself or her family her health was as bad as it was:

I tried to do everything. I used to be short of breath. I used to have to push the pots back and forth and ... I had to start peeling the vegetables in the night. But I never said anything to them [family] ... because ... they never would let me do it.

Participants wanted to avoid placing too much of a burden on their families and thus chose placement as a viable option before that occurred. One woman recognized the risk of becoming a burden to her family.

My youngsters would be tickled too [placement] because they are all fooled up [too busy] They come here in the night time and they either have to come early or they don't come 'til late because they have places to go. The whole time I was in hospital...they were always there, beat out I don't feel right about it.

Another participant also resisted receiving help from her family because of not wanting to burden them: "I don't need them. I hate for her [daughter-in-law] to come here [and help] she says mom I'm coming down Saturday morning and help you wrap some gifts."

Similar sentiments were expressed by another participant: "But I'll tell you know, I suppose I'm selfish staying here because the family, they worry, you know, and if I was in a home they wouldn't worry as much."

With all of the participants seeking ways to remain independent, it was apparent that the decision to seek long-term placement was a reluctant one. One participant was clearly

resistant to moving from her seniors' cottage to a nursing home: "I like it here ... I want to stay as long as I can boil the kettle for myself because I only lived in the next settlement." "Going to a nursing home, I don't know but I would rather die first, but you don't die when you like either." Another woman was very resistant to move from her home despite pressure from her family: "To sell this and move it'd break my heart [but] they [family] want me to go."

5.3.3 Summary

The Adjusting to Life Changes construct captures the interplay among the physical, emotional, mental and social health spheres. As participants struggled to accept deteriorating health while retaining what was left of their independence, they had to accept constant change. Autonomy was only maintained by carefully balancing small decisions (acquiring homemaking services, giving up driving, altering daily routines and lowering expectations) with more significant ones (moving from a family home and/or from familiar communities).

Many participants had already responded to declining health by moving out of their community or neighbourhoods. One negative consequence of this was reduced social independence until a new social network was created. This was sometimes successful, but not always with some participants experiencing even greater loneliness. The ongoing struggle for balance left many of them resisting further change to guard what was left of their independence and autonomy. The move to a LTC facility symbolized a trade-off between safety, security and social contact versus maintaining independence and dignity.

5.4 Appraising the Quality of Supports

The Appraising the Quality of Supports construct is comprised of three properties that capture participants' perceptions of informal and formal support networks. Key properties include the meaningfulness and usefulness of tangible and intangible informal supports. What is reflected here is participants' assessment of the type and frequency, availability and continuity, and suitability or relevancy of informal supports for meeting perceived or actual needs. The second property focuses on participants' ability to recognize and accept the limitations of informal supports. The final property deals with participants' perceptions of the importance of accessing formal supports to help fill the gaps present in informal support networks.

5.4.1 Meaning and Usefulness of Tangible and Intangible Informal Supports

The interview data suggest that participants perceived informal supports to be critical for optimal well-being and independent living. Although spouses and children were the primary sources, extended family members, friends and neighbours were also important in their absence. Support from informal network members came in two forms – intangible and tangible. The meaningfulness and usefulness of intangible support is defined in terms of social, emotional, and informational benefits. Direct contact from network members, whether in person or by telephone, provided participants with a break from social isolation and reinforced feelings of significance and being cared about. In addition, participants benefited from discussions that centered on concerns and problems, like the decision to apply for long-term care placement. In contrast, tangible support refers to how

network members assisted with meal preparation, personal care, running errands, transportation, financial management, or general household management.

The type and frequency of contact with family members heavily influenced how participants' rated their informal support networks. Several couples and single participants experienced greater feelings of security when there was daily contact. The following quotations illustrate how the perceived quality of supports seemed to improve with more frequent contacts from immediate family members.

When they're [family] not here they're on the phone. They want to speak to poppy or want to speak to nanny. And then my daughter who [works] here in [city], she's on the phone everyday. And of course he's [son] going back and forth all the time, we've got a number of hands to call on.

They [family] all couldn't be any better. Saturday, [daughter in-law] was here and [son] was here, and my granddaughter was here. I always have a crowd, and my dear, if I want anything all I have to do is phone. I'm lucky that way.

We talked to him [son] last night. He phones almost every night.

Participants described how family members helped them deal with the mundane tasks of daily living. With only three of them driving, the presence of others for transportation and running daily errands was crucial to independent living. One participant spoke about the extensiveness of family assistance: "She [daughter] takes me to the supermarket and takes me to the drugstore, and whenever I have to go to the hospital or to the doctor to get things, she's there." Another participant noted how pleased she was with her children's availability: "They're [family] good to each other and me. If they only think I want something.... [Daughter-in-law] takes me out for a drive, does my banking, anything at

all I want done.” A third participant echoed similar sentiments: “My son gets my groceries for me He sees to all the things that I would have to so I don’t have to worry.”

Besides encountering difficulties performing daily errands, meal preparation was sometimes a chore. Most participants were able to prepare light meals, but frequently relied on family members for the main meal. One woman described how she divided this responsibility with her children: “I do that [lunch] myself, a drop of soup. And anyway, the family will get it for me.” Other participants discussed how family members helped with meals: “My daughter comes in three or four times per week and I have meals done up. I can go a week without going outdoors I always have something to fall back on.”; “They [grandchildren] are good to me We go out sometimes to have dinner.”

Although participants’ children were the dominant forms of informal support, extended family members also provided assistance. This aspect is reflected by a single woman’s situation: “My sister and her husband ... take me to their place ... Actually I think [I’m doing] well with [niece] doing things for me and [sister] picking me up and taking me to the bank.” A couple, who resided with their daughter and family, relied on extended family members when the daughter was unavailable due to work commitments: “I went to get my cat scan and [daughter] took me up to my husband’s brothers’ and he took me because she was working.”

When participants experienced acute illness episodes, additional strain was often placed on immediate family members. One woman noted that her son was unable to provide the increased level of support needed when her husband became suddenly ill but extended family members were able to fill in the gap: "Now I was pretty lucky when he [spouse] was in bed because my niece dropped everything and she was the nurse, and her husband was the chauffeur I don't know how I would have managed without them."

5.4.2 Recognizing the Limitations of Informal Supports

The presence of strong informal networks did not always translate into sufficient levels of intangible and tangible support for participants' needs due a couple of factors. First, the quantity and timing of informal supports were a function of proximity to participants' place of residence and personal responsibilities (job and immediate family). Second, all participants had serious reservations about living with family members, even those already doing so, because of not wanting to overburden them.

The proximity of family members to participants significantly restricted the amount of available support. A single woman who lived alone in an apartment did not consider her sister as someone she could really depend upon: "She [sister] lives in [place] so I don't worry her too much, she's too far away." Similarly, another woman who lived with her daughter just outside the city discussed how she could depend on her son for support in some situations but not in others: "I have a son here, but he's out in town. It's so far away. He comes ... whenever he's needed but if he was wanted in an emergency it would

take him 20 minutes or more to get here.” Problems posed by distance were reiterated by other participants: “I have a son in [another province], he’s there 25 years, so that’s his home.”; “He [son] can’t give up his job if I get sick. He works in [another province].”

Although the proximity of family members significantly influenced availability, equally important were work and family obligations. Many informal supports were not only part of nuclear families with parental responsibilities but also both members of the dyad often worked full-time. Participants acknowledged that work obligations restricted the availability of family members: “No, no they [family] don’t have time. She [daughter-in-law] works everyday and you know I don’t expect, she’s not living near.”; “We don’t [depend on sons], they haven’t got time for us.” Two other participants described how other obligations diminished the quality time that their children could spend with them.

Now my son if he gets a chance, he comes up and has a game of crib with me but there are nights that no one calls. It is killing him; it’s not what he wants to be doing [spending time with me]. The oldest son is always travelling. The other two girls are working, [one] has a family; and the other one lives just up here [but] she works 12-hour shifts.

Of course my daughter is [good to me] too, but the difference is [daughter-in-law and son] they got their own business, and that means she [daughter-in-law] can get off when she wants to. But the other two girls work for someone else, and they work 9 to 5 all day.

Another participant acknowledged that she would like more social contact with family members: “I mean I can’t expect them [family] to come in the night [for company]. They clean up and they put out the garbage and they make up my lunch and make a pot of tea in the morning.”

Because participants placed so much emphasis on accessibility problems with informal supports due to distance and work and family schedules, they were asked if any consideration had been given to moving in with family. The consensus was that this would not resolve any issues and could possibly create more problems for their families. One participant felt that her children had too many other responsibilities to deal with her needs. "They [family] wouldn't want me to do that [move in with them]. They can't take care of me, I had mom [mother-in-law] for years....No, I wouldn't go with my kids." A second participant, who had previously lived with one of her sons, knew that the amount of time spent alone would not change: "I'd rather not [move back in with son] because he still works and his wife is working all the time. So I still would be by myself." Another participant, who lived in a senior's cottage, explained why moving in with her family was not an option: "None of my children can take me because they haven't got the space. One of them has small children and I have a daughter in [place] and I have one in [Province]. [Son] is the only one that can take me ... [but] they're working."

In other cases participants received limited support from family members. One woman spoke about the infrequent contact with her daughter since moving from her community to live with her daughter's friend and ultimately into a personal care home: "I've only seen her [daughter] once since she left [living at home]. I saw her once and ... last Christmas I think I saw her again." A widower living in a senior's apartment complex also had limited family support. Although he has two sisters, they are elderly and seem to have more support needs than him. His feelings of loss and limited supports were captured in the following text: "I have a sister. She's upstairs, she's no good ... to help

me. And I have a sister over in [place] and she's 89 years old. I have a daughter up on the mainland I have nobody now."

5.4.3 Importance of Accessing Formal Supports

Most participants used some type of formal supports to supplement informal supports, which were either paid for completely by participants or subsidized by a recognised community group or Health and Community Services. Formal supports consist of home supports, community and residential services and professional health care. Home supports include such services as personal care, meal preparation, housekeeping and general household management. Community services were provided by a variety of organizations (e.g., Department of Veterans Affairs, Victorian Order of Nurses, Meals on Wheels). Residential services include access to an on-site superintendent and recreational and transportation services. Health care providers form the final category of formal supports.

Fourteen of the twenty participants relied predominantly on home supports and community services as an adjunct to informal supports. Access to community-based resources increased following critical health events and/or when participants tried to reduce the demands on informal supports. Although assistance with household activities and personal care was the primary intent, there were psychosocial benefits. Participants' ratings of most formal supports varied considerably but were mostly positive.

Some participants used a combination of home and family supports to help them manage household activities. One woman commented: "I have girls [home support workers] come in and do all the work. I still do a little bit of cooking with my husband's help but I have girls come in all the time." Another woman, who recently suffered a fall, had someone come in a few hours a week to help her with household chores. She reported being very satisfied with the quality of this service: "It couldn't be better [home supports]. The people who come in to do my work, they're good. I have no complaints."

A male participant, who relied heavily on home support services due to declining health, was generally pleased with the support provided by various workers: "[I get] two hours of care [a day]. They [home support workers] come in and get my supper and clean up the place." "It's less than a year [receiving home supports] It has been working out well."

A couple who required more extensive services had privately paid home support to help the husband care for his wife who had early stage Alzheimer's. The presence of a home support worker on a daily basis helped alleviate the strain and gave him an opportunity to do other things: "She [home support worker] comes in the morning. She's here for six hours so that gives me a chance to do things, and I don't have to worry about someone being here with the wife."

Besides assisting with household chores, formal supports were also meeting social and psychological needs. One woman derived comfort, as well as a sense of security, from visits with a home support worker: "I have a bit of help [home support] coming in and for

company and all the rest of it.” Psychosocial benefits were especially important to those who had no or limited family support. One man spoke about the family-like relationship that he had cultivated with the hired help: “I have a woman who carts me around. She used to do that for the wife too. We’ve had five years. I wouldn’t part with her for the world. She’s some good.” Another man, although satisfied with psychosocial benefits, had concerns with the varying capabilities of home support workers: “The girls [home support workers] I have coming here, they’re nice. They can’t do too much for you, some can cook, some can’t.”

In some instances, support needs exceeded what participants were receiving from both informal and formal systems. One participant was using all available resources within her support networks to help meet her care requirements: “Normally I depend on her [home support worker] but when my daughter comes, she’ll get it for me.” She was also frustrated with the lack of continuity among home support workers and their varying abilities: “Usually three [home support workers per week]. I had one come in the morning and she said she does not cook, she only does house cleaning She spent more time walking back and forth.”

While participants’ ratings of home supports were generally positive, there were several complaints voiced about other community services. Although one woman and her family managed most of her meals, she relied on Meals on Wheels for three days a week to fill the gap rather reluctantly: “About the only thing I complain about is that I always liked to

cook, and Meals on Wheels is for the birds. The reason I get them is my family wanted me to. I'm afraid to cook, because of this hand." Similarly, another woman managed light snacks and depended on Meals on Wheels for main meals but the service was sporadic: "We get Meals on Wheels here, they stopped the middle of June and that's it until the middle of September. It's only when school is open I haven't got what it takes to spend my time over the stove cooking a meal."

Other participants found it difficult to access transportation services. The participant who lived in a personal care home felt isolated: "If you want to go to the store, it's so far away that you can't unless you went in a car. No it's not very easy to get transportation."

Another woman, who lived in an apartment building, had similar problems: "Sometimes in the winter it's difficult to get out for groceries ... and get the mail down They bring the mail in but they don't bring it out. That's the only fault I have in this place."

Some participants were frustrated by the inconsistency of residential services. One woman voiced the following concerns about services provided in her seniors' apartment building: "You don't get good service here [senior's complex] and they [superintendent] won't come to do anything." A second woman had similar complaints with her apartment building: "I've had my troubles here ... leaks in the bedroom ... and if you want anything done you have to wait so long." Despite the inadequacy and inconsistency of residential services, they were critical to one's ability to live independently.

The final category of formal supports consisted of services by health care providers. Key factors shaping participants' perceptions of the quality of health care were consistency and availability. One couple decided to move in with their daughter because of the difficulties experienced accessing health services. However, this did not solve access problems: "It was necessary [to move] because if I lived over there [rural community] I'd have to travel ten miles in order to see the doctor or [go to] the hospital so it wouldn't be any point for me to stay over there."; "I went down to see the doctor and I thought to get down to her, it's handier...but she's not taking on any new patients."

Simply organizing visits to the doctor could be a challenge for some participants, particularly when family members had work commitments. One woman was forced to change physicians because he did not do house calls: "He [present doctor] doesn't do house calls I had to give up my regular doctor ... I had a real bad spurt last week and I would have been in some spot if I had no one to call." However, not all participants were dissatisfied with accessibility to health care services. One woman who lived alone described her experience after a fall and injury to her wrist: "I had some bandages so I bandaged it up myself and the next day I called and he [doctor] came."

Limited reference was made to the quality of health care. One woman was displeased with the adequacy of communication with her doctor: "I have pain in my legs and I don't know what I feel like sometimes. I was over to the doctor yesterday but that doctor ... doesn't talk to you about anything." In contrast, a second woman, who had major surgery

prior to the interview, reported having a very positive relationship with the nurses who visited her: “You have lots of help ... the nurses are coming ... all the time. Once in a while, I had their addresses, their phone numbers. [They say] call me if you want anything, or you know if you want me.”

5.4.4 Summary

Informal supports were crucial to the well-being of all participants regardless of health status. Tangible and intangible supports were provided by various members of the informal support networks but primarily spouses and children. Participants relied heavily on these supports for independent living.

Despite the presence of a strong informal support network, there was often disparity between care requirements and the level of care provided by informal caregivers. Formal supports emerged as a key asset, especially when home support and community services complemented informal supports. This type of support was vital in easing the burden for family members and filling gaps left by the informal support network. However, there were problems concerning accessibility, consistency and continuity of formal support services. Frequently, this support was fragmented and had many inconsistencies regarding accessibility and availability. Without high quality access to these critical services, participants were left in a vulnerable, unpredictable position.

In short, study participants had developed a 'system of support' comprised of available informal and formal supports. With these two networks, participants were more confident with their ability to cope on a daily basis. However, problems existed when the system broke down or was interrupted due to the work and family obligations of informal supports or the inaccessibility or inconsistency of formal supports. At these times participants were less confident with their ability to manage and began to consider alternatives. This "*weighing of support*" provoked feelings of greater perceived vulnerability in their present circumstances especially when compared with what they could receive from LTC settings.

5.5 Decision Making about Long-Term Care Placement

The final construct, Decision Making about LTC Placement, consists of three properties that capture the sequence of events that led participants to consider institutional placement. A key property of this construct is reconsidering independent living which illustrates how critical events triggered reconsideration of current living arrangements. An integral factor in seeking LTC placement was the belief that increasing demands following critical events would overburden family members. Critical events included illness episodes, declining health, loss of a significant other, and declining social circle, among others.

A second property is readiness for change. Although participants resisted losing their independence, actual effort expended fluctuated in response to sudden or gradual changes in their lives. Regardless of living arrangements, there was a growing awareness of the

need to either change one's environment or find the extra support that was or could be required in the immediate future.

The final property of this construct is appraising options. This property is defined in terms of how participants evaluated the conduciveness of each option for meeting their needs.

An important caveat was what would be lost if one option was pursued over another. This balancing act continued long after the decision was made to seek LTC placement, and in fact was responsible for refusals when contacted by particular institutions.

5.5.1 Reconsidering Independent Living

A major factor influencing reconsideration of current living arrangements was the fear of becoming too much of a burden for family members. This was the case whether or not participants were currently living with family members. An equally important factor was heightened feelings of vulnerability while living alone because of critical illness episodes or gradual declines in health and functioning levels.

One couple's primary reason for seeking placement was to lessen the burden and responsibility of increasing care needs on their daughter and her family. The wife commented on their dwindling abilities to manage alone: "I can't look after my husband and he can't look after me so we decided to go into one of the [nursing] homes." She provided further insight into how their increasing support needs were beginning to exceed the daughter's resources: "My daughter is working and her husband is working and she can't give up her job. And she has two children." The husband's perspective on their

current situation echoed those of his wife: "Some of the reasons why [seeking placement] is our age and another is our daughter is working. She's got her family. She is unable to stay at home and we wouldn't want her to do it."

The desire to avoid being an additional burden for family members was expressed by other participants. An eighty-six year old woman, who lived with her daughter and son-in-law, was concerned about becoming too much of a burden: "I don't want to be too big a burden on them [family] anymore than I can help. That's why [the placement application]." She elaborated further on the circumstances that existed when she pursued placement in a LTC facility: "A while back I said, I think I should apply for a nursing home, if the time came when I need one. I wasn't feeling then like I am now. So we got the papers, and I sent them in."

Another couple, who lived in a seniors' apartment building, were very clear about not wanting to pressure family members into agreeing to accommodate them in their home. The husband noted that it was important to avoid burdening family members: "He [son] has his mother-in-law with him now. He has a basement but I wouldn't go down there. I don't think he'd offer it I think it would [be a burden]." His wife concurred with him: "They [son and daughter-in-law] figures it's nice to have her mother there but they have enough of her now So this is why a home is better for us, because I wouldn't want to give them any trouble."

Besides wanting to lessen the burden on family members, some participants were beginning to feel more vulnerable living alone because of illness episodes and/or gradually declining health. One woman, living alone in a senior's apartment complex, was the most physically dependent of all participants, requiring continuous oxygen therapy. Upon returning to her apartment following an illness, she struggled to meet her basic needs: "Well, I have to go [nursing home] because I cannot do anything myself." Reflecting upon her situation, she realized that her illness had drastically altered her life:

I was in the hospital a little over a month. When I came home I figured I'd have one of those oxygen tents you could take and go out, go somewhere. They [health care providers] said forget about going anywhere for a long, long time. So, I figure if I were in a [nursing] home at least there would be the atmosphere.

Another woman found herself in a unique situation after experiencing several critical events in a short period of time that left her not only alone (i.e., sudden illness and placement of her husband in LTC) but also functionally impaired and without a home. She acknowledged that the decision to seek LTC placement had already been made for her: "My home is gone. I just have to go somewhere. I can't stay here [sister's home]. I am not able to do for myself with my arm broke and everything." Although the circumstances were quite different, a second woman commented on the inevitability of her decision. Still living alone in an apartment at ninety-three, she put her name on the LTC waitlist following a fall: "The unsteadiness in my legs [reason for placement decision], not mentally but physically [decline in health]. When I gave in my name [placement waitlist] I was really feeling miserable at that time."

For other participants, it was more of a gradual shift in health status or a changing perspective on life that influenced LTC placement decisions. One woman, who lived alone in a senior's apartment complex, indicated that loneliness was responsible for her application: "I did it [placement request] because I thought it would be better in there than in this apartment, it would be more company. Although the people go out there [common rooms] and I go sometimes but I don't go out there all the time."

One couple seemed to be managing quite well and had already downsized into a senior's cottage affiliated with a nursing home. The decision to downsize to a personal care home was attributed to a declining interest in performing household tasks. The wife commented thus: "You get tired of [it] here [senior's cottages]. We want to relax now because if you're sick you can't go over there [adjoining nursing home] ... and I'm tired of the kitchen, I'd like to relax now." An additional factor influencing this couple's decision-making was a changing health status: "We're getting old and there's work to do here [senior's cottage] [and] she's [spouse] kind of crippled. We have [to have] a car up here." Similar to other participants this couple did not want to overburden their son: "I am satisfied to go there [personal care home]. I wouldn't be depending on him [son] because he is a busy man."

5.5.2 Readiness for Change

This property discusses participants' readiness for change after initiating the LTC placement process. Despite a growing awareness of actual or potential increased support requirements, there was evidence of a fluctuating resistance to moving into a long-term

care facility in the short-term. What seemed to be impeding or facilitating the actual move was a combination of factors that ranged from variable health and functioning states and increased feelings of vulnerability to the availability of useful and timely supports. It seemed that future planning was the norm. One telling indicator of this was participants' refusal of one to two placement calls.

The message conveyed by many participants was that they were not quite ready to take the final step and actually move to a LTC facility. One woman commented on how her resolve to move into a nursing home lessened as she adjusted to variable health states.

She initiated the placement process after experiencing a critical illness episode (i.e., mastectomy) followed by an eye infection that impeded her ability to do things for

herself. As her words indicate, she was not totally committed to moving anytime soon:

"Only this morning my eyes were so troublesome that I thought maybe I would give it all up, but that just came in my mind. If they [eyes] clear up I'm alright here for the winter."

When asked directly about the finality of her decision, her answer was clear: "No, I don't want to go in a [nursing] home."

Similar critical events prompted male participants to apply for LTC placement. One man who lived alone in a senior's apartment building was content with current living arrangements, but his deteriorating health led him to pursue alternatives. Although on the active waitlist for a year at the time of the interview, he was hesitant about moving:

It's almost a year now [application for placement]. Well, I was expecting it would be at least that you see and I told them there was no urgency. Not at the present moment, but things can change, since I've been here this is the best year I've had.

A second eighty-three year old man who also lived alone in a senior's apartment building applied for placement in a personal care home following the death of his wife. Because he was fully independent and had no serious illnesses, he was hesitant about moving after adjusting to the loss of his wife: "After the wife died [applied for placement], I'd have gone, but I'm not ready just like that yet." One important reason for his hesitancy was the presence of adequate supports to complement his high level functioning:

I'm not going to consider that [placement] at all yet, as long as I have someone like [caregiver]. When she can't handle it, I'll get someone else to help her here to do the cleaning and the washing. I'd just have to do a bit of cooking then.

For those participants who lacked the will to move into a LTC facility, it was obvious that placing their name on a waitlist was a precautionary move. One woman, who lived in a senior's cottage outside the city, provided useful insight into her indecisiveness: "I didn't need to go anywhere then but I was looking ahead, just in case." Even when confronted with unpredictable illness events, she still could not commit to being placed in a LTC facility: "The doctor in town at the hospital said I should not be living alone after something like that [illness episode] happening to you ... and I had a couple of calls [for placement] before but I didn't feel that I was ready."

A second woman, who lived alone in a senior's apartment building for several years, placed her name on the LTC waitlist when encouraged to do so by health care providers and family members. She described in detail the factors influencing her application and her continued ambivalence about it:

So you know then [illness episode] they had the nurses coming ... and they said you were supposed to put down your name for a home [nursing home]. So I said, all right and I'll put down my name for a home and it wasn't long before they had

a place for me and I said ... I'm not ready to go in a home yet as long as I can cook for myself.

This desire to hang on until there were no options remaining is further reflected in her synopsis of things: "I couldn't think of, you know, giving up everything. I was always, always active all my life and I am past ninety-three now."

Other participants expressed similar sentiments. Although one woman indicated that she was ready to go to a nursing home, the final decision was intimately connected with her health and ability to manage on her own:

No, I don't think I'd go [nursing home] tomorrow. It would be a [big decision]. I'd like to wait a bit longer now before I went. I still want to go into a nursing home [and] I suppose if they said it's the only choice you'll have I'd accept it I think. I haven't refused because at ninety-three you don't want to refuse.

Another woman had changed her mind about placement since her husband's death: "I'm not interested [in placement], not yet I'm going to have to eventually make up my mind, but I'd like to hang it down another year or so." Moving to a nursing home would only become a viable alternative when she could no longer manage on her own: "I don't know how long that will be, when I ... can't look after myself, I'm going to have to make the decision [about placement] I can't stay in this big old place by myself."

One couple applied for LTC following the declining mental health of one of its members. The husband questioned the logistics of making such a move as long as they could manage within the confines of their own home:

Yeah, we put our name down. I don't know if that was a foolish move Honestly, what home or establishment here in [city] could offer me something

better than what I have and if we can look after ourselves ... because I can look after the wife, and I'm sure the wife can look after me.

When asked directly what he would do if the call came tomorrow, he replied thus:

Well some of these homes are alright. They're alright for a man and his woman and he's basically well cared for, but I'd have to be up in a squeeze in order to get up the courage to go there I suppose. We wouldn't go. No sir.

Similarly, another couple was managing quite well living in their home because of extensive formal supports. The husband discussed how they were adjusting to gradual declines in functional abilities due to ill health:

[I'm] in the stage where I have to be cutting my lawn and I don't think I'm able. That's taken care of by a landscaping firm and we have somebody come in once a week and do what [wife] doesn't feel like doing. So we're getting all the help that we need at the moment.

It was apparent that LTC placement was viewed as a viable alternative only if there was a significant change in current circumstances: "If it comes to the stage when that's [supports] not enough, we got to leave here, hopefully I'll be brought out first."

An eighty-seven year old woman, who lived in an apartment building, recently lost her sister who had lived in the same building. She accepted the inevitability of a nursing home placement: "I've lived with the idea that I'd be going in a home for sometime. So sooner or later it's just it." Despite acknowledging the possibility of this type of move, she had turned down a placement call just prior to the interview. It seems that her struggle was closely connected to her desire to remain independent for as long as possible. She made a couple of insightful comments concerning this:

I had an interview [placement]. I told her I didn't want to go in right away but to keep my name on the book. I don't know why I just got cold feet now if they sent for me I'd go; I have my mind made up now.

I'd stay here forever if I don't get in the home. I'm going but as far as it goes, I don't mind waiting.

Another couple's commitment to the actual move seemed to waver within the context of their day-to-day circumstances: "We're still able to manage. Now we don't [know] how long that will be, probably tomorrow or we'll be in the hospital or he [spouse] might be." The husband also spoke about their increased vulnerability: "Any day at all could put one or both of us out of commission and at that time, I want help, and I don't want to be waiting six months for it." Similar to other participants his comments reflected future planning: "I want people to know that we looked down the road as far as we could and saw that this could take place [need for long-term care] and took whatever precautions we could."

Other participants viewed their situation in terms of a decision already made regardless of their acceptance of it. These individuals realized that they had reached a point in their lives when the difficulties of self-management outweighed their drive for independence and autonomy. With self-reserves diminished considerably and restrictions imposed on further use of informal and formal supports, long-term care placement was viewed as the final alternative. With her husband already placed in a nursing home and her physical functioning capabilities compromised, one particular woman was reconciled to the inevitability of her decision:

I would rather go to the [nursing] home and have it over with cause I am not 16 anymore. When you get to be eighty-one or eighty-two there is not much you can do in your own home is it?

The definiteness of her decision was evident from the following commentary: "I would rather go in the [nursing] home now and everything is done for me and that is it. I can't do much for myself. If I had two good hands it would be different but I haven't."

Another woman, who lived alone in a senior's apartment, applied for nursing home placement because of declining health. She discussed her concerns about not being able to manage much longer on her own:

Soon I'll have to quit [housekeeping]. . . .I get awful tired. . . .this has been coming on me these past few years. Like I said I think it's time for me to move on now [to nursing home] and let someone else take the responsibilities and the worries instead of me having to see to it.

The certainty of her decision was also reflected in her unwillingness to consider options such as home supports: "I'd rather wait for one [nursing home] to see if I would get anywhere [rather than home supports]."

One couple was also quite determined to move into a LTC facility. The husband recognized that both of them were beginning to need help in managing the family home: "You get help down there. She [spouse] wants help. They told us down there that there is someone there [personal care home] to help." It was also evident that the placement decision was a joint one: "We talked about that [home supports], I don't think so. I'd rather be in now, where I have nothing to do only sit around." The wife reinforced her husband's position:

I think we just thought it was time. We had our name down for an apartment down at the home, we were going to move out but we didn't see any need to do that because it's still an apartment and we were still looking after ourselves at the time.

5.5.3 Appraising Options

The Appraising Options property provides insight into the actual decision-making process adopted by participants concerning the type and location of specific LTC facilities; especially regarding what was open for compromise and what was non-negotiable. Interestingly, there seemed to be limited information gathering about various options, with most participants' perceptions shaped by direct experience with, and/or the reputation of, specific facilities. Consequently, many participants had very definite opinions about LTC options with limited insight into the actual similarities and differences among them.

Although preferences varied along with the level of definiteness about what was non-negotiable, most individuals did appraise the various options and found one type to be more appealing than another. An important factor influencing participants' decision-making was location of the LTC facility. Priority was given to those facilities that were either in close proximity to family, home communities and/or community services, especially health care. A second factor was familiarity with the facility based on previous experience, reputation or a combination of both. Few participants had actually visited facilities to help with their choices. The final category of factors also had great importance for participants and was associated with the perceived conduciveness of the facility in providing such in-house services as personal living space, medical services, social activities and autonomy/independence, among others.

Proximity to a LTC facility often interacted with prior experience with or the reputation of a particular facility. For example, a facility close to family members or one's community could be eliminated as a possibility if it received negative ratings from experience or reputation. One couple discussed the pros and cons of moving to a personal care home close to their daughter. The wife voiced her concerns about the limited space and distance of one facility: "I wouldn't go out to those places [personal care home]. My brother is in a [one] now ... I mean there is no room." Her husband was adamant about not moving to a personal care home: "I wouldn't go [personal care home]. That's the same as the other side of the world."

Other participants spoke about personal care homes in a negative fashion. There were similar and disparate reasons for this perspective. One couple's objections were due to limited space and personal responsibilities: "I had a friend die in [personal care home]. It's awful out there. You can reach out and touch the other bed. I think they're allowed one dresser. I wouldn't want to go [to a personal care home]."; "I understand they have accommodations but you do everything else yourself. It's more like a boarding house; not interested." Even when participants had no direct experience with personal care homes, they tended to reject them solely based on reputation. One woman voiced her objections thus: "I don't want to go into any private homes ... I have never had any dealings with them. I have heard so much. I don't know if it's all true but I want to be on the safe side." Other participants made similar statements: "Oh glory be to God, I'm not going out anywhere like that, I'll stay here and die in the house. I've been living here too long to go [to personal care home]."; "I'm not familiar with it [personal care homes] The only

thing I don't like is going in a room with someone else and perhaps they're ready to die or something...I wouldn't go out there."

In some instances, a participant's experience with one personal care home became the catalyst for discounting these types of facilities as a viable option. One woman's refusal of a personal care home placement was based on what she had to endure when her husband was transferred to one following an acute illness: "My husband died in 95 he was 4 years in [personal care home] and that's what go me turned off A lot of those people are mentally ill." She elaborated further on why she would not consider such a placement: "That's the only [personal care home] I was in, but just the same it was recommended by the hospital I got turned right off; and its private." A third participant resided in a personal care home at the time of the interview. This particular facility had a "mixed population" with limited recreation facilities and was twenty minutes drive from the city. She was very clear that location was her main reason for pursuing alternate accommodations: "Well I'd like to be somewhere near a store. There's nowhere for you to go only just walk around the house. It's not very easy to get transportation."

Other participants indicated a preference for personal care homes over other LTC facilities. One couple who lived in a senior's apartment annexed to a nursing home chose to downsize further into a personal care home. This decision was based on direct knowledge of the attractiveness of the services provided.

We've been over there and looked at it ... your meals and everything is looked after. I have to take my [blood] sugar and they [personal care home staff] can help you with that. It's near everything and we can walk ... to my son's and to [supermarket].

Another participant's decision for choosing placement in a personal care home was due to various factors.

The [social worker] told me that it's not like a nursing home in there [personal care home]. She said you can come and go when you want and she told me I could bring my own bed. But I'll stay in the room with someone else, I'd like to have my own room but it's a lot of money and the bus is right across [the street] and I can walk to [son's] house.

A male participant chose a personal care facility based on word of mouth, location and available services: "I was never in there [personal care home], but I know a friend in there. She told me it was good." He elaborated further on the reasons for selecting a particular personal care home: "I'd go in [to personal care home] because your meals are all cooked and your bed [made]...it's [close] to [caregiver] and that's where my bank is."

Many of the participants had selected a nursing home over other available choices (personal care homes, senior's complex). Similar to the situation with personal care homes participants had engaged in limited information gathering to assist them with decision-making. One couple who had friends in different facilities used religious affiliation, experience and reputation to make their final selection. The husband commented on why they preferred a certain nursing home to others.

[Nursing Home 1] is run by the Anglican [Church]. My aunt died there and I have a number of friends in there now so I know that one intimately. [Nursing Home 2] I've never been in but its reputation is excellent. That's why I chose that. The [Nursing Home 3], we have been there and I'm a little bit familiar there, beautiful staff in there.

Another couple also carefully weighed their options when deciding on a suitable nursing home for them. The wife commented upon the information available to them thus:

We decided to go into one of the homes ... we saw some books [and] we had been to [Nursing Home 2] ... [and] my sister in law is there over in [Nursing Home 5], my cousin's wife is there I was in her room.

Single participants also relied on religious affiliation and/or familiarity with particular nursing homes to make their decisions: "[Nursing Home 4], the church is there. And then [Nursing Home 1], I have known people that have been there, they say it is nice."; "The [Nursing Home 4] I was more interested in because it was near and everybody you know is [there] and I have a stepdaughter working there."; "I know [Nursing Home 1] because I used to visit and I think I would like it."

The financial liability to be incurred by moving to a nursing home was a significant factor facilitating participants' indecisiveness. The financial cost of placement was a big concern for one couple: "The only thing I don't like about those [nursing] homes is what they're charging If we were going to throw it [money] away, it'd be better to throw it to our children." A second couple also had issues with the cost of moving to a nursing home: "They're [nursing homes] too expensive."

Regardless of how participants' rated the different types of facilities, it was evident that certain conditions had to be met before they would consider moving to any LTC facility. For many couples placement was conditional on whether it would provide them what they felt they needed without losing what was critical to them - sharing space with their spouse. The following quotations illustrate this aspect: "I would want a room with her

[wife] because she is able to do more than I am. I trust her for everything you see.”; “Well if she is down the hall, I don’t mind running down the hall ... but I think we’d prefer to have our own room, you know.”; “We’d like to have a bedroom. My sister was in one of them [nursing homes] for years and she had a private room.” One couple had already turned down a placement call because their privacy would have been compromised: “We could have went in February [but] we had to share a bathroom with other people. We want a private room, so we turned down that [placement offer].”

Important for study participants decision-making was how various LTC facilities fared on the gain/loss continuum. All of the participants weighed potential losses (i.e. autonomy, privacy) against potential gains (i.e. regular meals, social contact, safety, service access). Two participants discussed how they reached their decision to enter a nursing home despite obvious limitations.

Well, I know what it’s like [nursing home] and a lot of things that could be better. Well, first of all there are two [people] in a room. And there is very little room for your own personal belongings and one toilet between four people. But you can’t have everything and if you’re there long enough, you eventually might get a private room.

I used to go back and forth to her [friend] bedroom and she had to share a bathroom. That’s one thing I wasn’t fussy over but I mean you can put up with that. [Space] is very important to me because your family can visit when they like and we could go and have a meal together.

Many participants, especially the single ones, commented on the potential benefits from social interaction and accessing regular meals from moving to a LTC facility: “I’d play cards for anything. Yeah, a card game, bingo and everything else that is on the go [in a nursing home].”; “I chose the home because there would be somebody there and

something to do, someone to play cards with.”; “I think why I would like to go to [Nursing Home 1] because you get up in the morning, and go for your breakfast, lunch and supper.”

Social contact and meal preparation were not the only benefits identified by participants. For certain individuals LTC placement would help reduce fears of insecurity: “I have to have somebody, especially for the nights.” Another woman identified other equally important services: “There are doctors and nurses visiting, and they have [church] services every morning and two sittings for breakfast.”

The participants were given a description of a supportive housing facility and its most common components (supportive environment, 24-hour security, meal provision, independent living space). Not surprisingly, many study participants were receptive towards the idea of supportive housing. For many, it could reduce the problems that they were experiencing with current living arrangements and delay placement in a LTC facility. Only one of the study participants was familiar with this concept.

My friend in [City] ... was telling me about [supportive housing]. She's very happy there. She can go to her own little place if she wants to. She can go down to the common room. I wouldn't mind that but there are none of those places here.

A male participant who lived on his own was very receptive to the idea and explained why it would be conducive for meeting his needs at the present time.

The good thing about that [supportive housing] would be it would leave you free of the maintenance stuff and the care. I live here all right but I'm also responsible for taxes, up keep, I got to keep my garden in good shape. Now, those kinds of setups would alleviate the situation as I wouldn't be worried about mowing the

lawn or the garbage ... and that means something when you get too old and feeble to bother with it.

For participants who had diminished physical functioning supportive housing would not necessarily resolve existing problems. One woman was uncertain about her ability to manage with this type of accommodations: "That means that I have to have someone buy groceries and I'd have to look after myself completely wouldn't it? Someone there with me 24-hours if I needed anything."; "I don't know...there are things I can do and there's things I can't do to help myself. As I was saying, I have problems trying to walk." Nevertheless she seemed to be quite interested in this type of arrangement: "It's [supportive housing] food for thought? Yes, I could be interested in that."

It seemed that many participants were looking for something in-between current housing arrangements and a nursing home. What seemed to be important for most of them was the ability to retain as much independence and autonomy as variant health, mood and energy states would allow. One female participant who lived alone was very positive about the services offered by supportive housing.

It sounds alright. You'd have your own breakfast and lunch if you wanted it. It depends on where it's built ... I think that's [supportive housing] a nice idea, you still have to get some meals. Yes, I'd be for that; I would like that. I wish they would start that tomorrow and do it. Write me down for that.

A similar perspective was echoed by a couple.

It [supportive housing] would be better than a nursing home. I think you would feel freer because you are in the nursing home, you're there to be taken care of and I don't think you would have the same freedom as you would have in a place you're talking about I wish there was a place between where we are [senior's cottages] and a nursing home.

Still another single participant expressed similar sentiments.

I think that would be nice But maybe you wouldn't want to cook. You've got to get in some groceries just the same ... and you'd all be together [common rooms] ... so if anything happened you could call on someone That's something like renting, something almost like here.

Other participants were able to identify the positives that would be derived from supportive housing. An important qualifier was the affordability of this type of service.

One participant commented thus:

I'm all for it [supportive housing], something like that where you have ... somebody around if you get hard up, would get a meal, which most of the time you get your own as long as you can ambulate and take care of yourself find. I'd go for that. But it shouldn't go over \$2000 per month. What you described would be ideal.

If supportive housing was an affordable option, it was seen as a viable alternative by another participant.

Well it [supportive housing] sounds good. If you go into the other homes I think they take your entire pension and they give you a \$100 of your pension to put you through a month, that's not very much. Everybody has a grandchild or a son or daughter, what are you going to do with a hundred dollars?

The final property of the decision-making category is appraising options. This property is defined in terms of how conducive for their needs each participant considered the facility and also involved balancing what they would be provided with against what they would lose. Participants were felt engaged in deciding for what they saw as the next, and sometimes final, move in their lives. As each applicant made a decision, he/she used his/her perceptions of the options available that were rooted in experience and reputation. The applicants engaged in selected information gathering, whereby several had visited facilities at one time or another to meet friends and relatives. This familiarity determined

their decisions regarding preferences when application was made. Many had very clear and definite opinions concerning the varying options and negative perceptions did not necessarily have to originate from personal experiences. Rather, things the applicants had “heard” were adequate to dismiss a facility or entire housing option.

5.5.4 Summary

The third construct, decision-making about long-term care, captures participants’ assessment of LTC options as alternatives to current living arrangements. The why and when of participants’ decisions provide meaningful insights into their emotional states and levels of awareness of the different options at the time. It was apparent from the interview data that, for the most part, the final decision was the result of careful weighting of potential gains and losses. The struggle to relinquish control over coveted aspects of their lives was reflected in their thoughts and actions. It was a constant battle trying to retain the non-negotiable (i.e., privacy, closeness to the familiar and family/friends) when faced with diminished overall well-being and declining social networks.

Although various factors influenced participants’ decisions to apply for institutionalization, the most important among these was the declining health and functioning of the self or spouse. This reality placed participants’ overall well-being in jeopardy and created even greater feelings of vulnerability. Whether the change in status was real (actual critical event) or anticipatory, participants began to doubt their ability to cope independently and reluctantly sought placement in a LTC facility.

An important aspect of the application decision was first choosing among various long-term care options and then selecting a particular facility. With no formal evaluation process available, decisions were based on limited information. A rather sparse experience base with different options combined with the reputation of specific facilities weighed heavily in the decision-making process.

For the most part, participants had discounted personal care homes as an option with very little insight into the actual services provided by different facilities. Overall quality issues such as compromised personal space, low food quality, mixed population of residents and limited recreation facilities were dominant concerns. Although a nursing home placement would not necessarily resolve all of participants concerns with personal care homes, they viewed these places as being more attractive because of the depth and variety of overall services. Essentially, they were willing to trade-off such things as less autonomy and independence for greater security, reduced vulnerability, more balanced meals, and reputedly better services, among other things. It seems that participants had more confidence in what they “would be getting” from nursing home placements as opposed to personal care homes.

What was evident from the commentary on supportive housing was that participants viewed this alternative as a viable intermediary for all LTC options. Participants certainly liked what they heard about this alternative and were quite interested in receiving more detail on it. While most were opposed to personal care homes and concerned about the

restrictive environments of nursing homes, supportive housing seemed to present them with an acceptable transition from their current living arrangements.

5.6 Discussion of Qualitative Findings

There was a particular incident or time when participants made the decision for placement. However, the decision-making process was complex and interwoven into their life experiences as they aged. As their lives changed and they became more vulnerable or needs went unmet - through lack of family contact, a decline in health, and a declining social circle - adjustments became necessary to maintain consistency in their lives. This was done mainly by constructing and reconstructing a support network. As the construct model illustrates, this process was successful until there is either a gradual erosion or a critical incident occurred which signified to participants that their system was no longer manageable.

In order to maintain the status quo, participants relinquished considerable independence over facets of their lives that had defined their self-identity. They managed the changes in their lives by adjusting their circumstances and redefining themselves and their expectations of their environment and those around them. They were “holding out,” aware of what they would have to give up while continually weighing their decision. By accessing services and adjusting demands on their social support network, they attempted to manage and readjust to the ongoing physical, emotional and social changes in their lives. When their needs increased, they responded by using resources available to them, help from families, support services, company from neighbours or any support available

to fill the gaps. Although, they were largely content in their circumstances they also had a realistic expectation that their health would decline further and were aware of the precarious and fragile nature of their independence.

Although participants were unsure of their readiness for institutionalization, they were certain of what a facility could provide them that they were now missing. Participants were aware of what institutionalization meant in the sense that it could provide a reprieve from loneliness or social isolation, alleviate the stress and physical strain of daily chores such as housekeeping and meal preparation, and provide the knowledge that someone would be there to respond to their care needs. They also knew what basic criteria their choice of facility would require, specifically affordability, a convenient familiar location, private space, meal preparation and security. Without availability of such things they seemed to think it too much of a loss and discounted such a facility or an entire option.

The interviews were meant to provide answers to specific questions regarding the elderly's decision to move to an institution. The data provided insight into the psycho-emotional realm of the participants and their feelings regarding their environment, the changes occurring in their lives and ultimately, their decision to move to a long-term care facility. They conveyed the complex nature of the decision-making process and that the maintenance of self-identity was the source of the applicants' resistance to placement. The data illustrated that the participants avoided making the final decision until circumstances became unmanageable. Furthermore, an understanding of how factors such as critical events such as a sudden decline in health and a subsequent inability to

adjust appropriately with or without an intervention from their support network became the trigger for the decision and eventually institutionalization.

Chapter 6

Discussion

The elderly should be viewed as intelligent but imperfect actors trying to negotiate with place in varied and creative ways.

Malcolm Cutchin

6.1 Introduction

In our society, the notion of “going to a home” conjures up negative images of the final stage of life. Common ideas of solitude, isolation and despair are carried throughout life with little consideration until one is forced to consider going to a home. For the elderly in the current study, Cutchin’s (2001) “negotiating” captures the continual adjustments and readjustments that they made to their environments, dwelling places, supports and social networks, independence and ultimately, definition of self to avoid moving to a long-term care facility. This process of adjustment was ongoing and persistent until a point was reached when the decision to move into a nursing home became easier than resisting it.

The current study attempted to address some practical questions regarding the long-term care single-entry system in the Eastern Health region of Newfoundland and Labrador. The chart review component provided a valuable description of applicants with modest care needs but also gave little insight into their actual decision-making process. The qualitative component provided a means to investigate this process by presenting a narrative of participants’ experiences. The discussion that follows is focused on key findings from both phases of the research.

Although data collection for this study occurred between 1999 and 2000, study findings are still relevant today. Firstly, no major changes have been made to the long-term care single-entry system since inception of this research study. System issues concerning lack of affordable alternative housing options, excessive acute care use, and wait times for nursing home beds are similar to those existing in 2000. Secondly, similar issues related to outmigration and emigration from other areas of the province and an aging population continue to plague policymakers struggling to predict needs and reshape the long-term care system for future demands.

6.2 Discussion of Quantitative Findings

The chart review provided a unique perspective on applicants who had no professional care requirements. This review provided an opportunity to investigate an important subgroup of applicants whose needs could be addressed independently from those applying with higher functional needs. Distinguishing between these two groups is an effective approach to addressing potential shortcomings in the system.

The long-term care system is functioning at a less than optimal level. As documented by previous researchers, there is inappropriate nursing home bed usage, as well as a discrepancy between the demand for beds and options available to applicants due to inadequate investment in alternatives to nursing homes (MacDonald 2005; O'Reilly 1998). The current study's findings confirm the prevailing hypothesis that many individuals with modest care needs applying for placement are better suited to alternative

housing arrangements such as supportive housing facilities than personal care or nursing homes. Only 51.4% of Level I and II objectively measured applicants required skilled nursing home care for health or cognitive deficits. Indeed, few applied for placement for physical or cognitive reasons with just 34% citing health as the cause for application. Significantly, the majority of applicants identified social, emotional and environmental factors such as housing issues, lack of support and a need for greater social contact as their reason for seeking placement in an institutional environment.

Although many applicants did have a network of caregivers and support structures, there were problems encountered accessing both informal and formal supports as needed. First, for many applicants, informal support systems were either nonexistent or functioning at maximum capacity, with over 36% indicating that informal caregivers were either no longer able or willing to provide the required support and care. Problems were also illustrated by the short placement time of applicants living at caregivers' residences - the shortest time to placement of any category. Secondly, although many were receiving formal support or community services of some type, just over 17% were accessing either subsidized or privately paid home supports. These findings suggest that only a modest number of elderly are in receipt of formal support services when at high-risk for institutionalization. The fact that few of the elderly met the financial criteria for subsidized home supports could be responsible for those low numbers. With nonexistent or strained informal caregivers, accessible home supports could mitigate the risk of institutionalization.

The critical life events that preceded many applications further underscore the strain placed on applicants' support networks. A majority of the applicants had experienced hospitalization, a sudden decline in health, or the death of a spouse a short time before application. Similar life events have been documented to correlate positively with institutionalization (Akamigbo & Wolinsky, 2006; Cheek & Ballantyne, 2001; Glazebrook & Rockwood, 1994). The emergence of critical events that serve as precursors to long-term care application mark an appropriate time for increased community support to help counteract engagement in such decision-making.

While previous research findings on the single-entry system highlighted inappropriate usage of nursing home care in the general application population, the chart review in the current study focused specifically on the subgroup of applicants considered to be inappropriately placed. The findings provide insight into possible reasons for placement and applicants preferred options, existing problems with personal care homes, and possible deficits in the support networks of high-risk elderly in the community.

Significantly, the findings suggest that there is a greater need for alternative care options along the continuum, and the existing pattern of application and placement in the system will continue until alternatives are provided and intervention strategies instituted for high-risk elderly.

6.3 Discussion of Qualitative Findings

The qualitative component of the current study focused on a group of relatively well elderly who had applied for long-term care placement. The findings reveal that most applicants undergo a particular incident or breaking point that precipitates the decision for placement. However, the actual point of decision was one part of a process that was complex and interwoven into their life experiences throughout the aging process. As the construct model illustrates, the ongoing adjustments to changes were successful until this incident occurred or until gradual erosion signified to the individual that his or her system was no longer manageable. Within this process three main constructs emerged that are discussed below.

6.3.1 Adjusting to Life Changes

The findings suggest that life changes led to a continual process of adjustment by individuals who struggled to maintain consistency in their lives. Although some change was accepted as inevitable by participants, the most resisted changes were those that compromised autonomy. Importantly, when fears about overburdening family members superseded concerns about loss of personal autonomy, the decision was made to apply for a nursing home placement.

Although participant's health status factored largely into the decision to apply for placement, most did not have functional disabilities that required nursing home care. Rockwood (1994) defines frailty as "a vulnerable state resulting from the balance of interplay of medical and social factors." Rockwood's "multifactorial" definition of frailty

can be applied to participants in the current study. Declining health due to chronic illness or sudden acute illness episodes compromised participants' ability to function independently in their environment. Longino et al. (1991) argued that this weakening and resulting home relocation occur due to the pressure of "instrumental disabilities" between the individual and their environment. Indeed, episodes of sudden illness deflated participants' confidence in their circumstances that was followed by application for placement.

The gain/loss theory of aging describes how elderly individuals are in a continual adaptive process whereby negative occurrences in health (losses) are mitigated by adaptations (gains) to ensure optimal results (Baltes, 1987). Similarly, many participants had already adjusted by changing their home environments at least once previously, such as moving from their homes and even their communities to apartments or new environments that provided more conducive living spaces for their abilities. It was also apparent that most participants had made adjustments, before and after any move, to avoid institutionalization. Rowles (1983) refers to this strategy as "accommodation," whereby individuals institute measures to avoid moving by redefining relationships with children and extending support networks to include people who are available to compensate for the gaps left by existing supportive others.

Noteworthy is the fact that the process of adjustment and balancing for changing requirements continued beyond the point when the decision was made to apply for placement. As participants struggled to maintain equilibrium, a nursing home had become

a more palatable option than becoming a burden to families. Nevertheless, it was found that resistance to relinquishing personal autonomy and the struggle to maintain independence is central to an individual's sense of self-identity regardless of the finality of the decision to go to a nursing home.

6.3.2 Appraising the Quality of Supports

Study participants had an extensive support network that played a critical role in allowing them to cope with daily demands. The literature contains limited information on how the elderly choose individuals to comprise their support networks (Wielink 1999). The information is also inconsistent on whether formal support services in the community delay or prevent institutionalization (Tsuji 1995). Participants in this study developed a 'system of support' from available individuals that combined both informal and formal supports to help them meet daily needs. However, problems posed by the inconsistency and inaccessibility of support group members led participants to consider alternatives.

The importance of informal support networks for facilitating independent living and avoiding institutionalization is well-documented (Dwyer 1994; Rowles 1983).

Participants evaluated the quality and responsiveness of their support networks by the frequency of contact with and availability of family members and others in their most immediate circle. Only family members with few obligations and in close proximity were considered available to provide assistance. Proximity to supportive others has been found to be a significant reason for mobility of the elderly (Serow 1987). In the current study, the issue of proximity was especially emphasized during acute illness episodes when

additional strain was placed on immediate family members who could not respond in a timely fashion. Others have also found that inaccessibility of informal caregivers due to geography and personal obligations results in a greater likelihood of nursing home placement (Jenkins, 2000).

From participants' perspectives, their support networks appeared to be functioning at maximum capacity. Indeed, the quantitative findings indicated that difficulties with supports were a primary reason for application. Forbes and Hoffart (1998) defined this threshold as emerging when a network's ability to provide additional support is exhausted. As participants' confidence in current support networks broke down due to members' work and family obligations, they questioned their abilities to manage and weighed the benefits of present supports against potential gains from considering options such as nursing home application.

Formal supports were also an important component of support networks complementing informal supports. The data suggests that formal supports did not completely resolve some of the more crucial requirements of participants and, consequently, may, at best, have functioned to delay rather than prevent institutionalization. The theory of "push-pull factors" proposes that certain events later in life leads to a revaluation of one's situation. In this study, the inconsistency of formal supports and unavailability of informal supports (push factors) lead individuals to revisit the option of a nursing home placement that they believed would provide more consistent support (pull factors) (Serow 1987; Wiseman 1980). This "*weighing of support*," similar to the push-pull argument, highlights the fact

that participants are provoked by feelings of uncertainty due to the perceived inadequacy of support networks. This uncertainty is weighed against consistent support perceived to be the norm in a nursing home environment, and consequently becomes a principle motivator for promoting nursing home entry.

6.3.3 Decision-making

When study participants entered the decision-making process concerning nursing home placement, this option was viewed as an approaching necessity. Wiseman (1980) coined the phrase 'involuntary movers' to define this group because, although largely satisfied with their environment, several factors make their current situation appear too overwhelming to cope any longer. An important factor influencing participants changing perspective on nursing home placement was the occurrence of a critical life event. When such events occurred, it demonstrated to participants the fragile nature of their situation. Support for this is found in the literature (Cheek & Ballantyne, 2001; Rowles, 1983; Serow, 1987; Wiseman, 1980). Frequently, the decision was made during a hospitalization or following the death of a spouse. Both of these critical events have been found to promote institutionalization of substantial numbers of elderly persons (Talerico, Kao, Travis & Acton, 2004).

The findings also suggest that many participants felt pressure from family members to apply for long-term care. This pressure was internalized as feelings of becoming too much of a burden to family members, a pervasive theme in the literature on reasons for institutionalization (Cheek 2001; Wielink 1999). Despite resistance to burdening their

families, participants did not relinquish the decision-making fully to significant others as suggested by some researchers (Reed 1999). In contrast, study participants attempted to maintain a level of control over their lives and preserved their entitlement to the final decision. They were also cognizant of the fact that they could change their minds at any point in time or turn down placement, with several choosing this option prior to the interview. This uncertainty following application underscores the findings that the decision-making process continues long after making the initial decision to apply.

Researchers have suggested that individuals choose their moves or “search spaces” based on personal experience and/or “flow of information” about successful moves by others (Wiseman, 1980; Wiseman & Roseman 1979). Similarly, findings from the current study suggest that individuals’ preferences were based on personal experiences and information from friends and neighbours or knowledge about the general reputation of facilities. All but one nursing home had a favourable reputation, but personal care homes were generally viewed negatively. The positive ratings of nursing homes and negative ratings of personal care homes resulted in increased nursing home applications and led to the overburdening of the long-term care system.

Discussion surrounding a theoretical alternative housing option triggered a free discussion of existing options. Not surprisingly, one of the most appealing aspects of supportive housing was the ability to have a personal space of one’s own. Forbes and Hoffart (1998) found that for the elderly nursing home placement represented the definitive end of their independent lives through a total loss of control. Similarly, for study participants, the

potential loss of personal space represented a diminished sense of autonomy. Regardless of how positive the preferred facility was viewed, participants were hesitant about moving anywhere. On a certain level, they believed that relinquishing private space and personal possessions meant losing the last bastion of their self-identity.

Study participants continued to resist institutionalization despite inadequate support networks, declining health status and social circles, increasingly unsuitable environments, and completing applications for nursing home placements. Many held out hope that placement would never become necessary, delaying the finality of the move by turning down placement offers. Expectations were adjusted downward as they entertained the possibility that they could continue to manage on their own. Clearly, this resistance would probably continue until placement occurred or until the ability to live independently vanished.

6.4 Methodology

The methodology used in the current study differed from previous research on the long-term care sector in several ways. Firstly, it is the first research of the province's long-term care sector using both quantitative and qualitative methods. This methodological approach provided for an in-depth analysis of ongoing issues in the system. Secondly, the objective of this research was to document the preferences of clients with modest care needs, thus excluding Level III and IV applicants. The chart review specifically examined information related to placement of couples, reasons for application and reason for

facility choice. Thirdly, unlike previous research, home care was not considered an option and was replaced with a “supportive housing” category. The purpose was to determine clients’ eligibility and interest in this alternative option.

In comparison to research findings reported in the literature, this is the first study to combine quantitative and qualitative techniques to investigate elderly person’s decision-making process for institutionalization before actual placement but subsequent to making an application. Most research in this area has examined at-risk elderly in the community, in institutions or both. However, no study to date has investigated the decision-making process of individuals who were awaiting placement. The chart reviews provided an objective measure of participant’s health status and corresponding care needs. The qualitative data gave insight into the factors that guide relatively healthy elderly individuals to apply for institutional care. Consequently, this study provides a unique perspective on existing knowledge in this area.

6.5 Limitations

Study participants are from a white, homogeneous population in one Canadian province with a tradition of strong family ties. Consequently, the strength of informal support networks may be different from that of other populations. Nevertheless, research findings have documented considerable homogeneity in the Canadian elderly population concerning institutionalization (Rockwood, Stolee & McDowell, 1996). This suggests that study findings could have applicability for other populations in Canada, but wider generalizability is cautioned against.

The influence of the elderly individuals' informal caregivers is known to factor strongly into the decision-making process. This study does not include the perspectives of spouses and children regarding the appropriateness or optimal placement of their elderly relative. Consequently, the extent to which informal caregivers influence this decision-making directly is absent from this research.

It is apparent that the assessment tools used in this study were not entirely suitable for capturing the true needs of relatively healthy applicants in the community. For example, the Functional Need Score (RCS) determines need in the "eating" category by assessing whether the individual is able to use utensils independently or without assistance.

Generally, members of the study population (Level I and II applicants) do not require such assistance but may require support for meal preparation, grocery shopping and nutrition. Thus, these assessment tools do not capture the difficulties that seniors may experience at a functioning level or with their ability to adapt to changing needs in the community environment. Rockwood (1996) concludes that a comprehensive assessment of frail elderly that considers environmental and psychosocial health as well as functional and medical needs might be more appropriate than traditional medical assessments.

Jenkins (2000) also questions whether assessment of an individual should be based on traditional targeted areas or whether it should be more focused on the person's need for assistance and resource use. Arguably, assessment tools that are equally reflective of physical, mental and social needs of individuals as well as medical and nursing needs would be more effective in determining actual support and care requirements and in turn, optimal placement needs.

The research literature indicates that the financial resources of the elderly influence their ability to choose among available options (Jenkins, 2000). The socio-economic status of participants was unavailable for this study because this information is not available via Health and Community Services placement services. Consequently, it is not possible to comment upon participants' ability to afford extensive home support, or newer and more costly assisted living and expensive personal care homes. In addition, it is not possible to determine whether study participants are using the single-entry system as a means to receive subsidized services they cannot afford or access in the community. It could be assumed that if individuals could afford more expensive options available in the community they would not be applying via the single-entry route.

As previously discussed, the single-entry system does not include home support options for applicants. Consequently, an important component that might prevent or provide alternatives to placement is absent. Few participants received home support from Health and Community Services. Although many participants indicated that additional home support would not influence their final decisions, this assertion cannot be confirmed. In essence, what impact the present home support policy has on application rates to the single-entry system is unclear.

6.6 Recommendations for Future Research

Study findings suggest that individuals are both physically capable and, in principle, willing to move to alternative options which could delay placement or eliminate

institutionalization completely as a viable option. If alternative options become available, a research study could be designed to evaluate their effectiveness in delaying or avoiding institutionalization for many elderly.

Likewise, the question remains as to the impact of modifying the stringent criteria applied to subsidized home supports in the present system. If such a policy shift occurred, would more of the elderly choose this type of service and would this lead to an expected reduction in application rates for long-term care from this group? A study to determine the impact of home support on application rates for this group could provide important information to stakeholders.

Finally, the study did not focus on those who were cognitively impaired. At present, cognitively impaired individuals cannot consent to participate in research in the province. Therefore, an important and significant segment of applicants to the single entry system has been neglected. With a significant body of research in existence on alternative care options for individuals with dementia and Alzheimer's, further research into the viability and effectiveness of alternative care options for such elderly persons would be beneficial particularly given the prevalence of cognitive impairment in this population.

6.7 Conclusion

This research study provides a description of individuals who applied for institutional care in the long-term care system in an urban region of a Canadian province with similar functional status, environments, and support networks. It used qualitative and quantitative

methods to describe the decision-making process of the elderly applying for long-term care placement. The qualitative research provides an in-depth insight into the decision-making experiences of a group of elderly who were part of a larger cohort applying for institutional care. This group reflects the larger cohort in health and socio-demographic characteristics, increasing the study's relevance as findings can be extrapolated to similar applicants waiting for placement in the system.

While a considerable amount of research exists on reasons for long-term care placement, this is the first study to investigate the decision-making process leading to institutionalization. The findings indicate that preceding the application decision, individuals had already made adjustments to offset emerging deficits in their abilities, environments and support networks. Critical episodes acted as triggers in the process. Increasing dependence threatened autonomous living but participants continued to resist anything perceived as approaching relinquishing total control or increasing the burden for their families. In fact, total dependence was viewed as an intolerable state and one that they would and could avoid by going into a long-term care facility.

A gradual reconciliation period preceded the actual decision to apply for long-term care placement. This period was characterized by increasing awareness of declining abilities and greater vulnerabilities, diminished autonomy and growing dependency, and the inadequacy of existing support systems. For those study participants who had become totally engaged in the decision-making process, major tradeoffs had been considered and accepted. Although placement was viewed as their most viable option due to increasing

physical decline and unmet needs, the process of reflecting upon their circumstances and weighing of available options continued long after the application. In fact, “acceptance or rejection” of the call for placement was perceived as one of their last decisions.

Akamigbo (2006) found that expectations of placement are “rational” and reflective of elderly persons’ actual risk for institutionalization. The findings of this study support previous research that identified the limited availability of suitable options for applicants with similar care and support requirements.

Study findings suggest that the current system’s level of functioning and structure is not proactive in avoiding inappropriate applications. In fact, as the system exists presently, it is easier and more beneficial for elderly persons with strained informal relations or limited support and financial resources to apply for costly care via the single-entry system then remain in their own homes in the community. If the elderly increase their desire for institutionalization as their numbers also grow, the demands on the system will be even greater. Consequently, those responsible for future system changes must ask several questions. What options need to exist in the long and short term to delay or prevent application from Level I and II elderly individuals? How can these options be made available, accessible and affordable? Who will provide these options? What problems may arise from changes in the system? Moreover, will such changes be effective in the long-term or serve to increase financial costs to the system while increasing the demand for services from the community.

Chapter 7

Implications for Health Care Policy

7.1 Introduction

The study was motivated by the persistent problems faced by the Eastern Health and Community Services Board's long-term care single-entry system (SES). Although the 1995 implementation of a single-entry system streamlined the process of application and placement to nursing home and personal care homes, additional problems persisted, including wait times to placement, shortage of beds to meet demands, and acute care usage. Within this context, this study attempted to address one recognized problem that was affecting the system: a portion of applicants without the need for professional care were spending extensive periods on the waitlist in some cases, in acute care beds awaiting placement into scarce and costly Level I and II beds in nursing homes. The problem was worsened by an apparent preference for placement in nursing homes versus personal care homes and the lack of housing and care options in the system. The current study's purpose was to develop a thorough understanding of this subgroup's support and functional requirements, causes for application, perceptions of existing options and lastly, their level of interest in alternative options.

7.2 The Long-term Care System

Since the beginning of the 1990's, the provincial government has recognized that the long-term care system required particular attention. The system lacked both cohesion and a general strategy to deal with present and future demands. When the government

implemented the single-entry system in the then St. John's region in 1995, it was recognized that this was needed to streamline services and provide a gateway for the elderly to access long-term care programs and services. However, such a gateway functions in its true form only by determining the most appropriate option for an individual from the range of options available. This ensures optimal functioning for the both the individual and the system. Unfortunately, a true SES was not implemented since a significant option, home support, was excluded. The elderly who wished to access home supports were required to apply separately for this service from the SES. Moreover, those who attempted to qualify for home supports encountered restrictive financial criteria that were subsequently worsened by a budgetary freeze in 2001 that included the implementation of an emergency case only policy for applicants. As a result, the SES is primarily a gateway to institutional care in a nursing home or supervised care in a personal care home. This structure results in a fragmented system whereby it is easier to gain access to placement in a nursing home, the mostly costly option for government, than to subsidized home supports in the community.

The personal care home industry is another area that has posed long-standing problems for policymakers. There are 57 personal care homes in the Eastern Health Region, nine of which are in the metro region. In the 1990's this sector was deregulated, which included the discontinuation of restrictions of both bed capacity and licensing. This increased competition resulted in a growth of new homes and availability of beds in the sector. However, by 2000, this new policy had not fostered the expected improvements to older homes and the newer homes lacked the subsidies held by older homes, thus restricting an

individual's ability to choose newer homes if desired. It also created high vacancy rates in the older homes, many of which are located outside the cities. In order to address these concerns, in 2000, the government introduced a new "portable" subsidy structure whereby applicants could choose a preferred home and carry their subsidy to that home once assessed via the SES. While providing more choice for those who were able to access portable subsidies, few portable subsidies are available in the system. For example, in 2005 there were 1663 licensed beds in the Eastern Health Region, but only 665 were subsidized and only 155 of those were portable subsidies. Consequently, the portable subsidy policy has only marginally served to increase interest in personal care homes in general or increase access to more desirable ones.

A third issue is the lack of affordable and accessible long-term care options for elderly in the region. There are no options for those applying to the SES other than placement in a nursing home or personal care home. Over the last decade, there have been several additional options offered from the private sector including new personal care homes, a private nursing home with an assisted living section and an assisted living facility opened in the metro region. However, only the personal care homes are subsidized if accessed via the SES. Over 90% of seniors in this province have an income below \$40,000 a year with 50% of those below \$15,000. Consequently, many of these existing options are beyond the economic means for a significant proportion of elderly without financial aid. While there have been calls for a provincial housing strategy that would include housing options for low-income seniors in the community none have materialized.

The current situation facilitates a system that promotes nursing homes as the most appealing options to the elderly who cannot personally finance alternative options. In a 2006-2008 Strategic Plan, the Department of Health and Community Services attempted to address several of these problems by establishing short-term priorities for the long-term care system in the province. Included were several initiatives to increase access to community care, nursing homes and personal care homes. Recently, the government has implemented some of the intended changes to the system. Although there are no changes in access or funding of home supports, a new funding initiative from the federal government attempts to address unnecessary acute care use by providing short-term home support. This acute home care program provides temporary home support, including professional care, to prevent hospitalization and encourage discharge from hospital following an acute episode. Secondly, an increase in subsidy rates to personal care homes has increased from \$1138 to \$1500 per client subsidy per month. This has long been called for by the personal care home operators. In addition, a substantial increase for portable subsidies available in the system was announced. While numbers have yet to be formally released, the number of subsidies available in the system is expected to almost double.

Notwithstanding recent attempts to address these issues in the long-term care sector it appears that the government's newest policies do not address the issues that precipitate the demands on the waitlist in any real terms. Despite the benefit that additional housing and care options would make, the government has not formally committed to any policy that provides real funding opportunities in the form of housing subsidies to seniors, or

funding for either capital projects or community partnerships to encourage new housing options. Discussion is also absent on policies that might expand choices for elderly who cannot afford to pay privately for more expensive options that exist outside the SES. There are also no formal strategies proposed to encourage more consistent and accessible services, such as the Provincial Home Repair Program (PHRP) available through Newfoundland and Labrador Housing, that could facilitate continued community living. Although an increase in subsidies ensures that a greater number of clients in the system have access to portable subsidies, it is unclear whether these will be quickly absorbed into the system leaving newer applicants once again awaiting an available subsidy.²

7.3 Implications for Policy

This current study has met its goal to provide insight into the decisions of relatively healthy elderly in the community to seek care in the long-term care system. It also has highlighted the wider shortcomings in the present system and suggested potential solutions to problems in the system discussed above.

Firstly, the study's findings support previous research regarding the health and functional status of those applying for Level I and low Level II beds via the SES. It confirms that the care and support offered in personal care homes and nursing homes is unnecessary for many of the applicants in question. In large part, their needs fall into three main categories: instrumental need such as meals, laundry and housekeeping; home

² Once a client accesses a portable subsidy, it is unavailable to any other client until the holder is no longer in the system. Consequently, these portable subsidies in such small numbers are available infrequently.

maintenance needs such as snow clearing and upkeep; and social-emotional needs such as support for social isolation and loneliness. With many suffering from chronic illnesses and requiring some daily support, flexible, accessible options in the community could address many of their requirements rather than the continuous skilled care provided in institutional and supervised care settings.

The study's findings about the true needs of the applicants call attention to the lack of consistent and comprehensive community services available to the elderly and their informal caregivers. Traditionally, there has been a reliance on informal caregivers and families to provide the bulk of support to the elderly. It was assumed that due to strong family ties and traditional support, many of the needs of these elderly were being provided for by family members. While many elderly receive considerable support from family, networks are breaking down under growing demands and other social changes. The research provides insight into the changing role of family and perceived responsibilities of children to aging parents. Study participants clearly stated that they did not regard informal support as an acceptable approach to meet their growing needs. It highlights the changing care responsibilities of the family structure and emphasizes the need for a corresponding shift from policies founded on those assumptions.

The findings also suggest that home supports complement informal care. Consequently, inconsistent and inaccessible home supports in the community lead to increasing strain on the informal support network and, in turn, serve to exacerbate unnecessary application to long-term care. Because the home support policy is restrictive and financing private home

support becomes an economic burden, many of the elderly are motivated to seek alternatives to their present situation. For the subgroup of elderly in the community that require small quantities of consistent support services to maintain independent living this inaccessibility is unfortunate. Access to support could successfully function to complement and alleviate strain on the informal support network thereby at minimum delaying application to the system. Governments can no longer avoid providing a comprehensive system of community support by assuming that the needs of the elderly will be provided for by their family. The presence of such a policy causes the elderly and their families to seek care from all avenues available regardless of the appropriateness of the care option or the resulting impact on the system.

Importantly, the applicants cannot be viewed as a homogeneous group. There were several subgroups within the study group applying for long-term care: many were widowed women in their eighties living alone; others were married couples with one member having greater care needs than the other leading to application; and a significant portion had mild cognitive impairment that may or may not be in the stage to be deemed impaired by the SES panel. The diversity of the elderly and their circumstances in this study only further serves to illustrate the need for an equally diverse array of housing and care options to meet their needs.

Finally, the decision-making process leading to application and attitudes towards existing choices held by participants reveal useful results for policymakers. Firstly, many applicants resisted placement following application, hoping placement would never be

necessary. This underlines the struggle against institutional care and the desire to remain autonomously in the community. It suggests that interventions to avoid placement could be successful with this group of applicants. Secondly, the interest shown by participants in a theoretical model of supportive housing demonstrates an example of one alternative to the present situation that could address this problem. In general, the research reveals that timely interventions during the decision-making process for placement has the potential to avoid institutionalization for some applicants, particularly when attractive, affordable options exist in the community that provide for their needs.

7.4 Discussion

This study found that a population of the elderly with modest care and support requirements use the single-entry system to address their needs due to an absence of alternative options. While many have adjusted to the reality of institutionalization and leaving their community, a significant reason for application is their inability to access appropriate and consistent service options in the community when confronting increasing care needs. The result is expensive subsidization of long-term care via application and placement in nursing homes that exceed their care needs, but that are selected because they are the only subsidized accessible care available.

There are several alternatives discussed in Chapter 2 that, if available in the system, could help to correct some of the problems. For seniors who have the desire and ability to stay in their homes, a comprehensive subsidized home support program offering a range of

services from housekeeping and meal preparation to personal care is needed. In addition, housing programs that provide help with housing maintenance and grants to upgrade or modify homes to facilitate easier living could also be beneficial. An array of affordable housing options such as supportive housing and assisted living facilities that offer services on-site or in combination with a home support program would suit those elderly who are ready to leave their homes for reasons such as social isolation or loneliness but who wish to remain in the community. Finally, aging-in-place facilities should be designed with couples in mind. Even within institutional settings, options can be designed to facilitate the varying levels of independence found among couples with a disparity in care requirements. Furthermore, all of these options, including supportive housing and assisted living facilities, can be designed, with special attention, to meet the needs of elderly with cognitive impairment. However, we must be cognisant that those with cognitive impairment have very specific requirements and are suited to facilities designed specifically for their needs.

Since the development of new initiatives from the private sector in personal care homes and assisted living, there has been a noticeably increased demand from the larger community. This “woodwork effect,” whereby new options create a demand that was not previously apparent in the population, highlights the community’s true need for additional options. The problem with many of the new options is affordability. Even if many seniors could access the scarce portable subsidies, the cost of placement would still be out of reach for the many seniors with an annual income below \$15,000 year. These options are unaffordable for many in the long-term even when taking additional assets such as home

equity into consideration. Unquestionably, if a continuum of subsidized services and housing options were available to seniors the system would see a similar “woodwork effect” with increased demands. Given the inadequate levels of support in the community, the real level of demand is unknown. Therefore, such a surge should be anticipated in the short-term if such programs and services were implemented.

Housing alternatives such as affordable assisted living and supportive housing options will not be a panacea for the system, and will not avoid institutionalization for all elderly. There will always be a demand for institutional care. Moreover, long-term care expenditures are increasing and are expected to continue to grow into the future. It is not surprising that governments are hesitant to begin programs and services as well as capital projects that may encourage more demand from the community. This dilemma is understandable for those who develop policy and are conscious of fiscal restraints. However, a policy shift is required if the goal is to delay or avoid unnecessary institutionalization. For example, the new amount of subsidy of \$1500 per month available to residents in personal care homes could be easily transferred to elderly in supportive housing, assisted living or home support programs. It may encourage new initiatives from community groups, the private sector and other levels of government to undertake new housing programs that might begin to address this long-standing deficit in the system.

7.5 Conclusion

The current study highlights a lack of housing, care and support services in the community that could alleviate the strain of community living for some elderly. Without wider options, unnecessary use of the SES from this group will continue. One finding that benefits policymakers is that the decision process is characterized by ongoing resistance from applicants, thereby providing opportunities to intervene to avoid unnecessary institutionalization. However, the most straightforward mechanism to ensure more efficient and optimal placement is to provide interventions to high-risk elderly by matching service and housing options in the community to their needs before application occurs. To be effective, these options would have to exist and be accessible to the target population. Consequently, the dialogue should not be centred on whether those without medical needs should be institutionalized or solutions further restricting options and services to these applicants. Rather, policymakers must consider what range of support services and housing options should be available to those without medical or professional care requirements to avoid unnecessary and unwanted application. If the needs of those individuals who are vulnerable to institutionalization are not appropriately considered, it will only serve to prolong the ongoing problems within the system. Regardless of short-term problems that may occur with a new system, the findings highlight the need for the provincial government to provide a long-term care system that shifts away from the current reactive policies to an integrated and comprehensive system with a range of services that can proactively meet the needs of the elderly. It must be understood that the elderly vary vastly in financial, emotional and physical abilities and that an affordable, accessible system to respond to these individual needs along a continuum is required.

BILIOGRAPHY AND REFERENCES

- Aguero-Torres, H., von Strauss, E., Viitanen, M., Winblad, B & Fratiglioni, L. (2001). Institutionalization in the elderly: The role of chronic diseases and dementia. Cross-sectional and longitudinal data from a population-based study. *Journal of Clinical Epidemiology*, 54, 795-801.
- Akamigbo, A. & Wolinsky, F. (2006). Reported Expectations for Nursing Home Placement Among Older Adults and Their Role as Risk Factors for Nursing Home Admissions. *The Gerontologist*, 46(4), 464-473.
- Almind G. (1985). Risk Factors in Eighty-Plus Year-Olds Living at Home: An Investigation of a Danish Community. *International Journal of Aging and Human Development*, 21(3), 227-234.
- Angus, J., Kontos, P., Dyck, I., McKeever, P. & Poland, B. (2005). The personal significance of home: habitus and the experience of receiving long-term home care. *Sociology of Health and Illness*, 27(2), 161-187.
- Armstrong-Esther, C. (1994). Long-term care reform in Alberta, Canada: the role of the resident classification system. *Journal of Advanced Nursing*, 19, 105-113.
- Baker, P. & Prince, M. (1990). Supportive Housing Preferences Among the Elderly. In *Optimizing Housing for the Elderly: Homes Not Houses* (pp. 5-23). (n.p.): Haworth Press.
- Ball, M., Perkins, M., Whittington, F., Connell, B., Hollingsworth, C., King, S., et al. (2004). Managing Decline in Assisted Living: The Key to Aging in Place. *Journal of Gerontology*, 59B(4), S202-S212.
- Baltes, P. B. (1987). Theoretical Propositions of Life-Span Developmental Psychology: On the Dynamics Between Growth and Decline. *Developmental Psychology*, 23(5), 611-626.
- Bauer, E. (1996). Transitions from Home to Nursing Home in a Capitated Long-Term Care Program: The Role of Individual Support Systems. *Health Services Research*, 31(3), 309-325.
- Beland, F., Bergman, H., Lebel, P., Dallaire, L., Fletcher, J., Tousignant P., et al. 2006. Integrated Services for Frail Elders (SIPA): A Trial of a Model for Canada. *Canadian Journal on Aging*, 25(1), 25-42.
- Blazer D, Sachs-Ericsson, N. & Hybels C. (2005). Perception of Unmet Basic Needs as a Predictor of Mortality Among Community Dwelling Older Adults. *American Journal of Public Health*, 95(2), 299-304.

- Carpenter G.I., Maiw, J. & Turner, G.F. (1995). Case-mix for the Elderly Inpatient. Resource Utilization Group (RUG-III) *Validation Project. Age and Ageing*, 24, 5-13.
- Carriere, Y. & Pelletier, L. (1995). Factors Underlying the Institutionalization of Elderly Persons in Canada. *Journal of Gerontology*, 50B(3): S164-S172.
- Cates, N. (1994). Denmark: Changes in Health and Social Services for the Elderly and Comparative Observations. *Home Health Care Services Quarterly*, 15(1), 57-71.
- Chan, K.M., Wong, S.F. & Yoong, T. (1998). Nursing Home Applications-Reasons and Possible Interventions. *Singapore Medical Journal*, 39(10), 451-455.
- Cheek, J. & Ballantyne, A. (2001). Moving Them On and In: The Process of Searching for and Selecting an Aged Care Facility. *Qualitative Health Research* 11(2), 221-237.
- Chenitz, W.C. & Swanson, J.M. (1986). *From Practice to Grounded Theory: Qualitative Research in Nursing*, Menlo Park, CA: Addison-Wesley.
- Cleak, H. & Howe, J. (2003). Social Networks and Use of Social Supports of Minority Elders in East Harlem. *Social Work in Health Care*, 38(1), 19-38.
- Coleman, B. (1995). European Models of Long-Term Care In the Home and Community. *International Journal of Health Services*, 25(3), 455-474.
- Corbin, J. & Strauss, A. (1990) Grounded Theory Research: Procedures, Canons, and Evaluative Criteria, *Qualitative Sociology*, 13(1), 3-21.
- Cutchin, M. (2001). Deweyan Integration: Moving Beyond Place Attachment in Elderly Migration Theory. *International Journal of Aging and Human Development*, 52(1), 29-44.
- Dwyer, J., Barton, A. & Vogel, B. (1994). Area of Residence and the Risk of Institutionalization. *Journal of Gerontology*, 49(2), S75-S84.
- Eckert, K., Morgan, L. & Swamy, N. (2004). Preferences for Receipt of Care Among Community-Dwelling Adults. *Journal of Aging & Social Policy*, 16(2).
- Fishbein, G. (1975). Congregate Housing. *Geriatrics (Sept)*, 124-128.
- Fonda, S., Clipp, E & Maddox, G. (2002). Patterns in Functioning Among Residents of an Affordable Assisted Living Housing Facility. *The Gerontologist*, 42(2), 178-187.
- Forbes S. & Hoffart, N. (1998). Elders Decision Making Regarding the Use of Long-Term Care Services: A Precarious Balance. *Qualitative Health Research*, 8(6), 736-750.

- Friedman, S., Steinwachs, D., Rathouz, P., Burton, L., & Mukamel, D. (2005). Characteristics Predicting Nursing Home Admission in the Program of All-Inclusive Care for the Elderly People. *The Gerontologist*, 45(2), 157-166.
- Glaser, B. G. & Strauss, A. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine.
- Glazebrook, K. & Rockwood, K. (1994). A Case Control Study of the Risks for Institutionalization of Elderly People in Nova Scotia. *Canadian Journal on Aging*, 13(1), 104-117.
- Gnaedinger, N. (1998). *Supportive Housing: An International Review. Steering Committee on Supportive Housing*. Victoria, BC: British Columbia Ministry of Health and Ministry Responsible for Seniors.
- Golant, S. (2004). Do Impaired Older Persons with Health Care Needs Occupy U.S. Assisted Living Facilities? An Analysis of Six National Studies. *Journal of Gerontology*, 59B(2), S68-S79.
- Gupta N, & Galanos, A.N. (1996). Why Healthy Elders Move to a Continuing Care Retirement Community. *NCMJ*, 57(6), 378-380.
- Hawes, C., Phillips, C. Rose, M., Holan, S. & Sherman, M. (2003). A National Survey of Assisted Living Facilities. *The Gerontologist*, 43(6), 875-882.
- Hays, J., Pieper, C & Purser, J. (2003). Competing Risk of Household Expansion or Institutionalization in Late Life. *Journal of Gerontology*, 58B(1), S11-S20.
- Health and Welfare Canada. (1992). Classification of Long-Term Care Clients in Home Care. Ottawa: Author.
- Hernandez, M. (2005). Assisted Living in All of Its Guises. *Generations*, (Winter), 16-23.
- Hirdes J.P. (1997). Development of a crosswalk from a minimum data set 2.0 to the Alberta Classification System. *Healthcare Management Forum*, 10, 27-34.
- Interagency Committee on Senior's Housing. (1999) Report to Department of Health and Community Services, Newfoundland and Labrador: Author.
- Jenkins, C.L. (2000) Care Arrangement Decisions for Frail Older Women: Quantitative and Qualitative Perspectives. *Journal of Women and Aging*, 12(3/4).
- Johri, M., Beland, F. & Bergman, H. (2003). International experiments in integrated care for the elderly: a synthesis of the evidence. *International Journal of Geriatric Psychiatry*, 18, 222-235.

Klein, T. (1996). Determinants of Institutionalization in Old Age. *Developments in Health Economics and Public Policy*, 5, 103-113.

Kodner, D. (2002). The quest for integrated systems of care for frail older persons. *Aging Clinical and Experimental Research*, 14(4), 307-313.

Kontos, P. (1998). Resisting Institutionalization: Constructing Old Age and Negotiating Home. *Journal of Aging Studies*, 12(2), 167-184.

Krout J., Oggins, J. & Holmes, H. (2000). Patterns of Service Use in a Continuing Care Retirement Community. *The Gerontologist*, 40(6), 698-705.

Lagergren, M. (1996). Transferring to an Institution: An Analysis of Factors Behind the Transfer to Institutional Long-Term Care. *Canadian Journal on Aging*, 5(3), 427-441.

Lee, D.T.F. (1997) Residential care placement: perceptions among elderly Chinese people in Hong Kong. *Journal of Advanced Nursing*, 26, 602-607.

Litwak, E. & Longino, C. (1987). Migration Patters Among the Elderly: A Developmental Perspective. *The Gerontologist*, 27, 266-272.

Lo Sasso, A. & Johnson, R. (2002). Does Informal Care from Adult Children Reduce Nursing Home Admissions for the Elderly? *Inquiry*, 39, 279-297.

MacLennan J., Isles, F. E., McDougall, S. & Keddie, E.. (1984). Medical and Social Factors influencing Admission to Residential Care. *British Medical Journal*, 288(3), 701-703.

McAuley, W. & Travis, S. 1997. Positions of Influence in the Nursing Home Admission Decision. *Research on Aging*, 19(1), 26-45.

McAuley, W. & Travis, S. 2000. Factors Influencing Level of Stress During the Nursing Home Decision Process. *Journal of Clinical Geropsychology*, 6(4), 269-278.

McCann, T.V. & Clarke, E. (2003). Grounded theory in nursing research: Part 1--Methodology. *Nurse Res.*, 11(2), 7-18.

McDonald, J., Hibbs, J., Reddy, M., Stuckless, S., O'Reilly, D., Barrett B., et al. (2005). Long-Term Care in the St. John's Region: Impact of Single Entry and Prediction of Bed Need. *Healthcare Management Forum*, 18(3), 6-12, 50-7.

Mavundia, T.R. (1996). Factors Leading to Black Elderly Persons' Decisions to Seek Institutional Care in a Home in the Eastern Cape. *Curatons*, 19(3), 47-50.

Mollica, R. (2003). Coordinating Services Across the Continuum of Health, Housing and Supportive Services. *Journal of Aging and Health*, 15(1), 165-188.

Monk, A & Kaye, L. (1991). Congregate Housing for the Elderly: Its Need, Function and Perspectives. In *Congregate Housing for the Elderly* (5-19). (n.p.): Haworth Press.

Mustard, C., Finlayson, M., Derksen, S. & Berthelot, J-M. (1999). What determines the need for nursing home admission in a universally insured population? *Journal of Health Services Research and Policy*, 4(4), 197-203.

Newfoundland and Labrador Department of Health. (2005). *Personal Care Home Profile*. St. John's: Author.

Newfoundland and Labrador Statistics Agency. (2005). *Demographic Change: Newfoundland and Labrador – Issues and Implications*. St. John's, NL: Author.

O'Reilly, D., Parfrey, P., Barrett, B. & McDonald, J. (1998). Efficiency of institutional long-term care and annual demands for placement. *Healthcare Management Forum*, 11(3), 26-32.

Pampel, F., Levin, I. & Louviere, J. (1984). Retirement Migration. *Research on Aging*, 6(2), 139-162.

Pinquart, M. & Sorensen, S. (2002). Older Adults' Preferences for Informal, Formal and Mixed Support for Future Care Needs: A Comparison of Germany and the United States. *International Journal of Aging and Human Development*, 54(4), 291-314.

Pynoos, J., Liebig, P., Alley, D. & Nisthita, C. (2005). Homes of choice: Towards more effective linkages between housing and services. *Journal of Housing for the Elderly*, 18(3/4), 5-49.

Reddy, M. (2000). *Institutional Long-Term Care: Care Requirements and Population Rates in a Canadian Urban Region*. Unpublished masters thesis, Memorial University of Newfoundland, St. John's. Newfoundland and Labrador, Canada.

Rockwood, K., Fox, R. A. & Stolee, P. (1994). Frailty in elderly people: An evolving concept. *Canadian Medical Association Journal*, 150, 498-495.

Rockwood, K., Stolee, P. & McDowell, I. (1996). Factors Associated with Institutionalization of Older People in Canada: Testing a Multifactorial Definition of Frailty. *Canadian Journal of Public Health*, 44(5), 417-421.

Roos, N. & Havens, B. (1991). Predictors of Successful Aging: A Twelve-Year Study of Manitoba Elderly. *American Journal of Public Health*, 81, 63-68.

Rowles, G. (1983). Between Worlds: A Relocation Dilemma for the Appalachian Elderly. *International Journal of Aging and Human Development*, 17(4), 301-314.

Rubenstein, R. (1989). The Home Environment of Older People: A Description of the Psychosocial Processes Linking Person to Place. *Journal of Gerontology*, 44(2), S45-53.

Scocco, P., Rapattoni, M. & Fantoni G. (2006). Nursing home institutionalization: a source of eustress or distress for the elderly? *International Journal of Geriatric Psychiatry*, 21, 281-287.

Serow, W. (1987). Why the Elderly Move: Cross National Comparisons. *Research on Aging*, 9(4), 582-597.

Sheehan, N. & Oakes, C. (2003). Bringing Assisted Living Services Into Congregate Housing: Residents' Perspectives. *The Gerontologist*, 43(5), 766-770.

Sheldon, L. (1998). Grounded theory: issues for research in nursing. *Nursing Standard*, 12(52), 47-50.

Silverstone, B. & Burack-Weiss, A. (1983). The Social Work Function in Nursing Homes and Home Care. In *Gerontological Social Work Practice in Long-Term Care* (7-25). (n.p.): Haworth Press.

Splann Krothe, J. (1997). Giving Voice to Elderly People: Community-Based Long-Term Care. *Public Health Nursing*, 14(4), 217-226.

Statistics Canada. (2001). Fact sheet No. 1. *A growing population*. Ottawa: Author.

Statistics Canada. (2001). Fact sheet No. 2. *Canada's oldest seniors*. Ottawa: Author.

Supportive Housing in Supportive Communities: The Report on the Supportive Housing Review. (n.d.). Victoria, BC: British Columbia Ministry of Health and Ministry Responsible for Seniors.

Tsuji, I., Whalen, S. & Finucane, T. 1995. Predictors of Nursing Home Placement in Community-Based Long-term Care. *Journal of the American Geriatrics Society*, 43, 761-766.

VanderHart, P.G. (1995). The Socioeconomic Determinants of the Housing Decisions of Elderly Homeowners. In *Housing Decisions for the Elderly: To Move or Not to Move* (Chapter 2, pp. 5-35). (n.p.): publisher unknown.

Wielink, G., Huijsman, R & McDonnell, J. (1997). Preferences for Care: A Study of the Elders Living Independently in the Netherlands. *Research on Aging*, 19(2), 174-198.

Wilson, K.B. (1994). Assisted Living-A Paradigm of Consumers of False Hope. *Aging Today*, (January/February), 8-10.

Wiseman, R. (1980). Why Older People Move: Theoretical Issues. *Research on Aging*, 2(2), 141-154.

Wiseman, R. & Roseman, C. (1979). A typology of elderly migration based on the decision-making process. *Economic Geography*, 55, 324-337.

Wodchis, W., Hirdes J. & Feeny, D. (2003). Health-Related Quality of Life Measure Based on the Minimum Data Set. *International Journal of Technology Assessment in Health Care*, 19(3), 490-506.

Woo, J., Ho, S.C., Lau, J. & Yuen, Y.K. (1994). Age and marital status are major factors associated with institutionalization in elderly Hong Kong Chinese. *Journal of Epidemiology and Community Health*, 48, 306-309.

Wright, B. (2004). *An Overview of Assisted Living* (Brief #72). (n.p.):AARP Public Policy Institute.

Appendices

Appendix A LONG-TERM CARE CLASSIFICATION WORKSHEET

Initials: _____ Age: _____ Birthdate: _____ ID Number: _____ CC# _____

Sex: _____ Residence at assess: _____ Marital Status: _____ k

Assess date: _____ Panel date: _____ Health Region: _____ Household _____

composition: _____ Age of Spouse: _____ data abstraction date: _____ hosp

admission: _____ mdd: _____

Placement Preferences: 1. _____ 2. _____ 3. _____

Follow up status: placed(date) _____ deceased _____ awaiting placement (location) _____

Other: _____ facility: _____

Functional Need Score ☐ (1-5)

Resident Classification Score ☐ (A-G)

Informal Supports _____

RUGs-III ADL Score ☐ (4-18)

RUGs-III indicator _____

Formal Supports _____

Recommended
Nsg. Home

Supportive Housing

PCH

SH with support

LTC services: Assessor: _____ (level)

Researcher _____

comments: _____

Functional Needs*(same indicators as RCS)**(Other indicators used for Home Care classification)****Eating** ☐**Bathing** ☐***Toileting** ☐**Grooming** ☐***Transferring** ☐**Indoor Mobility** ☐***Dressing** ☐***Outdoor Mobility** ☐**Potential for Injury** ☐**Memory** ☐**Coping** ☐**Urinary Management** ☐ **Sum of 13 Functional Need Indicators** ____***Bowel Management** ☐**Functional Need Score (1-5)** ☐1- (1-5)
2-(6-10)
3-(11-20)
4-(21-25)
5-(26-62)

* for categories with n/a, total will have to be adjusted

Informal Supports: (Y/N)*(unpaid & unsupervised persons eg. family, friends)***Support services currently
in place****Resident Classification System 'RCS'** (using translation Paradigm from APPI)**Eating** ☐**Potential for Injury** ☐**Urinary Continence**☐**Toileting** ☐**Ineffective Coping** ☐**Bowel Continence**☐**Transferring** ☐**BDL Score** ☐**CCL Score** ☐**Dressing** ☐**ADL Score** ☐**RESIDENT CLASSIFICATION SCORE** ☐ (A-Low to G-Very

High)

RUGs III Professional Care Requirements ✓ if appropriate (describe in comments section)
 (based on RUGs III seven Hierarchical Categories)

Special Rehabilitation ☐
 Extensive Clinical Services ☐
 Special Care ☐
 Clinically Complex ☐

Impaired Cognition ☐
 Behaviour Problems ☐
 Reduced Physical Function ☐

Comments: _____

***RUGs ADL:** (refer to RUGs index ordinal scale)

Bed Mobility ☐

RUGs-III ADL Index Ordinal Scale

Toilet Use ☐

ADL Variables Score

Transfer ☐

Bed Mobility Independent or supervision 1

Transfer Limited assistance 3

Eating ☐

Toilet use Extensive assistance or total dependence:
 Other than 2-person physical assist 4
 2 or more persons physical assist 5

.....
Eating Independent or supervision 1
 Limited assistance 2
 Extensive assistance or total dependence 3

RUGs III ADL SCORE ☐ sum of ADL's (ranges from 4 "completely independent" to 18- "high")

Appendix B

Long-Term Care- Interview Schedule

Interview Script

Thank you for agreeing to participate in this survey on the support service needs of seniors. I understand that you made the decision to seek placement in a long-term care facility within the St. John's Region. I would like to ask you to take some time to reflect upon your reasons for seeking placement and why you prefer one type of housing option over another. Feel free to talk about whatever comes to your mind.

Examples of Probes/Questions to Facilitate the Interview

1. Could you think back to when you first thought about the need for long-term care services and describe what it was like for you then? [Probes – decline in physical health of self (or spouse), social restrictions, activity limitations, transportation problems, financial difficulties, loneliness.]
2. Thinking back to the time before you considered long-term care services and what it was like, could you describe any changes that you have experienced? [Probes – amount of support received from a significant other, family or friends; degrees of stress, problems with physical functioning, or physical health. Did you feel more confident about your ability to manage things in your own home – elaborate?]
3. What would you require to help you stay at home in the short term? [Probes: help with grocery shopping, cooking, house cleaning/repairs, laundry, or personal care: someone to be available during the day or night].
4. How do you feel about Home Support Services (public versus private) in general? What are some of the positives? Negatives?
5. Reflecting on what you know about Personal Care Homes, what do you find the most attractive about this type of support? Least attractive?
6. Reflecting upon what you know about Nursing Homes, what do you find the most attractive about this type of support? Least attractive?
7. Would you consider alternate arrangements to Personal Care Homes or Nursing Homes (for example, private apartment with kitchen facilities in a Seniors Complex with common areas for socializing and recreation; and housekeeping and personal care services provided by Health and Community Services)? What would make something like this more attractive to you?
8. Are there any other comments or thoughts that you would like to share with me about your perceptions of/experiences with long-term care services?

Appendix C

Alberta's Home Care Client Classification (HCCC)

Alberta has developed a classification system which groups clients according to their care requirements. Classification is based upon indicators of assessed functional need. Alberta's Home Care Client Classification System is based on the assessment of 13 functional need indicators. These 13 indicators are:

1. Eating
2. Urinary Management
3. Bowel Management
4. Toileting
5. Indoor Mobility
6. Outdoor Mobility
7. Transferring
8. Memory
9. Coping
10. Potential for Injury
11. Grooming
12. Dressing
13. Bathing

Appendix D

Alberta Resident Classification System (ARCS)

Indicators in the following three domains proposed by Alberta's Resident Classification System (ARCS) were used to classify clients needing institutional placement:

- **Activities of Daily Living (ADL) Indicators:**

1. Eating
2. Dressing
3. Toileting
4. Transferring

- **Behavior (BDL) Indicators:**

5. Ineffective Coping
6. Potential for Injury to Self and Others

- **Continence (CCL) Indicators:**

7. Urinary Continence
8. Bowel Continence

Alberta Resident Classification (ARCS) Category Definition

A resident's score on each of the 8 indicators is combined using a series of decision rules which places the individual in one of seven classification categories. These categories (A to G) are rank ordered from low to high in terms of care requirements and

resource use. Weights were assigned to each category based on the differences between the nursing resources used by residents in the seven categories.

When these weights are standardized, with category A having a weight of 1.0, then resource use measures for the seven categories are:

A	1.00
B	1.40
C	1.93
D	2.26
E	2.90
F	3.40
G	3.86

(A category B resident requires, on average, 1.4 times as much nursing care time as a category A resident, and a category G resident requires 3.86 times as much)

Category 'A' - patients with low ADL's, low BDL's and non-med incontinence problems. They have little or no functional impairment who require minimal supervision, although they may require a supportive environment to function at their potential levels (e.g. patients prepared for independent living or who require supervision to prevent deterioration in their condition).

Category 'B' - patients with a low ADL and a med to high BDL, or those with a med-low ADL and a low to medium BDL. These combinations require about the same levels of care (e.g. patients with minor physical handicaps that require restorative rehab, or in patients with mild cognitive impairment- early Alzheimer's). Higher BDL's are offset by lower ADL's in this category. Patients with highest level of incontinence are excluded.

Category 'C' - comprise three clusters of patients. As in 'B', the clusters represent different combinations of ADL and BDL levels: lowest ADL with highest BDL, med-low ADL with high BDL and med ADL with low-med BDL levels. However, in 'C', the BDL's are higher for any given ADL level than they are for 'B'. Patients with highest level of incontinence are also excluded (patients with early stage multiple sclerosis requiring little physical care, but are emotionally liable, or stroke patients with moderate physical deficits who need emotional support).

Category 'D' - comprise the largest number of combinations: patients whose combined ADL and BDL would have put them in A, B, or C but who have incontinence of both bowel and bladder; patients with no or occasional incontinence if they have med-low ADL's and very high BDL's, med ADL's and high BDL's, or med-high ADL's and BDL's from low-high (paraplegics having bowel/bladder retraining, younger CVA, MS, organic brain syndrome etc.).

Category 'E' - four different combinations: patients with lower ADL's must have either med-high CCL's or very high BDL's. Patients with med-low ADL's *only* if very high BDL's **and** need management or retraining for urinary incontinence. Those with medium ADL's and high BDL's and bladder management problems are also in this category. Patients with no or low incontinence are in this category only if they have very high BDL needs. Patients with med-high or high ADL requirements, whether they require management of urinary incontinence or have no incontinence, if they do not have very

high BDL requirements (very frail, confused elderly, old stroke patient, severely arthritic patient, alcoholic with Korsakoff's syndrome, brain injured patient).

Category 'F' - primarily patients with heavy care requirements: highest ADL's who also have some incontinence problems. Without the highest ADL's a patient could fit in category F, if the physical care requirements (ADL and incontinence) are complicated by behavior problems. Patients with very high BDL's are not included unless they have lower ADL's (advanced dementia, bedridden, non mobile with incontinence, MS, or palliative care).

Category 'G' - Highest BDL's and med-high ADL's. those with med-high ADL requirements must also have some incontinence (advanced neurological diseases such as MS, ALS, Huntington's Disease, Palliative Care, severe dementia requiring high physical care, severe rheumatoid arthritis).

Appendix E

Resource Utilization Groups-Version III (RUGs-III)

The RUGs-III classification system groups nursing home residents by resident characteristics so as to explain resource use. This system consists of seven main clinical groups devised as hierarchy, ranked by cost. These groups are:

Special Rehabilitation - combination of physical, occupational, or speech therapy.

Resident's must meet the criteria for one of the following four subcategories:

- **Very High Intensity Multidisciplinary Rehabilitation:**
450+ minutes rehabilitation therapy per week, 2+ of the three therapies provided, with 5+ days per week of one type of therapy
- **High Intensity Rehabilitation:**
300+ minutes rehabilitation therapy per week, with 5+ days per week of one type of therapy
- **Medium Intensity Rehabilitation:**
150+ minutes rehabilitation therapy per week, with 5+ days per week of one type of therapy
- **Low Intensity Rehabilitation:**
45+ minutes rehabilitation therapy per week, with 3+ days per week of therapy, and 2+ types of nursing rehabilitation.

Extensive Services - ADL index score of at least seven. Meets at least one of: Parental feeding, suctioning, tracheostomy, ventilator/respirator.

Special Care - ADL index score of at least seven. Meets at least one of: burns, coma, fever with vomiting, pneumonia, dehydration, multiple sclerosis, stage 3 or 4 pressure ulcers, quadriplegia, septicemia, 4 medications, radiation treatment, tube feeding.

Clinically Complex - Meets at least one of: aphasia, aspirations, cerebral palsy, dehydration, hemiplegia, internal bleeding, pneumonia, stasis ulcer, terminal illness, urinary tract infection, chemotherapy, dialysis, 4 or more physician visits per month, respiratory or oxygen therapy, transfusion, wound care, other than decubiti, including active foot care dressings or patients who meet extended service or special care categories but ADL index score is 4-6.

Impaired Cognition - ADL index score of 4-10. Cognitive impairment in all three of: decision-making, orientation (recall), short-term memory.

Behavior Problems - ADL index score of 4-10. Problems with: inappropriate behavior, physical abuse, verbal abuse, wandering, hallucinations.

Reduced Physical Function - ADL index score of more than 10 but do not meet any of the above categories 1-6.

Other Variables used in RUG-III

RUG-III ADL Index

ADL Variables	Score
Sum the scores for four ADL variables (index ranges from 4 -18):	
Bed Mobility, toilet use, and transfer:	
Independent or supervision	1
Limited assistance	3
Extensive assistance or total dependence:	
Other than 2-person physical assist	4
2+ person physical assist	5
Eating:	
Independent or supervision	1
Limited assistance	2
Extensive assistance or total dependence	3

Extensive Treatment Count

A count of extensive treatments (Extensive Services category). Count of the following criteria: parenteral feeding, suctioning, tracheostomy, ventilator/respirator.

Depressed Mood (Sad)

Signs and symptoms of a depressed or sad mood (tertiary split for the Clinically Complex category). Presence of a combination of symptoms, as follows:

Persistent sad or anxious mood and at least 2 other symptoms:

- Expressions of distress
- Agitation or withdrawal
- Early awakening with unpleasant mood or awake 7-hours/day
- Thoughts of death or suicidal thoughts

- Weight loss

Alternately, a diagnosis of depression or bipolar disease and either a persistent sad or anxious mood or at least one symptom from the above list.

Nursing Rehabilitation

Nursing rehabilitation activities are used as a tertiary split for the Impaired Cognition, Behavior Problems, and (Reduced) Physical Functions categories and as a criterion for the Low Intensity Rehabilitation category. A count of 2+ of the following activities occurring 5+ days/week: amputation care, active range of motion, passive range of motion, splint/brace assistance, dressing/grooming training, eating/swallowing training, locomotion/mobility training, transfer training, any toileting program (not used for defining Low Intensity Rehabilitation category).

