Care Planning: It's Not One Size Fits All

Cross-Sectoral and Individual Differences in Older Adults' Expressed Goals of Care

by

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AUTHOR'S DECLARATION

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners. I understand that my thesis may be made electronically available to the public.

ABSTRACT

Objective: This research explores the critical need for individualized care planning to ensure maximum cost savings by providing a balance between individuals' care needs and care wishes. The primary objective of this research is to identify common goals of care (GoC) expressed by long-term care residents (using the interRAI LTCF) and clients receiving community supportive services (using the interRAI CHA) or community mental health services (using the interRAI CMH). **Methods**: Three interRAI datasets were used to perform data analyses. The responses to the open-ended GoC item were quantified and grouped into common goal categories, which were then examined against the interRAI outcome measures and Clinical Assessment Protocols (CAPs). Demographic and clinical characterisitics were compared across the sample populations using the chi-square test. Logistic regression models were created to reveal variables that are predictive of not having a GoC recorded within each care setting. **Results**: Twenty-five GoC categories were created. Although the GoC responses were very diverse, many persons had no goal recorded. Nearly 70% of long-term care (LTC) residents and community support service (CSS) clients were unable to state a GoC. Different populations in different service settings had distinct GoC but had some commonalities as well such as goals that focused on general physical or mental health issues. GoC varied with the CAPs- the triggering of a CAP did not necessarily mean a corresponding GoC was noted. Each care sector had different predictor variables that were strongly associated with not having a GoC. **Conclusions**: There is not a "one size fits all" solution to care planning. The same goals and outcome measures are not appropriate or realistic for all persons. It is critical to incorporate self-reported goals into the development of effective and individualized care plans to ultimately improve one's quality of life, satisfaction with care, and success in achieving desired outcomes of care.

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1.0 **INTRODUCTION**

Most individuals develop a personal sense of what they like to do, what things they hope

for, and what brings them the greatest value and meaning in their lives. The ability to exercise

control over one's own destiny by making decisions for oneself is important throughout one's

life course. As individuals grow older and are confronted with illness, disease or even death,

their personal hopes and goals, and control over their own lives may change significantly.

In Ontario, health care is provided to older community-dwelling adults through home and

community support services (CSS), which help older individuals maintain their health and

independence, while remaining in their own communities. Individuals with greater service needs

are sometimes placed in long-term care (LTC) homes or complex continuing care hospitals.

In aging societies globally, health care systems are facing the challenge of allocating

limited resources to a growing older population. As resources continue to be stretched further, it

is becoming increasingly important to ensure the greatest cost savings by providing a balance

between individuals' care needs and care wishes. To ensure that the clinician, person, and family

are all striving for the same outcomes, with no unwanted or unneeded therapies being provided,

it is critical for the clinician to examine the person's preferences, treatment priorities, and overall

goals for care before developing or negotiating the care plan. Goals — representations of desired

states (Austin & Vancouver, 1996) — are pervasive motivating forces for achieving desired

human behaviour, and are clinically relevant to improving one's health status and quality of life

(QoL) (Bradley *et al*., 1999). It is important to include goal setting in the care planning process

in order to effectively evaluate clinical outcomes because goals provide a well-defined,

measurable endpoint of care to gauge the success of clinical practice (Leach, 2008). An

important method for determining patient preferences for treatment and care is the Goals of Care

(GoC) discussion, which is ideally a conversation between the patient, caregiver, and members of the health care team (Hahn, 2003). For the purposes of this proposed research, goals of care (GoC) will be representative of an individual's personally expressed care goals, and may be considered synonymous with other terms such as desired outcomes, wishes or what one would like to achieve (Locke & Latham, 1990). Granting individuals the opportunity to express their own GoC allows them to play an active role in their own health care. Additionally, providing care that respects each individual's preferences, strengths, needs, and values not only improves that person's satisfaction with the care he or she receives, but also improves health care quality (Johnson, 1999). GoC should guide the care and treatment that individuals and families choose and receive, as the process of goal setting has been shown to improve the achievement of desired outcomes of care (Bradley *et al.*, 1999). To deliver appropriate care, clinicians need to work with individuals to understand what they are striving to accomplish, and from that, develop a mutually agreed upon realistic set of GoC. Further, once clinicians identify an individual's GoC, they should monitor them periodically to evaluate progress and to determine if changes in that person's goals warrant corresponding changes to be made to their care plan. Health care providers who conduct clinical decision-making without involving the person can create conflict, anger, misunderstanding, resentment and lower quality care between the person and the provider (Kagawa-Singer & Blackhall, 2001; Krakauer *et al.*, 2002). An explicit and collaborative GoC discussion among the clinician, care recipient, and family may help to resolve conflicts or disagreements surrounding GoC and permit the negotiation of goals, resulting in a list of shared GoC. Clinicians need to involve individuals in their care by not only striving to pay attention to their personal preferences for care, but also their cultural and social situation, their expectations of medical interventions, and their communication style. It is especially important to have a

GoC discussion with persons who have chronic disease(s). These individuals do not have the option of curing his or her disease and thus, their choices for potential GoC are limited to goals relating to accepting and adjusting to life with disease, since curative goals are not realistic. This may be difficult for certain individuals to understand or accept, and may consequently create tension and conflict between the person and their care provider. Cognitive impairment and dementia can deprive individuals of their ability to meaningfully participate in decision making, which may result in clinicians and caregivers developing care plans without gaining explicit knowledge of persons' preferences and goals for care (Corcoran, 2009). Once an individual's GoC have been identified, they should guide the care planning process to help reach a mutually agreed upon care plan between the clinician, person, and family. Providing care that is tailored toward each persons' care wishes and health status indicators, may improve one's success in achieving his or her expressed care goals, and his or her satisfaction with care.

The process of goal setting in clinical practice has received little attention in the literature, despite its importance in the achievement of desired outcomes of care (Bradley *et al*., 1999). Developing explicit GoC may be one of the most neglected steps in clinical care today (Zubialde *et al*., 2007). Whether having goals is necessary or whether health care providers should force individuals to create GoC is debatable.

If GoC are not articulated, providers may provide care that is ultimately less effective or less satisfying to the person, the family, and the health care system as a whole. There is not a "one size fits all" solution to care planning because the same goals and outcome measures will not be appropriate or realistic for everyone (Stolee *et al*., 1999b).

Assessing individuals' personally expressed GoC in a systematic way can be a challenge in itself. However, interRAI (www.interrai.org) — an international non-profit collaborative

network of researchers and clinicians — has designed comprehensive, standardized assessment instruments that can be used to evaluate the strengths, needs, and goals of persons in many health service settings (Hirdes *et al*., 1999). The Resident Assessment Instruments (RAI) serve as an integrated health information system that provides a common language across all major service settings; assists clinicians with determining a person's level of functioning, potential problems and needs; and provides guidelines for further analysis to assist with care planning.

In the past, interRAI assessments have been criticized for promulgating the "medicalization" of care by placing more emphasis on the clinical status of individuals than on their personal needs and wishes (Uman, 1997). An editorial by Uman, entitled "Where's Gertrude?" noted that it is impossible for the RAI to achieve individualized care planning when the individual is lost during the assessment process because he or she is broken down and examined as separate clinical parts instead of as a whole (1997). However, interRAI assessments do provide a means of evaluating individuals' values, goals, and desired outcomes for care. These are addressed in both the assessment form and in the associated Clinical Assessment Protocols (CAPs) (Morris *et al*., 2008).

The interRAI assessments that will be used in this study all have an embedded item labelled, "Person's Expressed Goals of Care". With this item, the assessor seeks information directly from the individual by asking two questions: "What are your personal goals of care?" and, more specifically, "What is your primary goal of care?" Ideally, clinicians could then use individuals' self-reported responses from the GoC questions, in addition to their results from the other 300 assessment items, to create individualized care plans specific to each person's care needs and care wishes.

In an effort to gain a better understanding of commonly desired outcomes of care in clinical practice, this study identifies cross-sectoral and individual differences in personally expressed GoC among LTC home residents (using the interRAI Long-Term Care Facility assessment [RAI LTCF]), and clients receiving Community Mental Health services (using the interRAI Community Mental Health Assessment [RAI CMH]), or Community Support Services (using the interRAI-Community Health Assessment [RAI CHA]).

2.0 LITERATURE REVIEW

2.1 The Importance of Goal-setting in Clinical Practice

The World Health Organization (WHO) considers "autonomy with respect to a person's participation in choices about their own health" to be an important quality marker for health care systems (Kerssens *et al*., 2004; Murray *et al*., 2005). According to the WHO, patient involvement in care is not only desirable, but a social, economic, and technical necessity (Waterworth & Luker, 1990; Guadagnoli & Ward, 1998). Although not all persons are interested in participating in their own health care, it is still critical to consider each of their concerns, desires, and values and to incorporate them as much as possible into decisions made about their care (1998). The topic of goal-setting has received little attention in the medical literature even though the articulation of goals may be fundamental to devising appropriate care plans and to the achievement of desired clinical outcomes of care (Bradley *et al*., 1999). Recently, however, attention has been placed on the importance of providing targeted, comprehensive services that are tailored towards the specific goals, needs, and circumstances of individuals, rather than a one-size-fits-all approach to care (Benjamin, 1999). The process of goal-setting, when embraced in a participative and explicit way, may facilitate communication between clinicians, the individual and the family (Stolee *et al*.,1999b). Further, this will help to forge shared and meaningful GoC, which in turn will enable the effective evaluation of clinical outcomes (Bradley *et al*., 1999). If a person's GoC are clearly stated, and the promotion of outcome-based care plans proves useful in clinical practice, it would be important to conduct periodic evaluations to assess if a person's previously set goals are being achieved, whether their needs and desired outcomes of care have changed, and finally if their care plan needs to be adjusted as their health and personal circumstances evolve.

Older adults tend to bring complex and highly individualized medical, functional, and social problems to their clinical encounters. They often have perceptions of and preferences for care that differ or conflict with the clinician's preferences (Naik *et al*., 2005). Due to the inherent complexity surrounding geriatric care, it is imperative for physicians to understand their clients' values and the specific, subjective goals that arise from those values, in order to recommend ways to best achieve the expressed goals (Waters & Sierpina, 2006). Given the complex and multidimensional nature of health problems among older adults, individualized outcome measures, such as Goal Attainment Scaling (GAS), have been used to measure each person's health outcomes and GoC (Stolee *et al*., 1999b). GAS is particularly effective in geriatric assessment because it provides, "a responsive and clinically meaningful individualized measure for use with older people" (Stolee *et al*., 1999a). GAS provides a means for individuals to target important problems as goals by giving the person and their caregiver a voice in discussions about what outcomes and treatments are clinically relevant to them, while also providing a numerical score which allows for comparisons to be made across individuals and other program outcomes (Stolee *et al*., 1999a & Rockwood *et al*., 2007).

Individualized GoC reported by the person tend to emphasize the global life goals and the overall reasons for wishing to be well. Identifying the individual's general GoC and life values is a key element in developing more specific GoC for the care plan. Clinicians can use general GoC as the starting point for developing more measureable and specific health-related GoC that will provide a means for tracking goal achievement and help individuals to better attain their life goals. Goal-setting approaches have been shown to increase progress toward mutually agreed upon goals (Rockwood *et al*., 1993) and to foster adherence to physicians' recommendations (Bogardus *et al*., 2004). Having their personal GoC incorporated in the care plan could be a

powerful motivator for individuals, as they may be more likely to strive to achieve the goals that

they selected and deemed important compared to goals selected by others (i.e., researchers or

clinicians). Lastly, goal-setting can enhance the doctor-patient relationship through increased

communication, discussion of preferences for care, and development of patient-physician

agreement regarding treatment goals (Murray *et al*, 2006). In summary, the determination of

each individual's personally expressed GoC is a valuable process that can maximize the

individual's autonomy and QoL, and help them to achieve the most desirable outcomes of care.

2.2 Goal Categories

There are endless possibilities for personal GoC, but most can be categorized based on

common goal categories in the areas of functioning (including domains of safety, independence,

and living arrangements), psychosocial concerns (such as caregiver relationships, stress, and

emotional health), and more traditional medical concerns (such as diagnosis, medications, and

behaviour) (Bogardus *et al*., 1998). No single goal is inherently more important or more valid

than another, and multiple goals may apply simultaneously (Rodriguez & Young, 2005). The

current literature on the evaluation of individuals' desired outcomes of care includes a number of

studies in which the most commonly expressed GoC included goals relating to improving or

maintaining quality of life, remaining/returning home, achieving more symptom-specific control

(pain or suffering), accomplishing a particular personal goal, strengthening social relationships,

preserving independence/autonomy/control, and/or providing support to family/caregiver.

2.3 Advance Directives

The determination of GoC may provide a basis for development of advance directives, which enable competent persons to express their wishes and provide instructions about their future medical care in the event that they lose decision-making capacity at a later time. Advance directives facilitate communication and clarification of persons' care preferences, which provides a means for individuals to continue to be able to direct their medical care in the event that they can no longer make healthcare decisions on their own (Furman *et al.*, 2006; Leland, 2001). Because health care proxy designations and living wills have not been sufficient in determining nursing home patients' wishes for care, many have advocated that determination of patient preferences begin with a discussion of goals of care (Furman *et al*., 2006).

2.4 interRAI Instruments

interRAI is an international research consortium that develops comprehensive assessment tools that are compatible in multiple care settings and across the health care continuum (interrai.org). The Resident Assessment Instruments (RAI) are used in a wide variety of health care settings for a large number of purposes, such as care planning, outcome measurement, and quality indicators (Gray *et al*., 2009; Bernabei *et al*., 2009)**.** The interRAI assessments are comprehensive, standardized instruments for evaluating the needs, strengths, and preferences of persons in various care settings (interrai.org). Over 300 assessment items are included in most of the interRAI assessments, and they cover a large range of personal characteristics, including functional status, admission history, medical conditions and other information (Bernabei *et al*., 2009). Clinicians should use these assessments to assist them with developing individualized care plans through the Clinical Assessment Protocols (CAPs), which are generalized guidelines

to facilitate decision making and care planning in areas where potential problems or risk areas are identified (Morris *et al*., 2008). The instruments share common data items, assessment methods, outcomes, scales, and decision-support tools that facilitate communication across multiple health care settings, as well as individual items that are specific to each care setting (Hirdes *et al*., 2008). interRAI instruments have been tested through extensive international research and clinical activities and have been found to provide valid and reliable standardized data (Hirdes *et al*., 2008; Poss *et al*., 2008). The compatibility of assessment elements across instruments improves the continuity of care across multiple settings, and promotes a person-centered approach to care (interrai.org).

2.5 Individual Characteristics and Goal Setting

Different individuals desire different dimensions of care, and the results that can be achieved or are desired greatly vary among individuals (Glazier *et al*., 2004). Each person comes to the clinical encounter with their own set of relatively stable and personally specific values embedded from one's knowledge and experiences (Bradley *et al*., 1999). From these personal values, GoC or desired outcomes are generated, which are specific to contextual factors including economic, cultural, community, social, and lifestyle factors that influence health (1999).

Peoples' health concerns become more complex as they age, and their conditions, problems, and aspirations become more diverse. Characteristics of individuals that may influence goal setting include risk-taking, personal self-efficacy and the degree to which a person accepts their current state (Bradley *et al*., 1999). Maintaining QoL in the face of declining health and functioning may be the most ambitious goal for some individuals, while for others

improvement in specific functional areas and QoL is a more realistic expectation (Benjamin, 1999; Kane & Kane, 1987). Patients' preferences or values play an important role in understanding one's general health perceptions and overall QoL. For any individual, certain symptoms are more burdensome than others, and each individual values and is willing to tolerate different symptoms differently (Wilson & Cleary, 1995).

Previous research has shown that GoC vary from the most general statements of goals concerning overall well-being to extremely specific goals focusing on functional outcomes (Bradley *et al*., 1999; Bogardus *et al*., 1998). General goals are simplistic and situation-specific goals relating to one's overall desired state (e.g., being healthy); whereas, specific goals are more associated with immediate tasks at hand and are directed at components of the general goal (e.g., balancing medications, continuing to work) (Bradley *et al.*, 1999).

Clinicians can provide their expertise in identifying specific recommendations for individuals who are only capable of generating general GoC for themselves, which will help move individuals along the path toward achieving his or her personal goals. At the same time, individuals and their family can provide assistance to the clinicians who are less knowledgeable about their personal values, wishes, and desired GoC.

Disease-specific experiences can further alter the personal goal setting process depending on whether the condition presented is irreversible (Bradley *et al*., 1999). Irreversible chronic conditions and multimorbidities (Britt *et al*., 2008) can limit the possibilities of potential GoC, because any goals that involve attempting to cure the disease are not feasible and only GoC that focus on adjusting and adapting to the condition are realistic.

The following subsections outline individual characteristics that may affect GoC, such as cognitive impairment and variations among persons residing in different care settings.

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2.5.1 **Goal Setting Among Persons With Cognitive Impairment**

Cognitive impairment, including Alzheimer's disease and other types of dementia, affects one in four Canadians over the age of 65 and the incidence dramatically increases to two out of three Canadians over the age of 85 (CIHR, 2008). According to the Canadian Medical Association, "dementia is diagnosed when acquired cognitive deficits are sufficient to interfere with social or occupational functioning in a person without depression or clouding of consciousness" (CMA, 1994). The effects of cognitive impairment can be very extensive to the point that those who have cognitive impairment are likely to experience a decline in their QoL. Many individuals with dementia or cognitive impairment may find it particularly challenging and complex to establish and express their personally desired GoC. Often, the predominant objective of care among these individuals is to establish GoC that involve adapting to the condition rather than impractical curative goals (Bogardus *et al*., 1998).

According to Mezey *et al*. (2000), "Rarely is incapacity absolute; even people with impaired capacity usually possess some ability to comprehend, to communicate, and to form and express a preference." Many older adults with significant cognitive impairment can still answer basic questions about their QoL and their desired outcomes of care (Mozley & Huxley, 1999). A person who possesses the decisional capacity to actively take part in the development of their own care plan must be able to demonstrate the ability to choose among various goals, understand and communicate relevant information, and reasonably apply information to decision-making (Yoshikawa & Ouslander, 2007). However, it is often difficult to accurately assess an individual's cognitive capacity to be able to take part in discussions surrounding their own care plan. In many cases, family

members and clinicians develop care plans without full participation of the individual due to their inability to reason about and express their personal GoC. A substantial number of individuals may be incapable and when this is the case, a surrogate should be consulted to speak on behalf of the person.

2.5.2 **Goal Setting among Persons Residing in Long-term Care Homes**

Persons residing in LTC homes typically have cognitive impairment, physical frailty, and chronic disease that will be with them for the remainder of their lives. It is important to recognize that in this subpopulation, curative GoC are not realistic (Waters & Sierpina, 2006). These individuals are likely to benefit from actively exchanging ideas and negotiating with the clinician and family regarding what their personal GoC should entail. However, a major finding from a study looking at GoC in nursing homes identified that there is a lack of systematic attention to GoC discussions within the nursing home setting- this includes lack of coordination and involvement across disciplines (Furman *et al*., 2007). In many cases, the person's GoC will be discussed with proxies speaking on their behalf to make their preferences for healthcare interventions known. For this reason, many LTC homes are developing structured approaches to advance care planning which include the prioritization of GoC.

The health values of the seriously ill vary considerably from person to person, and they cannot be easily predicted simply from a person's current health status. In this regard, it is critical for LTC homes to create systems that encourage decisions to be consistently made by persons themselves, in an effort to maximize autonomy, despite disability and the institutional setting. Many LTC homes are already working to create

this system of care through the implementation of a comprehensive assessment known as the Minimum Data Set (MDS) 2.0 which is mandated across all LTC homes in Ontario. The MDS 2.0 provides a standardized approach to assessing the health, functional and psychosocial needs of older adults residing in LTC homes and complex continuing care beds (interrai.org). The interRAI LTCF instrument is a newly revised version of the Resident Assessment Instrument (RAI) version 2.0 for LTC facilities. The interRAI LTCF yields measures of persons' functional capacity, emotional status and integrates personal goals and preferences for care within the assessment. The LTCF identifies opportunities where interventions may be required to improve function and enhance independence. Thus, the interRAI LTCF provides a means for LTC homes to achieve this enhanced person-centered system of care by providing opportunities for each individual to express their needs and wishes and further be able to participate in the decision-making process surrounding their care.

2.5.3   **Goal Setting among Persons Receiving Community-Support Services**

With an ageing population and an increased life expectancy rate in Canada, there are an increased number of older adults who are able to continue living and aging in the comfort of their own homes. However, many of these individuals will require community support services (CSS) in order to be able to remain at home and in their community. CSS clients include persons who can still live independently at home with a minimal to moderate amount of assistance with their activities of daily living (ADL), encompassing a wide range of health and social services. CSS can include any of the following services: adult day programs, meals-on-wheels, home maintenance, personal

support with ADLs and IADLs, and assisted living in supportive housing. Supportive

housing is specifically designed for people who can live independently with minimal to

moderate care (such as homemaking, bathing assistance, light housekeeping, case

management, etc.), but do not yet require the 24 hour care provided in LTC homes and

hospitals. Accommodations usually consist of rental units within an apartment building.

Supportive housing helps older adults carry out their day-to-day living by providing a

physical environment that is safe, secure, enabling and homelike (CMHC, 2007). The

average age of persons utilizing CSS or supportive housing in Ontario is 75 years and

approximately two-thirds are female. The majority of persons in these settings have ADL

and IADL impairments, chronic health conditions, and daily pain; however, 95% of them

are cognitively intact and report that most of their needs are being adequately met in this

care setting.

   The data that was used in this study from community-dwelling older adults only

included individuals who were assessed using the interRAI CHA. It is currently being

considered as the common assessment tool for all CSS agencies in Ontario. Previous

research has found that common GoC expressed by older community dwelling Canadians

include the desire to remain living at home, avoid institutionalization, and maintain

independence (Brink & Smith, 2008). For individuals who are able to achieve their

desired GoC, this achievement not only satisfies the respective person's wishes, but it

also simultaneously guarantees that quality cost-effective care was provided to the

individual. In turn, this places less pressure on the health care system as a whole because

homecare is significantly less expensive than care provided within LTC homes and

hospitals.

2.5.4 **Goal Setting among Persons Receiving Community Mental Health Services**

Mental health refers to an individual's sense of well-being, control over his or her life and ability to interact positively with others (CMHA, 1993). Mental health status has been shown to affect physical health and the use of health care services (Constantian, 1997).

Aside from the physical ailments that normally come with aging, three psychiatric conditions are dominant in the lives of the mentally ill older adults including depression, anxiety and dementia. Schizophrenia is also a common diagnosis among clients of CMH services. Other problems that this group are likely to experience include: physical health problems, grief over friends or partners dying, feelings of isolation and loneliness, language barriers, and abuse (CAMH, 2009). Persons suffering from severe mental illness may encounter difficulties being able to maintain safe and affordable housing as they have a wide range of needs that cannot be met through a single kind of housing or support service delivery (2009). Instead, they require a range of housing options, from group supportive housing to independent living with flexible supports ranging from assistive devices and home modification to services such as delivered meals, transportation and personal attendant services.

For persons with mental illness and addictions, conducting comprehensive assessments of their strengths, preferences and needs is essential in order to provide person centered care to the individual. The interRAI Community Mental Health instrument (Martin *et al*., 2009) provides a means to help clinicians provide person centered care if they take their strengths and personal preferences for care into

consideration when completing their care plan. If these individuals with mental illness are able to achieve their desired GoC, then their success should help to create therapeutic environments, as well as offer the possibility of enhancing their well-being and positively affecting their QoL (Ryden & Feldt, 1992).

Previous research has shown that personal GoC stressed among community mental health clients include a desire to live at home and avoid institutionalization, to feel socially accepted within their community, and to be able to exercise control over their own lives (Lee *et al*., 2009; Steinbach, 1992). Integrating individuals with mental health disabilities into the community does not simply entail providing the same services and program plan to all those alike. Facilitating community living instead involves the need to accommodate the large diversity among these individuals by making modifications to their care plans based on their personal needs and goals, and their physical and social environment (Lee *et al*., 2009).

By incorporating social interaction, emotional support, and personal GoC into care plans, this should help to re-socialize individuals back into the community, as well as, contribute to destigmatization among individuals with mental disabilities (Steinbach, 1992). A clear statement of GoC that are mutually agreed upon by the individual, their caregiver(s) and the clinician will not only provide beneficial outcomes directly to the person, but the caregiver will also benefit as they will gain confidence in their ability to act in the person's best interests. Further, identification of common GoC amongst this population may lead to the development of clearer guiding principles and exercises that could be incorporated into programs for community mental health adults.

2.6 Study Rationale

There appears to be broad consensus in the published literature that understanding an individual's GoC and having a discussion about those goals is beneficial and important to all parties involved, including the person, the family, and the clinician. According to Bradley and colleagues (1999), individual GoC tend to be more general than specific and are usually centred around the following categories: safety; independence; social and family relationships; personal health (including physical, emotional, mental and spiritual health); economic stability; and autonomy. Although GoC are often mentioned as a key content domain in discussions about end-of-life care, it is less common to find listings of particular goals in the published literature and the lists that do exist tend to lack consistency. "Despite the advantages of planning, it is claimed that few clinicians document clear goals in clinical practice, involve patients in the management of their care, or fully understand patient concerns, beliefs and preferences" (Furman *et al*., 2006; Leach, 2008). For example, Cavalieri *et al*. found that 47% of physicians discussed end-of-life care with their patients with mild to moderate Alzheimer's disease (Cavalieri *et al*., 2002). Staff may not engage in the planning of individualized care due to time limitations, system restraints, a lack of skill in developing client-centred goals, or a lack of awareness of the importance of goal setting (Bergeson & Dean, 2006). Based on the relative scarcity in the literature on GoC surrounding geriatric care, as well as the lack of consensus regarding the number and description of goal categories that should be considered, the purpose of this study was to identify the most commonly articulated GoC derived directly from the individuals themselves. This work examined how the expressed GoC differed among individuals and across care settings and is presented in such a way that the results will be applicable to the enhancement of person-centered clinical care, the furthering of education, and the expansion of research.

It is critical for clinicians and nurses to understand the diversity of persons and their desired outcomes of care. They should support each individual's independence and personal interests by continuously developing and changing the person's care plan to incorporate the person's wishes. The new suite of interRAI assessment tools provides an opportunity to compare GoC across different service settings reaching different populations. This is of interest because people may come to different sectors with different service expectations. Also, different sectors serve populations with varied age and sex distributions and a diverse set of clinical needs. Variations in life stage, social factors and clinical situations may yield different goals of care. This study directly compared the expressed GoC of those receiving care from CSS, LTC homes, and community mental health service settings, in an effort to determine whether the expressed GoC were significantly different among individuals and across care settings. This research will add to the field of comprehensive geriatric assessment (CGA) which is a multidimensional, multidisciplinary diagnostic process to determine the medical, psychosocial and functional capabilities and limitations of elderly patients (Mann *et al.*, 2004). This research will highlight the importance of eliciting individual preferences for desired GoC or health-related outcomes (such as maximizing QoL) and providing direction for future research. Understanding the extensiveness of individuals' desired outcomes of care may elucidate the need for GoC to be continuously assessed in future evaluations.

2.7   Research Objectives/Questions to Consider

An individual's expressed GoC represents personal goals for what he or she wants to achieve in life (Locke & Latham, 1990). Thus, understanding each person's GoC is essential for identifying meaningful outcomes against which to measure the success of their care plan and

treatment choices. This research aimed to develop a deeper understanding of individuals'

expressed GoC and how goals are distributed among functional, medical, spiritual, and social

dimensions of care; to study how that distribution varies across different sectors (i.e., community

mental health, LTC, and CSS); and to evaluate similarities and differences between individuals'

expressed GoC. It was hypothesized that the findings would show that many persons, especially

those in LTC homes, may not be able to grasp the concept of goal setting leading to vague GoC

being mentioned, such as the desire "to be healthy". This may be due to a lack of understanding

of what possible GoC may entail or a result of the process of setting personal care goals for one

self may be a foreign concept to many individuals, especially older adults in this sample who

may not be used to being asked what they personally desire in their care. This would represent

the fact that goal setting is a foreign concept among these individuals and that they may not have

had the opportunity to properly develop their concept of goals in greater depth before their care

plan was confirmed (Schulman-Green *et al*., 2005). This research aimed to answer the following

research questions:

> **Question #1:** What are the variations in self-reported goals of care among adults in
>
> the community support sector (including those in supportive housing programs),
>
> community mental health sector, and those in LTC facilities?
>
> **Question #2:** a) What demographic differences exist across care settings? b) What is
>
> the prevalence of various health conditions, disease diagnoses, and other characteristics
>
> among the three clinical populations? c) How do the summary scale scores differ based
>
> on the service sector being examined? d) How well do the identified GoC correspond
>
> with triggered CAPs?

Questions #3: What factors are predictive of an individual not having a GoC

recorded? How do these factors differ depending on care setting?

Question #4: How are the factors that predict individuals not having a GoC different

among short stay and long stay LTC residents?

3.0 **METHODS**

3.1   Study Participants

The study eligibility criteria included individuals who were residing in a LTCF or
accessing CSS or community mental health services. These individuals needed to have been
assessed with the respective interRAI assessment form as part of regular clinical practice. This
study included a population sample of 1,334 CSS clients, 304 clients in community-based mental
health service settings, and 786 LTC residents.

3.2   Data Source

This study involved secondary analyses of cross-sectional interRAI assessment data
collected as part of normal clinical practice from trained clinicians who conducted the
assessments at admission and discharge, using the interRAI CHA in the CSS sector, the interRAI
LTCF in LTC homes, and the interRAI CMH in community-based mental health service settings.
Following the initial admission assessment, these instruments are designed to be used for
reassessment at a specified interval or at discharge. However, only the initial admission
assessments were used in these analyses. Using the most recent assessment to determine the
GoC may provide a different perspective on the care setting in which a particular person is
residing; however, an advantage of using the initial assessment is that individual's GoC are more
likely to be captured upon entrance into the new care setting. Individuals undergoing an initial
assessment do not have to wait months before they are asked what their personal goals are and
how they want to achieve them.

The data from the interRAI assessments were collected at the respective care sites and
housed at the University of Waterloo after all of the patient identifiers were removed. All of the

datasets contained sufficient information to accurately conduct the desired analyses. Due to

copyright laws, the assessment instruments cannot be displayed within this document; however,

they may be accessed through the interRAI website (www.interrai.org). These instruments that

were used in this study are further described below:

3.2.1 interRAI Long-term Care Facility

The interRAI LTCF instrument is a newly revised version of the Resident

Assessment Instrument (RAI) version 2.0 for LTC facilities. The interRAI LTCF

promotes a person-centered approach to care by providing a way to ascertain individuals'

preferences for and satisfaction with care through questions about their personal

characteristics, including lifestyle and psychosocial considerations, and their personal

GoC (interrai.org). The sample is comprised of 786 assessments, mainly from older

adults, which were collected from 8 LTC homes across Ontario from 2007 to 2010. This

sample was collected for the Canadian Staff Time and Resource Intensity Verification

(CAN-STRIVE) project which aimed to validate and refine the RUG-III case-mix

systems for use in Ontario LTC homes and complex continuing care hospitals/units.

3.2.2 interRAI Community Health Assessment

The interRAI CHA is a standardized tool which has the ability to efficiently assess

community dwelling older adults to identify individuals at risk of progressive frailty and

functional decline and flag those who merit further assessment (Morris *et al*., 2006). This

assessment is currently being used by all CSS agencies in Ontario, which includes

persons in supportive housing and assisted living programs but excludes those receiving

home care services. This sample of CSS clients included mainly elderly persons who are still living independently at home with minimal to moderate assistance with activities such as homemaking, bathing, and light housekeeping; however, they do not yet require 24hr care provided in LTC homes and hospitals.

Trained assessors employed by community support agencies generally conduct the assessments within the individuals' homes. This sample of clients was involved in the pilot study of the CHA and consists of 1,334 assessments, which were collected from 2005 to 2009.

3.2.3   interRAI Community Mental Health

The interRAI CMH is an assessment from the new suite of interRAI assessment tools. This instrument is designed to be used on community-based individuals with a broad range of mental and physical health needs. In order to enhance continuity of care, the interRAI CMH is fully compatible with the RAI Mental Health instrument which is used within inpatient mental health populations. However, the interRAI CMH expands on specific areas that may affect a person's ability to function in the community (e.g. social support, housing, involvement in social and occupational activities, and substance abuse).

The CMH sample includes 304 assessments, which were collected from 2009 to 2010. Trained assessors conducted the assessments on all adults aged 18 and over in community mental health service settings. Some of the clients were older adults but the majority were middle-aged. This instrument was pilot tested in large trials in Newfoundland and Ontario. The psychometric properties assessed included inter-rater

reliability and validation against gold standard measures of depression, psychotic

symptoms, social adjustment, behaviour disturbance, mental status, and well-being.

3.3   Reliability and Validity of the interRAI Assessment Items

Within the interRAI suite of assessments tools, 96% of items were tested for inter-rater

reliability and the instruments exceeded the acceptable standard cut-offs for all but a small

number of items that were subsequently modified or deleted (Hirdes *et al*., 2008). The interRAI

instruments also reach high reliability coefficients when used across care settings, establishing its

utility for cross-sectoral comparisons to be examined.

The GoC item within the assessments was not tested for reliability because open-ended

items do not lend themselves to inter-rater reliability testing using traditional methodology, the

way quantitative items are. It would be unrealistic to require a word for word match on

responses from open-ended items, and it would be imprudent to draw an arbitrary line and

designate responses on the same side of that line as conceptually identical, and responses on

opposite sides of the line as distinguishable. For example, would the GoC, "I'd look forward to a

brighter future" be considered synonymous with, "I want to feel better about myself"? These

GoC may be recorded differently by different assessors. The validity of the GoC item can be

tested within this study by examining whether the reported GoC have reasonable relationships to

other features within the assessment such as disease diagnoses, treatment choices, and

relationship to the interRAI Scales and Clinical Assessment Protocols (CAPs). In order to study

the reliability of the item, a future study could test whether respondents GoC significantly

changed from one assessment to the next. The GoC item is not intended to solely predict what

care plan and treatment choices an individual should have. Goal choices have an important role

to play in structured assessments tools and should complement the other quantitative assessment items, not replace them. General information about individuals' values and goals, in a variety of forms, can complement the other assessment information collected, giving clinicians a better understanding of their clients' desires.

3.4 Scales Embedded within the interRAI Instruments

In addition to the individual assessment items within each of the interRAI instruments, there are a number of embedded scales that are compatible across the new suite of interRAI assessments. These scales cover a number of clinically relevant domains which can aid the care planning process by providing a means of outcome measurement against which the success of a treatment or care plan can be analyzed. These scales were originally developed to help clinicians understand the characteristics of a client's state of functioning (Morris *et al*., 2000). They are calculated using the same or similar items across the suite of interRAI assessment tools and are generated once the assessment instrument is entered into the database. This enables an assessor to determine the level of functioning (quantitatively) in a given domain. For example, the Cognitive Performance Scale (CPS) measures a person's level of cognitive impairment. Such information can be helpful in care planning and goal evaluating (Mor, 2004). For all of the scales, higher values are associated with more impairment or greater problem severity. The GoC will be examined against an array of scales that serve as severity and outcome measures, which can all be calculated from the interRAI instruments. For the purposes of this study, the following scales will be used in the analyses:

3.4.1 The Cognitive Performance Scale

Cognitive functioning can be estimated using the CPS (Jones *et al.*, 2010; Landi *et al.*, 2000; Morris *et al.*, 1994). The CPS is a hierarchical index used to rate the cognitive status of clients, and it has been validated against the Mini Mental State Examination and Test for Severe Impairment (Hartmaier *et al.*, 1995; Landi *et al.*, 2000; Morris *et al.* 1994). The CPS score is based on short-term memory, cognitive skills for daily decision making, expressive communication and eating self-performance (Morris *et al.*, 2000). The scale score ranges from 0-6 with a score of 0 representing cognitively intact and a score of 6 representing very severe cognitive impairment.

3.4.2 The Depression Rating Scale

The Depression Rating Scale (DRS) can be used as a clinical indicator of minor or major depression, and is based on 7 items embedded within the interRAI assessments (Burrows *et al.*, 2000; Hirdes *et al.*, 2002; Martin *et al.*, 2007a; Martin *et al.*, 2007b). Each of these items is coded according to symptom frequency, resulting in a DRS score range of 0 to 14. Higher scores denote a higher level of depressive symptoms. Previous research analyzing the sensitivity and specificity of the DRS scale has shown that a score of 3 or more is considered a risk factor for depression, and signals the need for care plan development and further investigation. The DRS has been validated against the Hamilton Depression Scale and the Cornell Scale for Depression in Dementia (Burrows *et al*, 2000).

3.4.3 The Changes in End-Stage Disease Signs and Symptoms

The Changes in End-Stage Disease Signs and Symptoms (CHESS) scale was developed to detect instability in health (Armstrong *et al*., 2010 & Hirdes *et al*., 2003). The CHESS attempts to identify individuals at risk of serious decline and can serve as an outcome where the objective is to minimize problems related to declines in function in the elderly population. The CHESS scale uses 6 items and is scored from 0 (no health instability) to 4 (very unstable health) (2003).

3.4.4 The Activities of Daily Living Self Performance Hierarchy Scale

The Activities of Daily Living (ADL)-Hierarchy Scale measures the level of assistance needed to execute ADL (Landi *et al*., 2000 & Morris *et al*., 1999). A score of 0 through 6 is assigned based on 4 items which include toileting, personal hygiene, locomotion, and eating. These items were designed to measure activities across a wide range of functional independence levels to enable the detection of functional changes in individuals with both high and low levels of functioning (Landi *et al*., 2000 & Morris *et al*., 1999). Each item is scored based on the amount of assistance required for performance, with higher scores indicating greater dependence.

3.4.5 The Instrumental Activities of Daily Living Involvement Scale

The Instrumental Activities of Daily Living (IADL) involvement scale is a measure of one's capacity to carry out independent activities. This measure is based on the aggregate of 7 items: meal preparation, ordinary housework, managing finances, medications, phone use, shopping, and transportation. The 7 items are summed to

produce a scale that ranges from 0 to 21, with higher scores indicating a greater level of difficulty in performing instrumental activities (Landi *et al*., 2000 & Morris *et al*., 2000).

3.4.6   The Pain Scale

The Pain Scale is an algorithm scale that was originally developed for use in nursing homes and later translated for use with other interRAI instruments (Fries, Simon, Morris, Flodstrom & Bookstein, 2001). This scale measures pain severity, which is based on 2 items: pain intensity and pain frequency. Together, these items create a scale score ranging from 0 to 4, with a higher score indicating a more severe condition (interrai.org). The Pain Scale has been validated against the Visual Analogue Scale for Pain (Fries, Simon, Morris, Flodstrom & Bookstein, 2001).

3.4.7   The Aggressive Behaviour Scale

The Aggressive Behaviour Scale (ABS) (Perlman & Hirdes, 2008) measures aggressive behaviours and is based on 4 items to create a scale score ranging from 0 (no aggressive behaviours), to 12 (very severe aggressive behaviours). Higher ABS scores indicate a greater number of behaviours occurring at a greater frequency.

3.5   Clinical Assessment Protocols

The interRAI instruments are also designed to help clinicians develop individualized care plans using the Clinical Assessment Protocols (CAPs) (Morris *et al*., 2008). The CAPs are compatible across most care settings; thus, replacing both the Resident Assessment Protocols (RAPs) and Mental Health Assessment Protocols (MHAPs) which were only applicable in LTC

homes and mental health settings, respectively (Fries & Morris, 2007; Martin *et al*., 2009). Each CAP is specific to a certain clinical issue and the clinical triggers within each CAP help identify individuals requiring further evaluation. The CAPs assist in clinical decision-making and facilitate the care planning process by alerting the assessor to a problem, a risk, or a potential for improvement that should be addressed in the care plan. Also, the CAPs provide a collaborative approach to the development of care plans by allowing clinicians to work with the person and family to determine what their priorities and preferences for care are.

3.6   Analytic Approach

Before the actual analyses were conducted, the data were checked for duplicates and data quality problems. Due to the large sample sizes, it was possible to set any out of range values to missing. However, the corresponding person was only omitted from that specific item response, not from the entire database. Key findings including frequency distributions on specific items common within the interRAI assessments, summary scale scores, and the triggered CAPs among individuals and across care settings were examined using Statistical Analysis Software (SAS®), version 9.0 (SAS Inc., Cary, North Carolina) for quantitative and descriptive analysis.

This cross-sectional study design required the analysis of open-ended questions from data in an iterative analytic process, which can provide important information relating to GoC themes. The purpose of the qualitative GoC items within the interRAI assessments is to gather information from individual responses that cannot be accurately predicted categorically. Therefore, to probe this subject area more fully, the interRAI suite of assessments all have an embedded item within them labelled, "Person's Expressed Goals of Care," which is displayed below in Figure 1. This item is comprised of two open-ended questions. The assessor is

required to seek information directly from the individual by first asking, "What are your personal goals of care?" and then more specifically, "What is your primary goal of care?" To fully investigate common and recurring GoC themes without biasing the responses, the first question allows for the individual to list multiple GoC if they have them. The second question is intended to limit the respondents GoC to one, to determine which goal is most important for them to achieve.

Figure 1: **interRAI Goals of Care Assessment Item**

10. PERSON'S EXPRESSED GOALS
Enter primary goal in boxes at bottom.

←*Response to the 1st question, "What are your personal goals of care?"*

←*Response to the 2st question, "What are your personal goals of care?"*

Goal categories were created from individuals' responses to the GoC questions using content analysis. Content analysis is "a systematic, replicable technique for compressing many words of text into fewer content categories based on explicit rules of coding" (Mays *et al.*, 2005). Content analysis can measure how frequently each goal category occurs and make generalizations based on the dominant findings. It is fundamentally a quantitative method since the data are eventually converted into frequencies; however, qualitative skills and underlying theory are needed to identify and characterize the categories into which findings are to be grouped (Mays *et al.*, 2005). The term quantizing has been coined to describe the process of transforming coded qualitative data into quantitative data (Tashakkori & Teddlie, 1998). There is some controversy about the legitimacy and feasibility of transforming qualitative findings into

quantitative data, and it has been suggested that attempts at aggregation destroy the integrity of individual studies (Sandelowski, 1999). This study employed a method of converting raw, open-ended qualitative data from large samples into meaningful, quantitative statistics. Although this process of data collection is time consuming, it results in a deeper probe of the topic area, particularly when the results cannot otherwise be accurately predicted. This study affirms that quantitative and qualitative data can be blended together to strengthen the findings of the research.

3.6.1   Qualitative Methods

The purpose of this question is to gain a better understanding of how diverse individuals' expressed GoC are and how their goals are distributed among functional, medical, spiritual, and social dimensions of care. In order to answer this question, the data first needed to be quantized by transforming the qualitative findings for identified GoC themes. This was completed through a data holding program called NVIVO 8 (Edhlund, 2008; QSR International, 2009). NVIVO software is used to manage, code, analyze, and report text data. This program allowed for the individual responses from the open-ended GoC questions to be coded into a series of quantified responses which could be grouped into common GoC categories. This procedure had several steps, outlined below:

1) The GoC qualitative responses from the assessments were entered into word files, one file per care setting. These files were each imported into NVIVO by introducing a "New Internal" into the "Sources" navigation pane. At this point the open-ended responses could be sorted to form common GoC categories.

2) The qualitative data were sorted and connected by creating GoC "nodes" within NVIVO. The two main types of qualitative data nodes are "free nodes" and "tree nodes." Free nodes represent a single theme, whereas tree nodes can connect many free nodes. For example, two common GoC responses from LTC residents included: "increase energy levels" and "appreciate life, enjoy each day". Initially, both of these responses were considered as potential GoC categories and entered as two separate free nodes. However, these two free nodes could be further collapsed because of their semantic relationship- a relationship in which a free node could be considered a subcategory of another free node. "Increase Energy Levels" and "Appreciate Life, Enjoy Each Day" are subcategories of another common GoC, "Improve Quality of Life". However, once all the data were coded, all three of these nodes became subcategories of the final tree node: "Improve Health, Wellness, and Quality of Life".

3) All of the GoC qualitative responses were coded, with new goal categories (free nodes & tree nodes) emerging as necessary. As additional goals were identified, other categories were collapsed, deleted, or modified, as appropriate.

4) After the goal categories were formed, they were quantized for use in descriptive analyses. Thus, the goal categories (in which each category included the patient identifier and corresponding GoC for each respondent who had reporting having that specific goal) were exported out of NVIVO and back into Microsoft Excel were they could be quantized.

5) Quantizing the GoC categories involved taking the coded qualitative data and converting the actual codes into binary variables. For example, if a LTC

resident's GoC was to reduce pain and move back home, then the goal categories, "Reduce pain" and "Age in home" would be coded with a value of 1. All of the other categories would be coded with a 0 for that person.

6) Once all the responses were coded into binary variables, the original qualitative GoC responses became variables that were quantified and imported into SAS®, version 9.0 for quantitative and descriptive analysis purposes.

3.6.2   Quantitative Methods

3.6.2.1 Demographic Differences across Care Settings

Univariate analyses (mean, standard deviation, N, frequency/proportions) were completed on a number of demographic variables to describe the three samples separately on the following demographic information: (1) Age, (2) Gender, (3) Marital status, (4) Primary language, and (5) Living situation in the last 5 years. Each of the variables was compared between the three samples to examine whether the differences in mean or proportion are statistically significant using the Pearson Chi-square test of independence.

3.6.2.2 Prevalence of Various Health Conditions, Disease Diagnoses, and Other Characteristics within Three Clinical Populations

Disease diagnoses and health conditions were of interest for descriptive purposes and as possible determinants of having expressed a personal GoC. Cross-tabulation was used to examine any associations between the variable data (e.g., diagnoses, depressive symptoms, cognitive performance). The Chi-square was used to test for significant associations of the cross-tabulation table between care settings. The following disease

diagnoses and health conditions outlined below were examined using various assessment items common across all three of the interRAI assessments; thus, allowing for comparisons to be made across sectors.

(1) *Cognitive status*: short term memory impairment, a decline in cognition, and dependent for decision making.

(2) *Communication*: difficulty making self understood and understanding others

(3) *Sensory impairment*: any visual or hearing impairment.

(4) *Psychosocial and mood*: reduced social interaction, self reporting depression or anxiety, and presence of a strong and supportive family.

(5) *Physical Functioning*: less than 1 hour of activity in last 3 days, difficulty bathing, ADL decline, poor locomotion and personal hygiene.

(6) *Instrumental Activities of Daily Living (IADLs)*: ability to do housework, manage finances and medications, go shopping, and require help with transportation.

(7) *Substance Use*: tobacco used and alcohol use.

(8) *Health Conditions*: 1 or more falls in the last 90 days, chest pain, shortness of breath, fatigue, daily pain, and poor self-rated health

(9) *Disease diagnoses*: dementia, Alzheimer's, depression, diabetes, cancer, hypertension and anxiety

(10)   *Multimorbidity*: divided into three grouping – one or less diseases, two to four diseases, and greater than five diseases

3.6.2.3   Summary Scale Score Differences Based on Service Sector

Cross-tabulation and Chi-square test were used to compare the scale scores between the care settings and individuals. The scale scores that were examined included: CPS, DRS, CHESS, ADL scales, IADL scales, Pain scale, and ABS.

3.6.2.4   Correlation Between Goals of Care and Triggered CAPs

A commonly expressed GoC was identified among each of the care settings and compared to an associated CAP to examine if persons' expressed GoC correspond with the CAPs they trigger. Cross-tabulation and Chi-square were used to compare the specified GoC and CAPs among the respective care settings. Within the LTC sample, one of the more frequently expressed GoC "improving health, wellness and QoL" was compared against the ADL CAP. Within the CMH sample, many clients expressed the goal of wanting to further their education or to seek employment. This GoC was compared against the Vocational Rehabilitation Mental Health Assessment Protocol (MHAP). Among the CSS sector, the GoC to improve pain and suffering was compared against the Pain CAP.

3.6.2.5   Determinants of not Having a Goal of Care Recorded within Each Care Setting

Multivariate logistic regression models were created for each care setting to assess the relationships between selected predictor variables and not having a GoC recorded. Where possible, scales were used as potential independent variables, because they provide a more comprehensive measure of a domain than individual assessment items do.

Bivariate and multivariate analyses were performed separately in the three

populations to examine what variables were predictive of not having a GoC recorded.

Bivariate analyses were carried out to determine what variables should be included in the

multivariate analyses. The association between all of the variables and not having a care

goal were assessed with the Chi-square statistic and crude odds ratios. A p-value <0.05

was used to measure the significance of the variables. Logistic regression analysis was

then performed by running the full model with all significant variables identified in the

bivariate analyses. The best-fitted models were self-selected by examining the

relationship between the variables through odds ratios, the corresponding 95%

confidence intervals, and the fit of each model which was reported through the c statistic

calculated for the independent variables. The final models included variables with

significant regression coefficients at the 0.05 level. Multicollinearity was tested for and

found not to be a concern for the variables included in the equations. In the subsequent

logistic regression tables, the parameter estimates reflect SAS output for effects coding

when using the CLASS statement. These estimates cannot be directly exponentiated to

obtain odds ratios as could be done with dummy variables. The reported p values reflect

tests of significance for the overall variable rather than individual response levels for the

independent variable.

3.6.2.6 Predictors of Not Having a GoC with respect to Short-stay and Long-stay Long-term Care Residents

The purpose of this question is to determine if long stay residents are substantially

different from short stay residents within the LTCF sample. Using the interRAI LTCF

dataset, the prevalence of goals was examined by splitting the dataset into residents who had their admission assessments completed within 1 year of entry into the facility (short stay) and residents who completed their admission assessments after one year in the facility (long stay).

The model predicting not having a GoC recorded in the LTC sample was tested on both short stay and long stay residents to determine if the model was appropriate in both subpopulations. The probable odds and predictive strength of variables, and the c-statistic within the model were assessed and compared between the subpopulations.

Cognition and physical functioning were also compared between the long stay and short stay subpopulations using the CPS and ADLH scales, respectively.

4.0 ETHICS

The datasets that were used in this study were obtained from the interRAI research organization after an application for access to the anonymized data was submitted to and approved by the University of Waterloo Office of Research Ethics.

5.0 RESULTS

5.1 Self-reported Goals of Care Across Populations and Sectors

Numerous GoC themes arose after coding the interRAI qualitative GoC item across the three care settings. These themes were synthesized into the 25 most commonly expressed goal categories, as shown in Table 1. The frequencies of the goal categories are illustrated in chart

form, one for each care setting (see Figure 1, 2, and 3). The overarching goal categories that emerged within all three care settings and example quotes for each of the GoC are outlined below:

(1) Finding employment or furthering education

- "Go to school, get a job and have my own place" –CMH

- "To maintain my current state, find work and avoid relapse" –CMH

- "To return to school and be able to converse with friends" –CMH

- "Secure highschool education. Find a career and eventually a job" –CMH

- "Finish psychology university degree and remain positive" -LTCF

(2) Needing mental and emotional support

- "I need help coping with my day-to-day stressors, support with my weight gain, self-esteem and social skills to do well" –CMH

- "I'm depressed, suicidal, with psychotic symptoms" –CMH

- "[I want to] become mentally well" –LTCF

(3) Increasing social interaction, programs, activities

- "[I want to] see my great grandchildren" –LTCF

- "[I want to] start a quilt, go gambling, keep dancing, and bake" –LTCF

- "Cope with social anxiety, learn relaxation techniques so I can gradually seek and be able to cope with part time employment" –CMH

- "I want to find a girlfriend and be happy" –CMH

- "If we have extra help it would relieve stress at home and we would not feel so alone and so isolated" –CHA

- "[I want more] Adult Day Program Services" –CMH

(4) Getting help with addiction problems

- "Stay off drugs, and start my life over" –CMH

- "[I want} to get my kids back and stay clean from drugs and alcohol" – CMH

- "Quit smoking and improve meals here" -LTCF

(5) Having the desire to age in home

- "[I want] to go home, I can care for myself" –LTCF

- "[I want] to get out of here and go home" –LTCF

- "[I want] to remain in home and stay out of the hospital and continue to have good relationships with the children" –CMH

- "I wish I could stay home for the rest of my days" –CHA

- "Stay in house until I drop dead" –CHA

- "To be honest if you ever have to move me to a nursing home you better do it fast or I'll go right to the river" –CHA

(6) Content with current services

- "I'm happy here, nothing could be better" –LTCF

- "[I am] satisfied, I have no other option" –LTCF

- "[I'd like] things to stay the same, I'm happy with the way things are" – CHA

(7) Needing financial support

- "Learning to relax and better manage my finances" –CMH

- "[I want] to earn money and enjoy previous activity" –LTCF

- "Increase funding for services" –CHA

- "My pension is small and any assistance would be appreciated" –CHA

- "I want to stay in my home but money is tight" –CHA

(8) Improving health, wellness and QoL

- "Stay well and gradually get off all the meds" –CMH

- "To have good food, friends and live continue visiting family on the West Coast" –CMH

- "To relax and enjoy life each day" –LTCF

- "[I want to] to get rid itch" –LTCF

- "I wish they could make my eyes good again" –LTCF

- "Improve health and become more active" –LTCF

- "Increase energy, stay stress free" –CHA

- "[I want] to regain strength in my limbs so I can resume my normal day-to-day life" –CHA

(9) Improving IADLs (i.e., housework, laundry, meal preparation, shopping, medication management, appointment reminders)

- "Improve medication compliance, coping strategies, and improve day-to-day functioning" –CMH

- "To not depend on daughter for groceries" –CHA

- "My arthritis is so bad that I really can't do much housework" –CHA

- "Meal preparation, housekeeping, laundry, medication pick-up, security checks, transportation" –CHA

(10) Receiving illness education

- "Guide me with directions to seek help for treatment" –CMH

- "Gain insight into illness so I can better manage my psychiatric illness and then gain employment to help with financial difficulties." –CMH

(11) Gaining independence

- "[I want] to be more independent from family and take care of myself" – CMH
- "Live as younger people, be independent" –LTCF
- "[I want] to live as independently as possible with a friendly visitor" – CHA
- "[I want] to remain independent at home with the assistance provided by CSS agency" –CHA
- "[I want] to be independent and able to provide support to family as much as possible with some assistance" –CHA

(12) Receive more care or support

- "I would like more time for care and for the care to be less rushed" – LTCF
- "Can't look after self, I need more care" –LTCF
- "Have some help so I don't feel so distressed" –CHA
- "We plan to stay here until we die. I am already burned out, I do everything for [my spouse]" –CHA

(13) Gaining ability to stabilize oneself

- "[I want] to stabilize my illness and address substance abuse issues" – CMH

(14) Transition into another care setting (other than in home)

- "To live somewhere else where I can get more care, like a retirement home" -CHA

(15) Help with transportation

- "Buy a bike so I can get around more" –CMH

- "[I'm] not managing well when my family is working because I can't get to my appointments" –CHA

- "Social recreation and transportation" –CHA

- "I can only go a few minutes and I have to sit down, I need help with transportation" –CHA

(16) Reducing pain severity

- "Get people to believe me about my pain" –LTCF

- "[I want] to be pain free" –LTCF

- "Extreme pain has caused immobility and lack of ability to continue with day to day tasks" –CHA

(17) Providing respite care to their caregivers or receiving it themselves

- "[I want] to stay at home and not go to a nursing home but I have to reduce daughter's burden of care" –CHA

- "Weekly respite care with housekeeping during care as well" -CHA

(**18) Personal care support** (foot care, dressing, bathing and toileting)

- "In and out bathing and washing my back" –CHA

- "Bathing, meal prep, and help getting into bed every night" –CHA

(19) Safety and security checks

- "Get the electric working in here" –LTCF

- "More safety features and activities" –CHA

- "Safety and security checks, 24hr emergency" -CHA

(20) Language barriers

- "Language barrier present, can't understand her" –LTCF

(21) Dying

- "To be with my wife" –LTCF

- "To get wings and fly to heaven" –LTCF

- "To old, get to heaven" -LTCF

(22) Living longer

- "Maintain quality of life and survive" –LTCF

- "Have some more good years" –LTCF

(23) Vulgar, incoherent, or hostile response

- "[That's] none of your business" –LTCF

- "Confused response and then he kicked me" –LTCF

(24) Goals unknown, not expressed

- "Never thought about it" –LTCF

- "Too old for goals" –LTCF

- "Do I really have to answer that?" –LTCF

- "I don't get that question" –LTCF

- "I'm still not sure why you're asking me this, nothing is wrong" –LTCF

- "Not at my age, I don't have any goals" -LTCF

(25) Responses that were left blank.

Among clients in the CSS sector, nearly 40% reported wanting to receive more help with their IADLs, most specifically with laundry, shopping, and housework (help with outdoor housework was frequently reported among the female sample). The second most common GoC among these clients was the desire to stay and age in the comfort of their own homes (29.2%) Other common goals included the general wish for more care, assistance with personal care (e.g., bathing, dressing), maintaining independence, improving safety and increasing security checks.

Among CMH clients, 67.4% of the sample had a blank response to the interRAI GoC item indicating that they had no goal or care or it was not filled in by the assessor. The most frequently stated GoC among responding individuals was to improve health, wellness and QoL (25.9%), followed by wanting to find employment or wanting to increase education levels (21.9%), and wanting to receive more mental and emotional support (9.6%). Other common goals included wanting to become more socially engaged within the community, the desire to become more independent, the need for help with addictions, and receiving education about illness in order to learn and understand how they can better help themselves.

A large portion of LTC residents were unable to state a goal of care (67.7%), and thus their responses were placed in the, "Goals unknown, not expressed" goal category. The most commonly stated GoC among these residents was the desire to improve health, wellness and QoL (12.4%). Many residents also expressed the general wish for more care and support (5%). Perhaps surprisingly, a large portion reported that they were content with the care that they were already receiving and just wanted everything to stay the same (4.5%). Other common GoC expressed among this group included the desire to leave the LTCF and return back to their home and community, have more social programs available within the home, and many reported wanted to see their family and friends more often.

Table 1: **Frequency of Common Goals of Care Categories by Care Setting**

	Goal Categories	CHA[1] N=1333 % (n)	CMH[2] N=304 % (n)	LTCF[3] N=786 % (n)
1	**Improving IADLs**	38.4 (511)	4.0 (12)	0 (0)
2	**Having the desire to go home**	29.2 (389)	9.3 (28)	3.1 (24)
3	**Receive more care or support**	17.5 (233)	4.3 (13)	5.0 (39)
4	**Personal care support**	11.9 (159)	0.0 (0)	0 (0)
5	**Gaining independence**	10.1 (134)	5.0 (15)	0.9 (9)
6	**Content with current services**	8.9 (118)	1.0 (3)	4.5 (35)
7	**Safety & security checks**	8.5 (13)	0.0 (0)	0 (0)
8	**Blank**	7.8 (104)	67.4 (203)	1.7 (13)
9	**Improving health, wellness or QoL**	5.6 (74)	25.9 (78)	12.4 (97)
10	**Help with transportation**	5.6 (74)	0.3 (1)	0 (0)
11	**Needing respite care to their caregivers**	3.9 (52)	0.0 (0)	0.6 (5)
12	**Finding employment or furthering education**	3.7 (49)	21.9 (66)	2.0 (16)
13	**Increase social interaction, programs, activities**	1.8 (24)	7.3 (22)	2.2 (17)
14	**Transition into another care setting**	1.6 (21)	0.3 (1)	1.3 (10)
15	**Needing mental & emotional support**	1.1 (14)	9.6 (29)	0.5 (4)
16	**Needing financial support**	1.1 (14)	2.0 (6)	0 (0)
17	**Goals unknown, not expressed**	0.8 (11)	1.7 (5)	67.7 (531)
18	**Reducing pain severity**	0.6 (8)	0.0 (0)	0.3 (2)
19	**Receiving illness education**	0 (0)	3.7 (11)	0 (0)
20	**Gaining ability to stabilize oneself**	0 (0)	2.7 (8)	0 (0)
21	**Language barriers**	0.0 (0)	0.0 (0)	1.5 (12)
22	**Living longer**	0.0 (0)	0.0 (0)	1.4 (11)
23	**Vulgar, incoherent or hostile response**	0.0 (0)	0.0 (0)	1.3 (10)
24	**Dying**	0.0 (0)	0.0 (0)	0.9 (7)
25	**Getting help with addiction(s)**	0 (0)	5.7 (17)	0 (0)

[1] Community Health Assessment

[2] Community Mental Health

[3] Long-term Care Facility

Figure 2:

Frequency of Goals of Care Among Community Support Service Clients

Figure 3:

Frequency of Goals of Care Among Long Term Care Facility Residents

Figure 4:

Frequency of Goals of Care Among Community Mental Health Service Clients
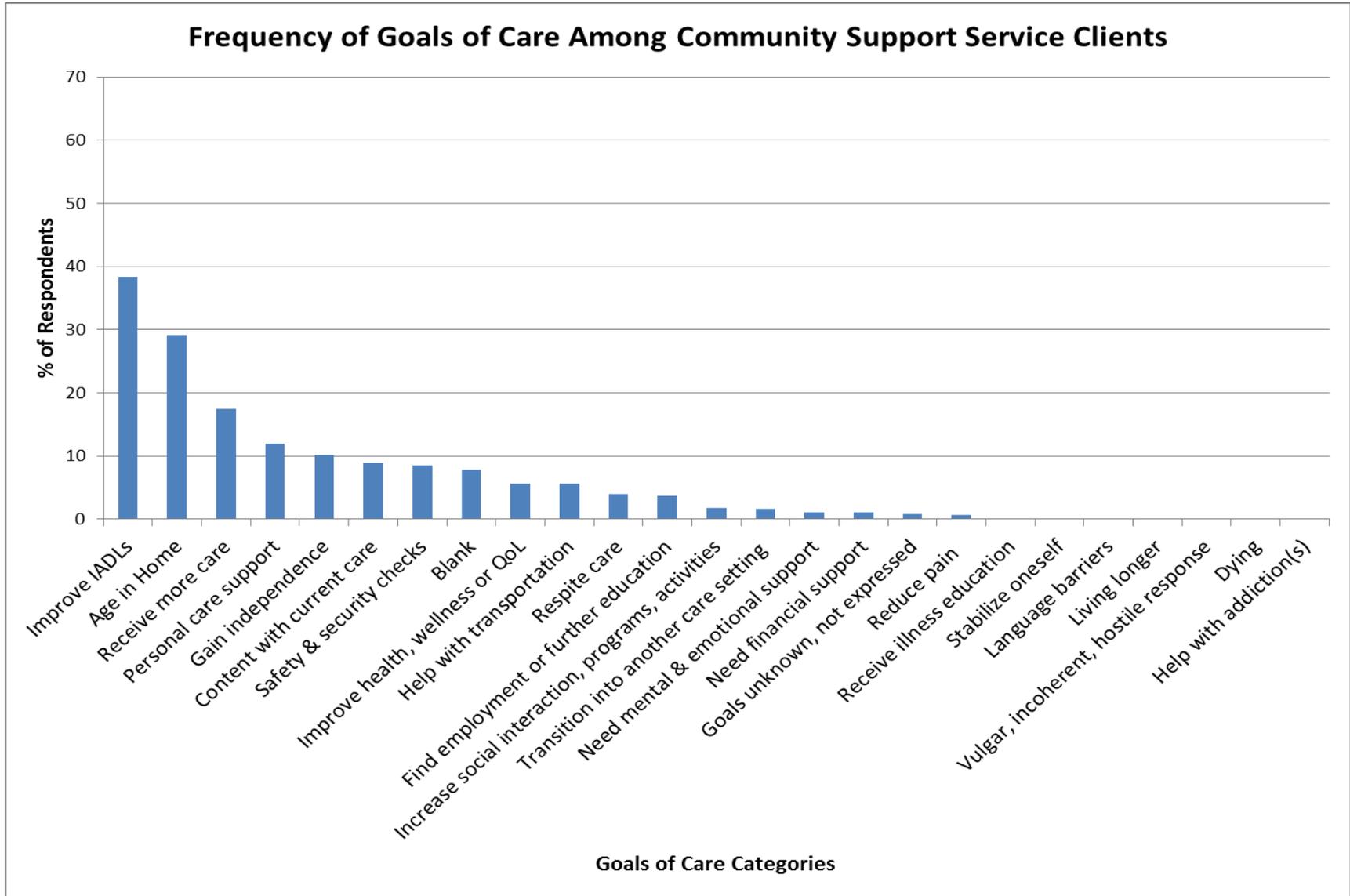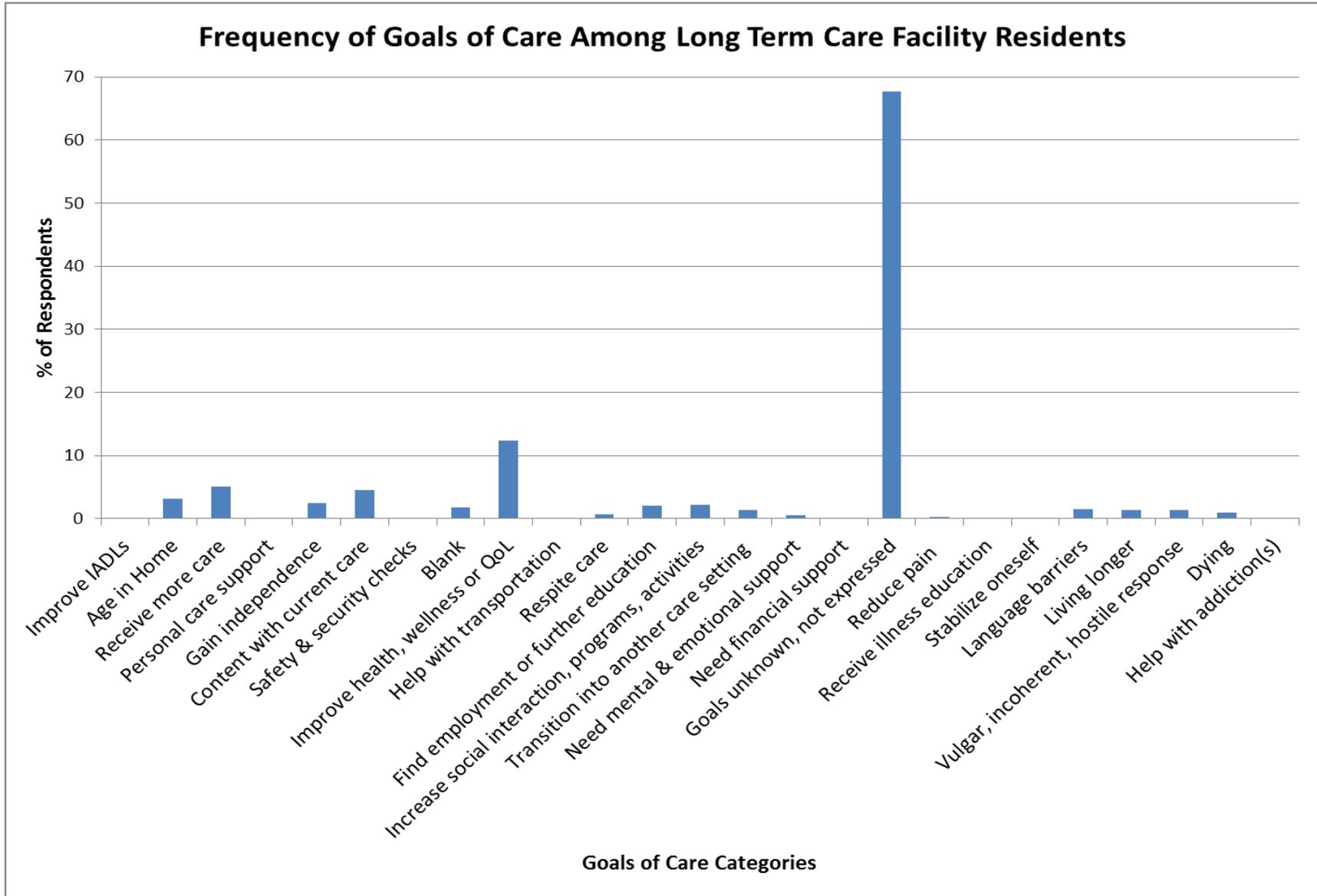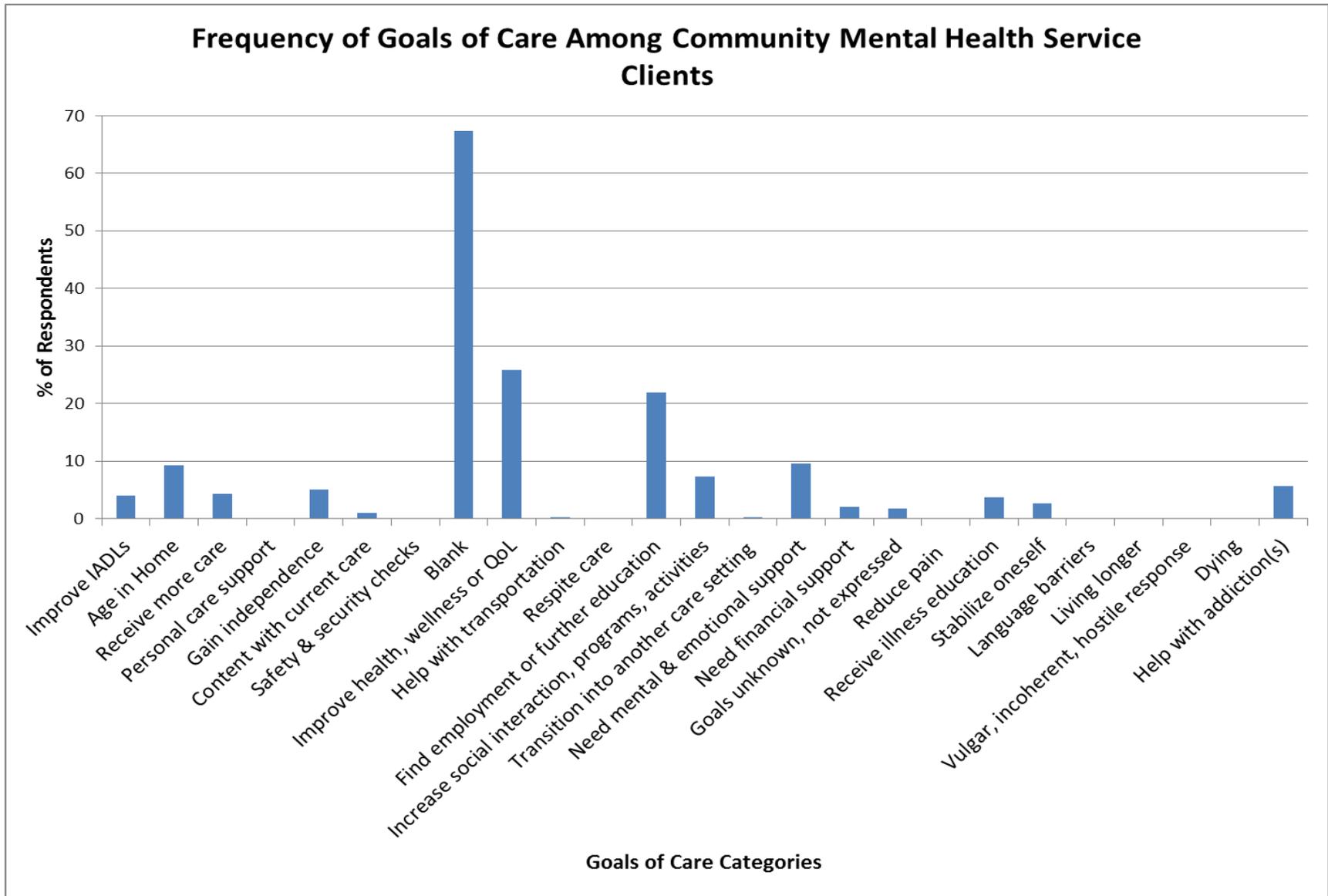
5.2 Demographic and Clinical Differences Across Care Settings

5.2.1 Demographic Differences

Table 2 outlines the demographic characteristics of the three clinical samples. With regards to the CHA and LTCF samples, most individuals were female (73.0% and 72.5% respectively). However, the CMH sample was comprised of a higher proportion of males than females, with 68.1% of the sample being male. The three datasets contained a differently aged population. The mean (SD) ages were 41.9 (13.7) years in the CMH sample, 79.3 (10.4) years in the CHA sample, and 84.0 (10.2) years in the LTCF sample. Over 50% of persons in the CHA and LTCF samples were widowed, and the remainder of the population were likely to be married. CMH clients, on the other hand, were more likely to be divorced, separated or to never have been married. Only 11.0% of CMH clients were married and 2.3% were widowed. In all of the samples, the large majority of clients spoke English as their primary language. The CSS sample was the only population that had a large proportion of clients living alone prior to admission (68.1%). Only 28% of CMH clients lived alone and 27.6% of LTCF residents lived alone prior to admission. Of those who did not live alone in CMH settings, most lived with a parent (25.6%) or non-relative (25.9%). Clients who were not living alone in the CHA sample were more likely to live with their spouse (23%). In the last five years, most clients in CMH and CSS settings lived in a private home (76.7% and 85.5% respectively). In LTCF, 31.5% of residents lived in a private home, 27.0% lived in a nursing home, and 18.8% lived in an acute care hospital in the last five years. A higher percentage of CHA clients' usual living arrangement was an assisted living facility or some form of semi-independent living (11.8%).

Table 2: **Demographic Summary Table by Care Setting**

Variable	Response Set	CHA N=1,334 % (n)	CMH N=301 % (n)	LTCF N=783 % (n)	*p*-value
Age	>65	7.6 (98)	96.7 (291)	6.5 (50)	p<.0001
	65-74	17.4 (225)	3.0 (9)	6.7 (52)	
	<75	75 (969)	0.3 (1)	86.8 (670)	
Gender	Female	72.5 (967)	31.9 (96)	73 (562)	p<.0001
Marital Status	Married	28.5 (380)	11.0 (33)	19.6 (150)	p<.0001
	Widowed	50.8 (678)	2.3 (7)	63.0 (482)	
	Other	20.7 (276)	86.7 (261)	17.4 (133)	
Language	English	88.6 (1173)	98.8 (168)	90.4 (705)	p<.0001
	French	4.2 (55)	0.0 (0)	0.8 (6)	
Lives Alone	Lives alone or lived alone prior to admission	68.1 (909)	28.0 (84)	27.6 (213)	p<.0001
Living Situation	Private home, apartment, or rented room	85.5 (1140)	76.7 (231)	31.5 (245)	p<.0001
	Board and Care	0.2 (2)	15.3 (46)	11.6 (90)	
	Assisted Living/Semi Independent Living	11.8 (158)	2.0 (6)	5.5 (43)	
	Mental Health Residence	0.0 (0)	4.3 (13)	0.0 (0)	
	Long-term care facility	0.2 (3)	0.0 (0)	27 (210)	
	Acute Care Hospital	0.6 (8)	0.0 (0)	18.8 (146)	

[1] Community Health Assessment

[2] Community Mental Health

[3] Long-term Care Facility

5.2.2 Variations in Health Conditions, Disease Diagnoses, and Other Characteristics

Table 3 outlines the clinical characteristics at the time of assessment among persons in CSS, CMH and LTCF service settings.

The majority of LTCF residents were severely cognitively impaired, with 81.1% dependent for decision-making and 74.9% with impaired short term memory. In contrast, roughly one out of five CCS and CMH clients were independent in their decision making abilities (78.3% and 82.1%, respectively). However, a much higher proportion of CSS clients had short term memory impairment compared to CMH clients (30.5% and 7.6%, respectively). Many of the younger adults who comprised the CMH dataset were completely cognitively intact and capable of performing their ADLs.

A significantly higher proportion of LTCF residents had difficulty with their ability to communicate with others, compared to CMH and CHA clients. Almost 40% of the LTCF sample had difficulty making themselves understood (37.3%) and understanding others (36.3%). While, only 5.3% and 1.7% of CSS and CMH clients had difficulty making themselves understood, and 6.2% and 5.3% of CSS and CMH clients experienced difficulty understanding others.

Sensory impairment was more severe among persons in CSS and LTCF settings than among persons in CMH settings. LTCF residents were more visually impaired than CSS clients (47.0% and 36.1% respectively); however, CCS clients had slightly more hearing impairment than LTCF residents. Only 3.7% of CMH clients had visual impairments and 3.0% had hearing impairment.

Among persons in all three care settings, at least 80% reported having a strong and supportive family relationship. CMH clients were most likely to have a reduced amount of social interaction (36.9%) compared to CSS clients (25.5%) and LTCF clients (17.2%). CMH clients were more likely to self-report having little or no interest in things they normally enjoy (28.2%); being anxious, restless or uneasy (43.9%); and feeling sad, depressed, or hopeless (36.5%) than were those in LTCF or CSS settings. LTCF clients were more likely to have received less than one hour of exercise in the previous three days compared to CMH and CSS clients (55.2%, 33.9%, and 24.0%, respectively). The LTCF population had the most trouble bathing and maintaining personal hygiene. Finally, close to 30% of the CSS reported a decline in their ADL functioning in the last 90 days, whereas, only 8% and 4% did in LTCF and CMH settings.

No information was collected on the Instrumental Activities of Daily Living (IADLs) in the interRAI LTCF, so comparisons could only be made between the CSS and CMH sectors. IADL impairment varied among clients in both the CSS and CMH sectors. CSS clients needed more help than CMH clients with activities such as, doing housework (57.9% vs. 34.9%), going shopping (40.2% vs. 21.3%), and with transportation (23.5% vs. 7.6%). On the other hand, CMH clients needed more help than CSS clients with managing their medications (26.9% and 20.8%) and they both needed help with finances (27.9% vs. 25.3%).

Almost 30% of persons in both the CSS and LTCF samples had fallen at least once in the previous 90 days; whereas only 4.7% had in the CMH sample. Those in the CSS sector were more likely to have experienced shortness of breath in the previous three days (41.9%), compared to 14.3% in the LTC sample and 17.6% in the CMH sample. Within

the CSS sample, 42.6% of individuals were moderately or severely fatigued, compared to 13.3% in the LTC sample and 8.0% in the CMH sample. The CSS sample had a significantly higher percentage of clients experiencing daily pain (46.8%) compared to those in LTC (14.0%) and CMH (7.6%). The majority of clients in the LTC and CMH sample experiencing any pain were pain-free (60.5% and 70.8%, respectively), while only 28.2% of clients in the CSS were pain free. Individuals within CSS were more than twice as likely to self-rate their health as being poor (16.9%) compared to those in the LTC sample (5.6%) and the CMH sample (7.6%). Differences in lifestyle choices between the three samples are apparent. Among those in the CMH sample, 9.7% of clients had a potential drinking problem (five or more drinks in one sitting). Only 1.7% and 0.3% of persons in the CSS sample and the LTC sample, respectively, had a potential drinking problem. In the CMH sample, 57.8% of clients were daily smokers versus 11.8% in the CSS sample and only 1.4% in the LTCF sample.

The distribution of disease diagnoses across the three care settings was quite different. A significantly higher proportion of the LTCF residents had multimorbidity, compared to the CHA and CMH samples. A third of the LTCF residents had two or more diseases present, while only half did in the CHA sample and 43.2% in the CMH sample. Many LTC residents were diagnosed with dementia (38.7%), Alzheimer's disease (26.7%), and depression (40.2). CSS clients were likely to be diagnosed with depression (18.7%), diabetes (26.7%) and hypertension (30.4%). The analysis of disease diagnoses among the CMH sample was limited because some of the items of interest were not included within the CMH assessment. However, among the variables examined, CMH

clients were most likely to be experiencing anxiety (19.1%) and have the highest

prevalence of diabetes (14.7%), compared to the other two sample populations.

Table 3: **Disease Diagnoses and Other Characteristics by Care Setting**

Variable	Response Set	CHA N=1,334 % (n)	CMH N=301 % (n)	LTCF N=783 % (n)	*p*-value
Cognitive Status	Short Term Memory - Impaired	30.5 (407)	7.6 (23)	74.9 (783)	p<.0001
	Dependent For Decision-Making	21.7 (289)	17.9 (54)	81.1 (630)	
	Cognitive Decline Prev. 90 Days	13.6 (182)	0.0 (0)	4.9 (38)	
Communication	Difficulty Making Self Understood	5.3 (70)	1.7 (5)	37.3 (290)	p<.0001
	Difficulty Understanding Others	6.2 (83)	4.7 (14)	36.3 (285)	
Sensory	Any Visual Impairment	36.1 (481)	3.7 (11)	47.0 (366)	p<.0001
	Any Hearing Impairment	39.4 (525	3.0 (9)	37.5 (292)	
Psychosocial & Mood	Reduced Social Interaction	25.5 (340)	36.9 (111)	17.2 (133)	p<.0001
	Strong and Supportive Family Relationship	84.9 (1133)	74.4 (224)	78.7 (610)	
	Self-report: -Little interest or pleasure	21.1 (282)	28.2 (85)	11.5 (89)	
	-Anxious, restless, uneasy	31.3 (418)	43.9 (132)	15.8 (122)	
	-Sad, depressed, hopeless	28.1 (375)	36.5 (110)	18.2 (140)	
Activities of Daily Living	Less than 1 Hr Physical Activity in 3 Days	24.0 (320)	33.9 (102)	55.2 (422)	p<.0001
	Locomotion In Home	11.5 (153)	0.7 (2)	24.7 (192)	
	Personal hygiene	13.3 (178)	4.7 (14)	87.4 (680)	
	Bathing	43.3 (577)	N/A*	81.6 (633)	
	ADL Functional Decline	27.4 (365)	4.0 (12)	8.0 (61)	
Instrumental Activities of Daily Living	Housework	57.9 (772)	34.9 (105)	N/A*	p<.0001
	Finances	25.3 (337)	27.9 (84)	N/A*	
	Managing Meds	20.8 (278)	26.9 (81)	N/A*	
	Shopping	40.2 (536)	21.3 (64)	N/A*	
	Transportation	23.5 (314)	7.6 (23)	N/A*	

Table 3 cont'd: **Disease Diagnoses and Other Characteristics by Care Setting**

Variable	Response Set	CHA N=1,334 % (n)	CMH N=301 % (n)	LTCF N=783 % (n)	*p*-value
Living Conditions	Potential Drinking Problem (5+ drinks one setting)	1.7 (23)	9.7 (29)	0.26 (2)	p<.0001
	Daily Smoker	11.8 (157)	57.8 (174)	1.4 (11)	
Health Conditions	1 or more falls last 90 days	27.7 (369)	4.7 (14)	26.7 (207)	p<.0001
	Chest Pain (in the last 3 days)	18.6 (248)	8.6 (26)	3 (23)	
	Shortness of Breath (in the last 3 days)	41.9 (559)	17.6 (53)	14.3 (110)	
	Fatigue: moderate or greater	42.6 (568)	8.0 (24)	13.3 (104)	
	Daily Pain	46.8 (624)	7.6 (23)	14 (109)	
	Poor Self-Rated Health	16.9 (225)	7.6 (23)	5.6 (43)	
Disease Diagnoses	Dementia	6.8 (91)	1.0 (3)	38.7 (300)	p<.0001
	Alzheimer's	6.0 (80)	N/A*	26.7 (206)	
	Depression	18.7 (250)	N/A*	40.2 (311)	
	Diabetes	26.7 (356)	14.7 (44)	21.4 (165)	
	Cancer	15.7 (209)	N/A*	15.2 (117)	
	Hypertension	30.4 (405)	N/A*	25.4 (195)	
	Anxiety	17.8 (238)	19.1 (57)	14.1 (109)	
Multimorbidity	0-1	49.9 (665)	56.8 (171)	24.4 (192)	p<.0001
	2-4	44.8 (598)	43.2 (130)	63.4 (498)	
	>5	5.3 (71)	0.0 (0)	12.2 (75)	

*Measure not available within instrument

[1] Community Health Assessment

[2] Community Mental Health

[3] Long-term Care Facility

5.2.3 Differences in Summary Scale Scores

Table 4 outlines the rates for the scale scores and how they differ across the three clinical populations. CPS scores were significantly higher among LTC residents compared to the CMH and CHA clients. LTC residents were almost twice as likely to have a DRS of 3+ (29.8%) than those in CMH (14.6%) and those in CSS (10.1%). The CHESS scale scores varied greatly across the three care settings. The CHESS scale was highest in the CSS sector, with 66.7% of clients having a score of one or higher, compared to 51.2% in LTC settings and 25.2% in CMH service settings. The LTCF sample population was very dependent in their ADLs. Nearly 75% of the sample had an ADL scale score of 3 or greater. The CSS and CMH samples were function well physically with only 9.9% and 9.3%, respectively, having a scale score of three or more on the ADLH scale. A higher proportion of CSS clients scored a three or higher on the IADL impairment scale score, compared to CMH clients (70.4% and 56.8%, respectively). CSS clients were much more likely to be experiencing severe levels of pain, with 22.6% of clients scoring 3 or higher on the pain scale while only 0.9% did in LTCF and 3.3% did in the CMH sample. No information was collected on the ABS in the interRAI CHA, so comparisons could only be made between those in LTC and CMH. The proportion of individuals with aggressive behaviours (verbally abusive, physically abusive, socially inappropriate and resisting care) was significantly higher in the LTCF sample than in the CMH sample, with 27.8% and 8.3% having a score of 3 or higher on the ABS scale, respectively.

Table 4: **Average Scores on Outcome Measures by Care Setting**

Outcome Measure	Trigger Level	CHA N=1,334 % (n)	CMH N=301 % (n)	LTCF N=783 % (n)
CPS[1]	0	59.8 (798)	66.8 (201)	16.9 (132)
	1 – 2	35.0 (467)	27.9 (84)	22.1 (173)
	3 +	5.2 (69)	3.7 (11)	61.1 (478)
DRS[2]	0	75.2 (1003)	60.1 (178)	36.8 (288)
	1 – 2	14.7 (196)	25.0 (74)	33.5 (262)
	3 +	10.2 (135)	14.6 (44)	29.8 (233)
CHESS[3] Scale	0	33.4 (445)	73.1 (220)	48.8 (382)
	1 – 2	55.3 (737)	25.2 (76)	46.5 (364)
	3 +	11.4 (152)	0.0 (0)	4.7 (37)
ADL[4] Scale	0	72.4 (270)	86.5 (256)	8.4 (66)
	1 – 2	17.7 (66)	4.1 (12)	17.6 (138)
	3 +	9.9 (37)	9.5 (28)	74.0 (579)
IADL[5] Scale	0	13.4 (165)	32.4 (96)	N/A*
	1 – 2	16.5 (204)	10.8 (32)	N/A*
	3 +	70.4 (864)	56.8 (168)	N/A*
Pain Scale	0	28.2 (374)	70.8 (213)	60.5 (474)
	1 – 2	49.2 (652)	24.3 (73)	38.6 (302)
	3 +	22.6 (300)	3.3 (10)	0.9 (7)
ABS[6]	0	N/A*	78.0 (231)	55.3 (433)
	1 – 2	N/A*	13.5 (40)	16.9 (132)
	3 +	N/A*	8.3 (25)	27.8 (218)

*Measure not available within instrument

[1] Cognitive Performance Scale

[2] Depression Rating Scale

[3] Changes in End-stage Disease Signs and Symptoms

[4] Activities of Daily Living

[5] Instrumental Activities of Daily Living

[6] Aggressive Behaviours Scale

[7] Community Health Assessment

[8] Community Mental Health

[9] Long-term Care Facility

5.2.4 Correlation between Goals of Care and Associated CAPs

Within the LTC sample, one of the most common GoC expressed was the desire to "Improve health, wellness or QoL," with 12.4% of residents having this care goal documented. Among these residents, 53.1% triggered the ADL CAP at trigger level one and 29.6% at trigger level two (see Table 5). However, similar findings were found among the residents who expressed any of the other 24 GoC, with 48.6% of residents triggering level one and 28.5% triggering level two of the ADL CAP. Another common GoC among this sample was the desire to receive more care in general. Among residents with that specific GoC, 55.6% triggered the ADL CAP at trigger level one, and 13.9% triggered the CAP at trigger level two, leaving 30.6% of not triggering the ADL CAP at all (see Table 6).

Table 5: **Correlation between Goals of Care and Associated Outcome Measures in Long-term Care Facilities**

Outcome Measure	Trigger Level	Health, Wellness & QoL %(n)	Any Other GoC %(n)
ADL CAP	0	17.3 (14)	26.0 (157)
	1	53.1 (43)	48.6 (294)
	2	29.6 (24)	25.5 (154)

Table 6: **Correlation between Goals of Care and Associated Outcome Measures in Long-term Care Facilities**

Outcome Measure	Trigger Level	More Care %(n)	Any Other GoC %(n)
ADL CAP	0	30.6 (11)	24.6 (160)
	1	55.6 (20)	48.8 (317)
	2	13.9 (5)	26.6 (173)

Within the CMH sample, a large proportion of clients expressed the goal of wanting to further their education or to seek employment (21.9%). Among this group of clients, 36.9% triggered the Vocational Rehabilitation MHAP. While only 16.2% of clients who had a different care goal, triggered the Vocational Rehabilitation MHAP. These results are shown in Table 7.

Table 7: **Correlation between Goals of Care and Associated Outcome Measures in Community Mental Health Service Settings**

Outcome Measure	Trigger Level	Employment/Education %(n)	Any Other GoC %(n)
Vocational Rehab MHAP	0	63.1 (41)	83.8 (192)
	1	36.9 (24)	16.2 (37)

Having a GoC to "Reduce Pain" was not commonly expressed among any of the care settings. However, the Pain CAP is commonly triggered across all care settings, especially in the LTC and CSS sectors. Among the eight clients who wanted to reduce their pain severity, 100% of them triggered the Pain CAP at either trigger level one (12.5%) or trigger level 2 (87.5%). Even though approximately half of the CSS clients triggered the Pain CAP (51.5%), only 0.6% of those clients had a GoC to reduce the pain they were experiencing. These results are outlined below in Table 8.

Table 8: **Correlation between Goals of Care and Associated Outcome Measures in Community Support Service Settings**

Outcome Measure	Trigger Level	Reduce Pain %(n)	Any Other GoC %(n)
Pain CAP	0	0.0 (0)	48.8 (647)
	1	12.5 (1)	24.4 (323)
	2	87.5 (7)	26.9 (356)

5.3 Determinants of Not Having Goal of Care Recorded within Each Care Setting

Logistic models were created for each care sector (CSS, CMH, and LTCF) to examine characteristics independently associated with not having a GoC recorded. The final models included variables/scales from a variety of relevant domains and provided high c statistics and significant p-values for each of the variables used. Variables that failed to reach significance were not included, in an effort to produce a better fitting and more parsimonious model. Analysis indicated that age and gender were not significant and therefore were not included in the final models. Having a positive outlook on life was one factor that was found to be a common determinant among the LTCF and CMH sample; however they had opposite directional effects on the dependent variable. In the LTCF model, having a positive outlook on life was associated with having a GoC recorded, but in the CMH model, having a positive outlook was predictive of not having a GoC recorded. A common determinant found within the LTCF model and the CHA model was depressive symptoms measured through the DRS. Again, their directional effects differed among the two samples. Among the LTCF model, being depressed was negatively associated with not having a GoC, whereas in the CHA model, being depressed was predictive of not having a GoC.

Within the LTC sample, residents who have health conditions (cognitive and physical impairment), do not have a consistent positive outlook on life or the desire to return back to the community, and are not depressed are most likely to not have a GoC recorded. Cognitive and physical impairment were the strongest determinants of not having a goal recorded. The analysis yielded an odds ratio of 1.69 for a one increment increase in the CPS scale and an odds ratio of 4.8 for a three point differential in CPS score. Thus, residents with score of three on the CPS are roughly five times (4.83) more likely to not have a GoC recorded than those with no cognitive impairment. This finding was not surprising, as individuals who are severely cognitively impaired are unable to formulate and communicate a GoC. The analysis yielded an OR of 1.23 for a one increment increase in the ADLH scale and an OR of 1.86 for a three point differential in CPS score. Thus, residents with score of three on the ADLH are approximately two times more likely to not have a GoC recorded than those with no physical impairment. The final c statistic for this first model was very high, 0.83. Table 9 displays the independent variables associated with not having a GoC recorded within the LTCF sample.

Within the CSS sample, non-married clients who did not regularly exercise, were depressed or cognitively impaired, but still capable of performing their IADLs were most likely to not have a GoC recorded. Cognitive impairment and depression were the strongest determinants of not having a goal recorded among this sample. The analysis yielded an OR of 1.27 for a one increment increase in the CPS and an OR of 2.04 for a three point differential in CPS score. Thus, CSS clients with score of three on the CPS are two times more likely to not have a GoC recorded than those with no cognitive impairment. The analysis yielded an OR of 1.13 for a one increment increase in the DRS and an OR of 1.44 for a three point differential in DRS score. Thus, CSS clients with score of three on the DRS are roughly one and a half times

more likely to not have a GoC recorded than those with no depressive symptoms. The final c statistic for this model was 0.69. Table 10 displays the independent variables associated with not having a GoC recorded within the CHA sample.

Within the CMH sample, having no insight into one's mental health condition, not having a substitute decision maker for personal care or financial decisions, having a consistent positive outlook on life and not having received crisis intervention were significant predictors of a client not having a GoC recorded. The analysis yielded an OR of 1.95 for clients with some insight into their mental illness and an OR of 4.29 for clients with no sight into their mental illness. Thus, CMH clients with some insight into their mental illness are two times as likely to not have a GoC recorded than clients who had full understanding of their illness. Clients with no insight into their mental health condition are almost four and half times more likely to not have a GoC recorded than those with full insight into their illness. The analysis yielded an OR of 2.19 for having a positive outlook on life. Thus, CMH clients with a consistent positive outlook on life are over two times as likely to not have a GoC recorded than are those with a negative outlook. The final c statistic for this model was 0.68. Table 11 displays the independent variables associated with not having a GoC recorded within the CMH sample.

Table 9: **Final Logistic Regression Model for Having No Goals among Ontario Long-term Care Home Residents**

Variables	Parameter Estimate (SE)	Crude OR (95% CI)	*p*-value
ADLH[1] Scale	0.21 (0.06)	1.23 (1.09 - 1.40)	0.001
CPS[2]	0.53 (0.06)	1.69 (1.50 - 1.91)	0.0001
Desire to return to community (ref= does not want to return)	-1.06 (0.44)	0.35 (0.15 - 0.81)	0.01
DRS[3]	-0.14 (0.04)	0.87 (0.80 - 0.94)	0.0005
Consistent Positive Outlook (ref= not positive)	-0.63 (0.20)	0.53 (0.36 - 0.79)	0.002

c Statistic = 0.83

[1] Activities of Daily Living Hierarchy

[2] Cognitive Performance Scale

[3] Depression Rating

Table 10: **Final Logistic Regression Model for Having No Goals among Ontario Community Support Service Clients**

Variables	Parameter Estimate (SE)	Crude OR (95% CI)	*p*-value
Married **(ref= not married)**	-0.64 (0.28)	0.53 (0.31 - 0.91)	0.02
1-2 hrs of Activity in the last 3 days **(ref= no activity)**	-0.56 (0.17)	0.46 (0.21 - 0.98)	0.0007
3+ hrs of Activity in the last 3 days **(ref= no activity)**	0.33 (0.18)	1.11 (0.50 - 2.47)	
IADL[1] Capacity	-0.19 (0.06)	0.83 (0.73 - 0.93)	0.002
DRS[2]	0.12 (0.05)	1.13 (1.03 - 1.24)	0.01
CPS[3]	0.24 (0.11)	1.27 (1.02 - 1.57)	0.03

c Statistic = 0.69

[1] Instrumental Activities of Daily Living

[2] Depression Rating Scale

[3] Cognitive Performance Scale

Table 11: **Final Logistic Regression Model for Having No Goals among Ontario Community Mental Health Clients**

Variables	Parameter Estimate (SE)	Crude OR (95% CI)	*p*-value
Limited Insight into Mental Health Problem (ref= full insight)	-0.04 (0.22)	1.95 (1.10 - 3.47)	0.02
No Insight into Mental Health Problem (ref= full insight)	0.75 (0.39)	4.29 (1.27 - 14.41)	
Has a Substitute Decision-Maker for Personal Care or Financial Decisions (ref= no decision maker)	-0.77 (0.36)	0.47 (0.23 - 0.93)	0.03
Received Crisis Intervention (ref= never received)	-1.49 (0.47)	0.23 (0.09 - 0.57)	0.002
Consistent Positive Outlook (ref= not positive)	0.78 (0.27)	2.19 (1.29 - 3.71)	0.004

c Statistic = 0.68

5.4 Predictors of Not Having a Goal of Care in Long-term Care Settings with respect to Short-stay and Long-stay Long-term Care Residents

The prevalence of goals was higher for short-stay residents than for LTC residents, with 44.2% of short stay residents being able to express a GoC, compared to 30.3% of long stay residents. Among long stay residents with no goal recorded, 80.1% (n=338) were severely cognitively impaired with a CPS score of three or higher and 84.8% (n=358) had higher levels of ADL impairment, score of three or higher. Among short stay residents with no goal recorded, 61.6% (n=53) were severely cognitively impaired with a CPS score of three or higher and 76.7% (n=66) had an ADL hierarchy score of three or higher. The logistic regression model for predicting not having a GoC among LTCF residents was examined separately among short stay and long stay sample populations (see Table 12). The directional effect of almost all of independent variables was not changed when the model was applied to both population samples. The only variable which changed its effect on the dependent variable was having the desire to return to the community. In the model for long-stay residents, the variable did not change, having the desire to return to the community was predictive of not having a GoC. However, in the short-stay model, not having a desire to return to the community was associated with having a goal of care. When the model was applied to the long stay residents, all of the independent variables remained statistically significant; however, many of the variables lost significance (*p*-value>0.05) when applied to short stay sample such as the activities of daily living hierarchy scale, desire to return to the community, and having a consistent positive outlook on life. The c-statistic dropped from 0.83 to 0.78 in the short stay sample and went up a little in the long stay sample to 0.84. Table 12 displays the independent variables associated with not having a GoC recorded within the short stay and long stay LTCF residents.

Table 12: **Final Logistic Model for Having No Goals of Care among Long-term Care Residents Stratified by Length of Stay**

Model 1: **Short Stay Long-term Care Residents**

Variables	Parameter Estimate (SE)	Crude OR (95% CI)	*p*-value	*c Statistic*
ADLH[1]	0.20 (0.13)	1.22 (0.94 - 1.58)	0.14	
CPS[2]	0.45 (0.13)	1.57 (1.22 - 2.01)	0.0004	
Indicates Preference to Return to the Community (ref= does not want to return)	-0.17 (0.71)	0.84 (0.21 - 3.37)	0.81	0.78
DRS[3]	-0.93 (0.41)	0.40 (0.18 - 0.89)	0.02	
Consistent Positive Outlook (ref= not positive)	-0.05 (0.08)	0.95 (0.82 - 1.11)	0.53	

Model 2: **Long Stay Long-term Care Residents**

Variables	Parameter Estimate (SE)	Crude OR (95% CI)	*p*-value	*c Statistic*
ADLH[1]	0.20 (0.08)	1.22 (1.05 - 1.42)	0.008	
CPS[2]	0.58 (0.07)	1.78 (1.54 - 2.06)	0.0001	
Indicates Preference to Return to the Community (ref= does not want to return)	-1.92 (0.62)	0.15 (0.04 - 0.49)	0.002	0.84
DRS[3]	-0.52 (0.24)	0.59 (0.37 - 0.95)	0.03	
Consistent Positive Outlook (ref= not positive)	-0.19 (0.05)	0.83 (0.75 - 0.91)	0.0001	

[1]ADLH= Activities of Daily Living Hierarchy Scale

[2]CPS= Cognitive Performance Scale

[3]DRS= Depression Rating Scale

6.0 **DISCUSSION**

This study involved the analysis of data collected from three interRAI datasets- the CHA),

the CMH, and the LTCF. As few studies have previously compared variations in self-reported

goals of care (GoC), the results from these comparisons will be discussed first. Second,

demographic and clinical characteristics will be described for persons in the CSS sector, the

CMH sector, and LTCF, along with an analysis of how well the GoC correspond with the CAPs.

Third, the logistic regression results from the investigation of predictor variables independently

associated with not having a GoC recorded will be examined with respect to each of the care

settings. Fourth, differences in factors that predict individual not having a GoC recorded will be

discussed among long stay and short stay LTC residents. Finally, implications for practice,

policy and research are presented, and the limitations of this study are discussed.

6.1   Self-reported Goals of Care across Populations and Sectors

The GoC categories identified in this study span across all domains and have varying

degrees of importance depending on the individual. The results indicate that different

populations in different service settings have common GoC, but many variations in goals exist as

well. Life stage, social factors and clinical situation may lead to the expression of different GoC.

Consistent with previous research conducted on individuals' GoC (Bradley *et al*., 1999;

Bogardus *et al*., 1998), most goals were distributed among common goal categories spanning the

areas of traditional health and wellness concerns (e.g., improving health, wellness, or QoL,

wanting more help with personal care and IADLs), functioning (e.g., wanting more safety and

security, independence, employment or education), and psychosocial concerns (e.g., increasing

social interaction, need for more emotional and mental health support, and respite care for caregivers).

One goal commonly present across all samples was the desire to either continue living at home (CHA, CMH) or wanting to move back home (LTCF). This finding makes sense when considering the aging population, increased life expectancy rates, and the help that is provided by CSS agencies for community-dwelling older adults. Many CMH clients wished to get well at home and avoid hospitalization. For example, one client stated, "[I would like to] avoid hospitalization, feel stronger/better/healthier, receive medication teaching, and move to suitable housing." Similarly, CSS clients generally wished to continue living and aging in the comfort of their own homes and avoid institutionalization. Some examples of GoC from CSS clients include:

- ➢ "[I want] to stay in my own home-i am 94 and don't want to move anywhere else"
- ➢ "[I want] to remain in home for as long and as independent as possible"
- ➢ "To be honest if you ever have to move me to a nursing home you better do it fast or I'll go right to the river"

LTC residents are in a different stage of life than CMH and CSS clients, because they have moved out of their homes and into LTCF to receive higher levels of care. However, many residents expressed their desire to return back to their home, with their family, in the community they grew up in. Some residents also argued that they should be able to return home. For example, one resident stated "[I want] to go home, I can care for myself." Another said "[my] family decided I needed to put in here, not me, I want to go home."

Another GoC common among persons in all three care settings was the desire to meet specific health, wellness, or QoL needs. The health values of individuals vary considerably from person to person and cannot be accurately predicted from a person's health status. These goals varied from the most general statements of goals concerning overall well-being to extremely specific goals focusing on functional outcomes.

The results show that as individuals move across the continuum of care, their GoC shift. Goals tended to be more specific and extensive among clients in CMH sample and still fairly specific in the CSS sample. However, the LTCF sample was more likely to report broad and general GoC. These differences may be reflective of individuals' clinical characteristics and what types of goals are appropriate and achievable. For example, CMH clients generally experience mental health illness or addictions, which can impede their ability to carry out day-to-day activities and live a normal lifestyle. Although generally not well, these individuals revolve their GoC around overcoming their illness and moving on with their lives. For example, one client's response was, "[I want] to get well, continue with treadmill to maintain weight loss and take meds as prescribed." Another's was to "Get my life together, stay out of hospital, feel better, improve coping, reduce psychiatric symptoms, remain stable, and find employment." On the other hand, CSS clients are more likely to be fatigued from chronic disease and physical impairments. Thus, these individuals were more likely to have GoC pertaining to their ability to perform their ADLs and IADLs, reflecting a high degree of importance placed on the ability to carry out these activities while living independently at home. For instance, a CSS client stated "[I want] to regain strength of my limbs so I can better resume my day-to-day life." Another's goal was "[to get more help with] personal care, housekeeping, laundry, meal preps, medication reminders." LTCF residents were the least likely to report specific functional GoC. Instead,

they tended to report broad and universal GoC, such as "[I want] to be healthy" or "[I want] to enjoy life."

Most GoC had a tendency to reflect pragmatic, functional issues, while few reflected aspirations in life (one LTC resident stated "[I want] to marry a millionaire"). Some of these differences may reflect the person's situation affecting the person's life. For example, CMH clients have mental health illnesses and addictions that can impede their ability to carry out day-to-day activities and upkeep a normal lifestyle. These individuals are generally not well, unstable, and have trouble maintaining a job and interacting in social settings. However, these individuals are also young adults who are cognitively and physically intact and are still at a stage in their lives where they can recover from their illness and return to normalcy. To that end, CMH clients appear to center their GoC around a desire to return to a stable lifestyle. Such GoC include finding employment, furthering their education, learning about their mental illness and receiving more mental and emotional support to help them cope with their illness. One CMH client's GoC was, "[I want to] work on my self-esteem and social skills, secure full time employment, and get my own place to live," and another client stated "[I want] to remain living independently and to be able to gradually seek and be able to cope with part time employment and remain as I am now, cope with my social anxiety and learn relaxation techniques."

Further, the variations in goals seen across the different service settings may be a result of people coming to different sectors with different service expectations. GoC may be reflective of what the service agency caring for the individual has to offer them. For example, an individual accessing CSS may be experiencing severe daily pain; however, since the clients are aware of the services provided by the CSS sector, they rarely mention pain management as a GoC. Many CSS clients' goals are directly associated with the care services that CSS provide, such as

laundry, housekeeping, medication management, transportation, safety and security, etc. For

example, one client indicated that he or she needed more help with "hot and frozen meals,

shopping, housekeeping, outdoor chores, transportation, errands, and foot care."

A lot of individuals had missing information for the GoC item. Within the CMH sample,

67.4% of the respondents left at least one of the GoC questions blank, while 67.7% of LTCF

respondents had an unknown GoC or reported not having any GoC. Clients may believe that

responding to every question is optional, inflating the rate of unknown or blank responses. If the

assessor is pressed for time, they too may resort to saying the person has no GoC or that they are

unable to state/formulate goals. Within the LTCF sample, very frequent responses to the GoC

item include "Unknown" or "Unable to express goal" or "None expressed." These GoC may be

more frequently reported among this care setting because LTC residents are typically cognitively

and physically impaired, and have multimorbidity. Rather than simply recording an arbitrary

response for these individuals, since they do not have the cognitive capacity to express a GoC,

the assessor should instead try to gain the family's perspective and come up with a mutually

agreed upon GoC that would best resemble the person's wishes.

Individuals personal GoC can provide clarity for health care providers on the current

reality of each individual's abilities and needs, and can be used as a starting point for developing

more measurable and specific outcome measures that will provide a means for tracking progress

toward achieving one's overarching goal.

6.2   Comparison of Person Characteristics across Care Settings

The three care sectors serve populations with different age and sex distributions and

different sets of clinical needs. The CHA sample was more similar to the LTCF sample than to

the CMH sample, and thus allowed for enhanced comparisons. Both samples are largely composed of widowed females over the age of 75, with closely comparable mean ages (79.3 years in the CHA and 84.0 years in the LTCF). In contrast, the CMH sample was primarily composed of single, middle-aged males with an average age of 41.9 years.

Individuals within the LTCF sample were typically less healthy than those in the CMH and CHA samples. LTC residents were characterized by having severe levels of cognitive impairment, physical frailty, depression, and chronic disease. These individuals were less likely to express specific curative GoC, and instead tended to report more general GoC such as the desire to return home, to improve general health, wellness or QoL, to increase social interaction, and to receive more care. Psychiatric conditions were common among the CMH clients including depression, anxiety and dementia. Predictably, the CMH GoC focused heavily on mental health issues.

A comparison of how well certain GoC are associated with the corresponding CAPs indicates that the GoC vary somewhat with CAPs that are triggered. For example, the Pain CAP is triggered much more frequently than the GoC to improve pain is reported. Also, among CMH clients who had a GoC to "seek employment or further their education," only 36.9% of them triggered the Vocational Rehab MHAP. Further, having a GoC to "Improve their health, wellness or QoL," was highly predictive of triggering the ADL CAP among LTCF residents. However, the results also showed that the majority of the LTCF residents were triggering the ADL CAP, regardless of the GoC they reported. These results indicate that triggering of a particular CAP does not predict documentation of a corresponding GoC. Therefore, the personally expressed GoC play an essential role in helping clinicians to identify what matters most to the individual and may help to flag an area of concern. However, the GoC by no means

should replace the CAPs which play a very critical role in facilitating the care planning process by alerting the assessor to a problem or risk that should be addressed in the care plan. Ideally, clinicians should take both the CAPs and GoC into consideration when developing individuals care plans.

6.3   Determinants of Not Having a Goal of Care Recorded within each Care Setting

This study identified a range of characteristics concurrently associated with not having a GoC in multivariate analyses in all three sample populations (CSS, CMH, and LTCF). Most determinants differed between the models generated, suggesting that differences in clients' demographic situation, clinical situation, and care setting can play a role in goal setting.

Within the LTC sample, residents who have health conditions (cognitive and physical impairment), do not have a consistent positive outlook on life or the desire to return back to the community, and are not depressed are most likely to not have a GoC recorded. Cognitive and physical impairment were the strongest determinants of not having a goal recorded. Residents with score of three on the CPS are roughly five times (4.8) more likely to not have a GoC recorded than those with no cognitive impairment. This finding was not surprising, as individuals who are severely cognitively impaired are unable to formulate and communicate a GoC. Further, residents with score of three on the ADLH are approximately two times more likely to not have a GoC recorded than those with no physical impairment. This result can be tied in with another predictor of not having a GoC. The more functionally dependent a person is on others for daily care, the worse their QoL and the more likely they are to have a negative outlook on life. Thus, these individuals may be less motivated to formulate a GoC for themselves as they have lost hope for recovery. LTCF residents who no longer express the

desire to return to their community may be less likely to have reported a GoC because they believe that they are too old or impaired to return home to their community. If these individuals are no longer optimistic about getting out of the facility they may be unlikely to believe they could achieve a care goal and thus fail to report one. Residents who are severely depressed are more likely to have a goal of care than those who are not depressed. This finding may be related to the length of stay of residents in the facility. Newly admitted LTCF residents may be more depressed about moving out of their family home and into a facility where do not know anyone. These individuals are likely to me more depressed than long stay residents who have had more time to accept the facility as their home. Short stay or newly admitted residents may still be hopeful that they will have the opportunity to leave the facility and move back home, and are thus more motivated to have a goal of care.

Within the CSS sample, non-married clients who did not regularly exercise, were depressed or cognitively impaired, but still capable of performing their IADLs were most likely to not have a GoC recorded. Cognitive impairment and depression were the strongest determinants of not having a goal recorded among this sample. CSS clients with score of 3 on the CPS are two times more likely to not have a GoC recorded than those with no cognitive impairment. This finding squares with reason, as cognitively intact clients would be more likely to be able to formulate a GoC for themselves than severely cognitively impaired clients who likely require a substitute decision-maker to answer these types of questions for them. Further, CSS clients with score of three on the DRS are roughly one and a half times more likely to not have a GoC recorded than those with no depressive symptoms. Within this care setting, it is logical that depressed clients who are generally disheartened and unmotivated to even carry out their day-to-day activities would be enthusiastic about created a GoC for themselves to work on

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and ultimately achieve. On the other hand, non-depressed CSS clients are more likely to report a

GoC in hopes that they will receive more support in that area from the CSS agencies, thus

helping them to age in home for as long as possible. Similarly, clients who have no problem

carrying out their IADLs are less likely to report a GoC since the client may not require

additional assistance from the CSS agencies at that time. However, clients needing assistance

with their IADLs are highly likely to report multiple GoC in the areas of activity that they cannot

carry out on their own. Non-married clients are less influenced or motivated by a significant

other to articulate a GoC, whereas married clients typically have more support from their spouse

to not only formulate a GoC reflecting their individual needs but more importantly to express

shared goals influenced by both partners needs and help support one another in achieving those

goals. Clients who do not exercise regularly (fail to complete a one hour or more of exercise

every three days) are less likely to care about their general health and well-being and thus less

likely to have recorded a GoC than are clients who make their health a priority and exercise on a

regular basis.

Within the CMH sample, clients who did not have a substitute decision maker, have a

consistent positive outlook on life but no insight into their mental health condition and have not

received crisis intervention are most likely to not have a GoC recorded. Not having insight into

one's mental health condition and having a consistent positive outlook on life are the two

strongest determinants of not having a GoC recorded. CMH clients with some insight into their

mental illness are two times as likely to not have a GoC recorded than clients who had full

understanding of their illness. Clients with no insight into their mental health condition are

almost four and half times more likely to not have a GoC recorded than those with full insight

into their illness. CMH clients with a consistent positive outlook on life are over two times as

likely to not have a GoC recorded than are those with a negative outlook. These characteristics may explain clients who never worry about anything and fail to seek help with their problems until they hit crisis level. Once a client has experienced a crisis and sought crisis intervention, it follows that he or she would be more likely to set goals, gain some insight into the mental illness, and have a slightly less positive outlook on life. Further, clients who have a substitute decision maker are likely to have GoC recorded as that decision maker will be determined to set a goal or multiple GoC for the dependant.

6.4   Goal Setting Differences among Short-stay and Long-stay Residents

The results of this study indicate that the predictors of not having a GoC are not as strong in short stay residents as they are in long stay individuals. The directional effect of each of the dependent variables was not changed when the model was applied to both sub-populations. When the model was applied to the long stay residents, all of the dependent variables remained statistically significant. However, the majority of the variables lost significance (p-value>0.05) when applied to short stay sample and the c-statistic dropped substantially. Almost all of the determinants stayed the same, such as functional and cognitive status, depression, and having a positive outlook on life. The only determinant that changed its directional effect was "desire to return to the community" in the short stay sub-population. This variable was significant when applied to long stay residents but not short stay residents. This may reflect long-stay residents who still had hope to return to the community. Therefore, even though the directional strength of the independent variables did not substantially change when applied to both populations, the model is more predictive among long stay residents than it is among short stay residents.

Short stay residents were more likely to express a personal GoC than long stay residents. Long stay residents have resided in the facility for a longer period of time and thus may have accepted the facility as their home, and are thus less likely to have GoC pertaining to leaving the facility or wanting to return back to their home and community. Overall, long stay residents are substantially more physically and cognitively impaired than are short stay residents. Consequently, they are generally unable to live outside the facility. Long stay residents may have reached a point in their lives where hopelessness or apathy has started to set in, resulting in a loss of enthusiasm and motivation to formulate GoC.

Therefore, it can be concluded from these results that short stay and long stay residents really are two distinctive groups. Short stay residents usually come from the hospital and are recovering from an acute illness. These individuals are more likely to have optimistic GoC to get well, leave the facility and return home not long after entry. In contrast, long stay residents are more likely to have accepted the fact that they will be in the facility the rest of their lives, and thus have truly become institutionalized, losing the desire to use GoC to help improve their health and return home.

6.5   Implications for Practice

The primary goal of clinical care is to improve patient outcomes. Although good clinicians have always recognized the importance of diagnosing diseases and functional impairments, empirical studies show that physicians do not assess patient-perceived health status accurately (Wilson & Cleary, 1995). In actual practice, the GoC item is collected whenever an assessment is conducted; however, beyond that, this item is rarely used in clinical practice. Further, GoC discussions between health professionals and clients do not systematically occur after the

admission process, nor do they regularly occur when clients' care plans are being developed. This could be due to poor accountability, time pressure, or a lack of family involvement, which may deter providers and staff from having the GoC discussion at all.

Clinicians have a responsibility to routinely discuss GoC and treatment priorities with each individual to whom they provide care. The GoC self-report item within the interRAI assessments is documented every time an assessment is conducted. The assessments are completed as an ongoing process, not a one-time event. Clinicians should use the responses from this item to frame the CAP and GoC discussions. Many CAPs are triggered that may not be identified as a GoC; however, the goals can be used to identify which CAPs are a priority to the person and should be addressed first. If this process was properly conducted and completed, a relationship between the person, family and clinician would be developed, along with an individualized care plan compatible with the person's expressed needs, wishes, and overall health status.

Health care staff can have a significant impact on the GoC discussion since they are working with the clients every day. However, many health professionals do not understand the concept of goals or goal-setting in clinical practice, or the importance of documenting responses to the GoC questions. Nor are they educated in how to properly conduct a GoC discussion. Therefore, a deliberate and strong emphasis needs to be placed on educational training to make it clear that this item is as important as any other interRAI item, and to educate staff to avoid entering information driven by ageism or preconceived notions of what they think the person wants. Increased efforts should also be made to develop successful strategies to prevent further under-reporting of the GoC item, and to achieve effective GoC discussions.

This research is one of the first studies to examine the interRAI GoC item by making use of routinely collected qualitative data, to look at GoC across three different health care sectors. Hopefully the findings from this research will help provide clinicians and health professionals with a clearer understanding of the large diversity in GoC that exists among persons in various care settings. This research should help to motivate clinicians to use the interRAI GoC item to design individualized interventions that are congruent with persons' expressed GoC in an effort to improve satisfaction with care and achievement of desired outcomes.

6.6 Implications for Policy

When conducting both clinical and research evaluations, it is important to measure individuals' health status and changes in health outcomes to determine the next steps or changes that should be made to one's care plan. The interRAI instruments collect data on the 300-400 items within each assessment, covering a large array of patient characteristics which can be used for care planning purposes and outcome measurement. Not all of the important assessment items can be assessed using objective measures, some need to be determined subjectively such as the open-ended GoC item. This item can be just as important (if not more important) for care planning and evaluating treatment or service priorities, since this is one of the few items that collects information directly from the individual on their care needs and wishes. General information about individuals' values and goals can complement care plans and specific intervention preferences, giving physicians a better understanding of the persons' desires (Fischer *et al*., 1997). GoC may also have a role in simplifying documents. For example, residents who select the GoC to "live longer" or "die" might not need to respond to more than a few confirmatory inquiries about specific intervention preferences or what form of comfort

treatment they would want; however, having a GoC to "want to die" may be a sign of depression that would require further assessment.

The results of this study revealed twenty-five GoC categories that were created from the qualitative responses. They were very diverse, ranging from the most simplistic goal ("[I want] to be healthy") to much more specific and complex goals ("[I want] to get rid of the voices, find the right meds for me, work for a few years, and then resume school or pursue a career" and an example from the CHA sample "I need help with cleaning. Two hours per week and foot care once a month. I am caring for my husband who is 94 years old. He has Cancer.") Some of the important goals identified through open-ended questions may not have been adequately assessed through the other assessment items. The large diversity of GoC that were identified demonstrates the need for ongoing assessment of this item within all care settings. However, this one item alone should not be used as the primary indicator of what services or treatments a person should be receiving. If clinicians simply obeyed clients' wishes, inappropriate services or treatments could be implemented or other health interventions could be discontinued prematurely, with deleterious effects on the individual. Therefore, it is critical for clinicians to look at the full range of assessment items along with the CAPs and scales embedded within the interRAI assessments to develop an accurate and comprehensive care plan for each individual.

6.7   Implications for Research

While the findings from this study provide a good profile of clients GoC in all three care settings, an abundance of persons reported having no goals; especially within the CMH and LTCF samples where responses were often left blank or marked unknown. These results raise questions as to the appropriate extent of the open-ended GoC question within the interRAI

assessments. It may also warrant redesign efforts to improve the under-reporting of the GoC item by changing the collection and documentation process.

The GoC responses that were examined in this study were inconsistently recorded, with most goals being carelessly and quickly documented. Case assessors tended to default to routinized responses, and often failed to describe the true "richness" of each individual personal GoC, which is sole purpose of why this item is qualitative in nature. Training should be directed at improving data quality for this item, for it to be useful in the large scale datasets that it is collected in.

Thus, a suggested solution to this problem is to create a newer version of interRAI assessment tools that does not collect purely qualitative responses for both of the GoC questions. Instead, the first GoC question, exploring persons' general GoC, could be set up as drop down menu with a list of standardized GoC categories, such as those identified within this study. While, the second question which assesses persons' primary GoC could be left as a qualitative measure and thus still allow for individual preferences.

This change to the item design would give more consistent answers to the GoC item, which would be easy to computerize. It would provide a quick and easy way for the assessor to capture the person's GoC with drop-down list of standardized goals. The drop-down list would also serve to remind respondents of goals that they may otherwise not have considered. For example, mental and emotional support, although important to clients and residents, it might be less accessible and elicited only by direct questioning. Another positive implication of changing the item design is that the GoC item would be able to be used in quantitative analyses of very large data sets.

There are also some negative implications that would arise from this suggested change to the GoC item. For example, it would be very difficult to produce a list of goals that would be sufficiently comprehensive and able to differentiate subtle, nuanced variations in GoC. To try to satisfy the diversity of GoC, the list of goals would have to be huge which would take away from the convenience of the drop-down menu. Most importantly, by removing the qualitative nature of the question, the unique, idiosyncratic aspects of each person's view will be diminished.

Further, another way to improve the under-reporting of the GoC item is by making it a mandatory item that the assessor must fill out before he or she is able to continue on with the assessment. This technological change would create "edit-checks" that would prohibit "blank" responses from being documented for the GoC items.

A future direction arising from this study may be the creation of a GoC questionnaire that could be supplemental to the interRAI assessments. This questionnaire, if used properly, would help articulate person's preferences and care goals. Also, by thoroughly documenting individuals' care goals on a periodic basis, miscommunication is minimized because there is enhanced clarity of patient care plans between the individual, family and health care providers.

Future studies are needed to determine the best way to discuss GoC in each of the health care settings and should test whether initially setting goals and reviewing them periodically using a goal-setting instrument may be a comprehensive and time-efficient way of integrating individuals' GoC into their care plans. Further, researchers and clinicians may be interested in understanding variation in GoC among other populations beyond those that will be used in this study. Thus, the replication of this study among other subpopulations may be of interest.

More research is needed surrounding patient involvement in their own care and whether actively participating in one's own care promotes improvement in the individuals' health and

QoL. Research needs to gain access to more details about individuals' care goals and examine patterns of GoC change by assessing changing in individuals' GoC from their initial assessment to their last most recent assessment to determine if longitudinal differences exist. Indeed, previous studies have discovered that goals and behaviours change considerably over time in cognitively impaired residents, warranting a close monitoring to assess the impact of ongoing discussion to determine if the same goals persist or if they are random, unexpected and constantly changing every time the person is asked.

The logistic regression models that were created within this study, identifying the variables that are associated with a person not having a GoC recorded, should be examined on larger scale samples from different locations to clarify the directionality of the relationship between the variables.

Future studies need to examine the impact of clinicians actually conducting GoC discussions with the clients and taking their GoC responses into account while developing their care plans. Such studies could also examine the impact of better staff training and education (in the areas of goal-setting and patient-centered care), physician characteristics, and management approaches on the success of achieving desired outcomes of care and ultimately improving one's health and QoL.

7.0 LIMITATIONS

Despite the advantages of the large sample sizes and standardized assessment tools providing information on numerous demographic and clinical variables, limitations exist and caution should be taken when interpreting the results and generalization of findings.

First, this study involved secondary data analyses of interRAI data that were not specifically collected for the purposes of this research. Therefore, the data set did not contain all the desired variables, but rather was restricted to variables present in the assessment tools. For example, some of the assessment items present within the interRAI LTCF and interRAI CHA are not included the interRAI CMH, such as disease diagnoses (Alzheimer's, depression, hypertension, cancer). Also, certain scales could be calculated in some assessment, but not others. For example, the ABS scale was not available for comparison in the CHA and the IADL scale was not available in the LTCF. Consequently these items could not be compared across care settings. Further, the interRAI CMH assessment used in its pilot study only collected information on persons' general GoC and mistakenly failed to include the second question about primary goals of care in the assessment. Such information would have been useful to clarify differences between persons' general GoC and their primary GoC and how they differ across care settings. The missing component of the item in the CMH assessment may have contributed to the variation in the frequency of GoC expressed across the case settings, as more goals were documented in the CHA and LTCF samples, which documented responses for both GoC questions.

Second, the GoC responses that were documented were dependent on the completeness of the respondents' answers and the willingness of the assessor to write in information. These limitations created the possibility for both non-response bias and assessor bias. Non-response

bias may have occurred if those who had a GoC recorded, differed from those who did not have a goal documented. Some respondents may have chosen not to answer the question fully or truthfully which may have led to the underreporting or misrepresentation of goals. Thus, caution should be taken when generalizing the results to the segment of the population that had no GoC identified. Further, even though the interRAI assessments have good inter-rater reliability in cross-national comparisons (Hirdes *et al.*, 2008), assessor bias may have been present since the assessments are completed by persons with varying backgrounds and experience, and whom work in different care settings. Assessors may have collected and interpreted responses differently depending on the subject they were assessing (for example, if the individual had severe cognitive impairment they may have decided to just skip this question assuming the individual would not be able to answer it). Such differences may help to explain the variations that exist in how well the GoC item is documented (i.e., the CSS staff recorded GoC more frequently than staff in CMH and LTCF settings).

Another limitation is that the interRAI LTCF has not yet been mandated in Ontario, therefore the generalization of the results is restricted by the fact that the LTCF sample may not be representative of all LTCF across Ontario, especially since the sample only included eight homes. Similarly, the CMH data is most recently collected from the new interRAI suite so the total sample size is much smaller compared to the CHA data that has been collected for several years. The smaller sample size makes it challenging to be sure that the results (25 GoC categories) can be generalized to other provinces within the country. For example, once more data are collected in both the LTCH and CMH sectors, the larger sample sizes will increase the frequency of GoC responses and other GoC categories may be identified.

Lastly, it is important to note that GoC may change over time especially as one's health status changes, and because this study is cross-sectional in nature it only allows for a snap-shot of persons' expressed GoC to be examined. Other patient groups and older adults in different circumstances may not have responded in the same way as participants in this sampling. Therefore, these results should not be directly projected to populations dissimilar to those included in this study.

8.0 CONCLUSION

Very diverse GoC exist among individuals and across care settings. Thus, there is not a "one size fits all" solution to care planning as the same goals and outcome measures will not be appropriate or realistic for all persons. Unfortunately, if individuals fail to articulate a GoC, providers may inadvertently provide care that is ultimately less effective and less satisfying to the person, the person's family, and the health care system as a whole. It is important for clinicians to collaborate with the person and his or her family, to determine the person's GoC. Clinicians should have this discussion with the person as early as possible, and periodically re-evaluate the subject as the individual moves through the continuum of care or through the course of their chronic illness. The interRAI suite of assessment tools provides a means for clinicians to incorporate a person's care needs and care wishes into individualized care plans, ultimately resulting in improved care quality and increased cost savings.

9.0 REFERENCES

Affordable Supportive Housing for Seniors: Developing a framework and action plan for Ottawa. (2007). Retrieved from United Way database.

Armstrong, J. J., Stolee, P., Hirdes, J. P., & Poss, J. W. (2010). Examining three frailty conceptualizations in their ability to predict negative outcomes for home-care clients. *Age and Aging,* (0), 1-3.

Austin, J. T., & Vancouver, J.B. (1996). Goal constructs in psychology: Structure, process, and content. *Psychological Bulletin, 120*(3), 338-375.

Benjamin, A. E. (1999). A normative analysis of home care goals. *Journal of Aging and Health, 11*(3), 445-468.

Bergeson, S. C., & Dean, J. D. (2006). A systems approach to patient-centered care. *Jama, 296*(23), 2848-2851.

Bernabei, R., *et al*. (2009). International Gerontology in Hazzard's Principles of Geriatric Medicine and Gerontology (Sixth Edition), New York: McGraw-Hill, March 2009.

Bogardus, S. T., Bradley, E. H., & Tinetti, M. E. (1998). A taxonomy for goal setting in the care of persons with dementia. *Journal of General Internal Medicine*, 13(10), 675-680.

Bradley, E. H., Bogardus, S. T., Tinetti, M. E., & Inouye, S. K. (1999). Goal setting in clinical medicine. *Social Science & Medicine, 49*(2), 267-278.

Britt, H. C., Harrision, C. M., Miller, G.C., & Know, S.A. (2008). Prevalence and patterns of multimorbidity in Australia. *Medical Journal of Australia, 189*(2), 72-77.

Brink, P., & Smith, T. F. (2008). Determinants of home death in palliative home care: Using the interRAI palliative care to assess end-of-life care. *American Journal of Hospice & Palliative Medicine, 25*(4), 263-270.

Burrows, A., Morris, J., Simon, S., Hirdes, J., & Phillips, C. (2000). Development of a minimum data set-based depression rating scale for use in nursing homes. *Age and Ageing*, 29(2), 165-172.

Centre for Addiction and Mental Health (CAMH). Services at different life stages. (2009). Retrieved 12/14, 2009, from http://www.camh.net/Care_Treatment/Resources_clients_families_friends/Challenges_and_Choices/challenges_choices_servlifestage.html

Canadian Medical Association (CMA) Infobase. (1994). Canadian clinical practice guidelines. *Ottawa: Canadian Medical Association.* Retrieved 02/18, 2010, from: http://mdm.ca/cpgsnew/cpgs/gccpg-e.htm.

Canadian Mental Health Association (CMAH). (1993). Aging and mental health fact sheet. Retrieved 01/25, 2010, from http://www.ontario.cmha.ca/fact_sheets.asp?cID=3229

Canadian Institute for Health Research (CIHR). (2008). Cognitive impairment in aging strategy and partnership. Retrieved 01/21, 2010, from http://www.cihr-irsc.gc.ca/e/26988.html

Constantian, A. R. (1997). Assessing the medical offset effect of mental health visits in a military population. *Abstract Book Association for Health Services Research,* 14, 328.

Corcoran, M. A. (2009). Screening for dementia: First signs and symptoms reported by family caregivers. *Geriatrics and Aging, 12*(10), 509-512.

Edhlund, B. (2008). NVivo 8 essentials: The ultimate help when you work with qualitative analysis. *Form & Kunskap.*

Fries, B. E., & Morris, J. N. (2007). Rethinking the Resident Assessment Protocols. *The American Geriatrics Society,* 55, 1139-1154.

Fries, B. E., Simon, S. E., & Morris, J. N. (2001). Pain in U.S. nursing homes: Validating a pain scale for the minimum data set. *The Gerontologist, 41*(2), 173-179.

Glazier, S. R., Schuman, J., Keltz, E., Vally, A., & Glazier, R. H. (2004). Taking the next steps in goal ascertainment: A prospective study of patient, team, and family perspectives using a comprehensive standardized menu in a geriatric assessment and treatment unit. *Journal of the American Geriatrics Society, 52*(2), 284-289.

Gray, L. C., Berg, K., Fries, B. E., Henrard, J., Hirdes, J. P., Steel, K., & Morris, J. N. (2009). Sharing clinical information across care settings: The birth of an integrated assessment system. *BMC Health.Services Research, 9*, 71.

Guadagnoli, E., & Ward, P. (1998). Patient participation in decision-making. *Social Science & Medicine, 47*(3-4), 329-340.

Hartmaier, S. L., Sloane, P. D., Guess, H. A., Koch, G. G., Mitchell, C. M., & Phillips, C. D. (1995). Validation of the minimum data set cognitive performance scale: Agreement with the mini-mental state examination. *The Journal of Gerontology, Series A, 50*(2), 128-134.

Heaney, C. A., & Burke, A. C. (1995). Ideologies of care in community residential services: What do caregivers believe? *Community Mental Health Journal, 31*(5), 449-462.

Hirdes, J. P. (2005). Minimum data set user's manual. Ottawa, Ontario: Canadian Institute for Health Information.

Hirdes, J. P., Fries, B. E., Morris, J. N., Steel, K., Mor, V., & Frijters, D. (1999). Integrated health information systems based on the RAI/MDS series of instruments. *Healthcare Management Forum./ Canadian College of Health.Service Executives., 12*(4), 30-40.

Hirdes, J. P., Frijters, D. H., & Teare, G. F. (2003). The MDS-CHESS scale: A new measure to predict mortality in institutionalized older people. *Journal of the American Geriatrics Society, 51*(1), 96-100.

Hirdes, J. P., Ljunggren, G., Morris, J. N., Frijters, D. H., Finne Soveri, H., Gray, L. (2008). Reliability of the interRAI suite of assessment instruments: A 12-country study of an integrated health information system. *BMC Health Services Research,* 8, 277-277.

Hirdes, J. P., Smith, T. F., Rabinowitz, T., Yamauchi, K., Pérez, E., Telegdi, N. C., *et al.* (2002). The resident assessment instrument-mental health (RAI-MH): Inter-rater reliability and convergent validity. *The Journal of Behavioral Health Services & Research, 29*(4), 419-432.

interRAI. (2009). Retrieved 01/31, 2010, from interrai.org

interRAI CHA newsletter: Enhancing system integration.(2009). Retrieved 01/18, 2010, from https://www.cssnetwork.ca/Lists/Announcements/Attachments/15/interRAI%20CHA%20Newsletter%20-%20Final%20Oct%2016%2009.pdf

Jones, K., Perlman, C. M., Hirdes, J. P., Scott, T. (in press). Screening Cognitive Performance with the Resident Assessment Instrument for Mental Health (RAI MH) Cognitive Performance Scale. *The Canadian Journal of Psychiatry.*

Johnson, B. H. (1999). Family focus when hospitals put the emphasis on patients and families, everyone benefits. *Trustee : The Journal for Hospital Governing Boards, 52*(3), 12-15.

Kagawa-Singer M., & Blackhall L. (2001). Negotiating cross-cultural issues at the end of life. *Jama*. 286(23), 2993-3001.

Kaldjian, L. C., Curtis, A. E., Shinkunas, L. A., & Cannon, K. T. (2008). Goals of care toward the end of life: A structured literature review. *The American Journal of Hospice & Palliative Care, 25*(6), 501-511.

Kaldjian, L. C., Shinkunas, L. A., Bern-Klug, M., & Schultz, S. K. (2010). Dementia, goals of care, and personhood: a study of surrogate decision maker's beliefs and values. American Journal of Hospice and Palliative Medicine, 27, 387-397.

Kane, R. A. and Kane, R. L. (1987). Long-term care: Principles, programs, and policies. *New York: Springer.*

Kerssens, J., Groenewegen, P., Sixma, H., Boerma, W., & Van Der Eijk, I. (2004). Comparison of patient evaluations of health care quality in relation to WHO measures of achievement in 12 European countries.

Krakauer E., Crenner C., Fox K. (2002). Barriers to optimum end-of-life for minority patients. *Journal of American Geriatric Society*. 50(1), 182-190.

Landi, F., Tua, E., Onder, G., Carrara, B., Sgadari, A., and Rinaldi, C. (2000). Minimum data set for home care: A valid instrument to assess frail older people living in the community. *Med Care*, *38*(12), 1184-90.

Leach, M. J. (2008). Planning: A necessary step in clinical care. *Journal of Clinical Nursing, 17*(13), 1728-1734.

Lee, S., Wong, Y. I., & Rothbard, A. B. (2009). Factors associated with departure from supported independent living programs for persons with serious mental illness. *Psychiatric Services, 60*(3), 367-373.

Leland, J. (2001). Advance directives and establishing the goals of care. *Primary Care*, 28(2), 349-363.

Locke, E. A., & Latham, G. P. (1990). A theory of goal setting & task performance. Englewood Cliffs, NJ, US: Prentice-Hall, Inc.

Martin, L., Hirdes, J. P., Fries, B. E., & Smith, T. F. (2007). Development and Psychometric Properties of a Assessment for Persons with Intellectual Disability- The interRAI ID. Journal of Policy and Practice in Intellectual Disabilitie. 4(1), 23-29.

Martin, L., Hirdes, J. P., Morris, J. N., Montague, P., Rabinowitz, T., & Fries, B. E. (2009). Validating the Mental Health Assessment Protocols (MHAPs) in the Resident Assessment Instrument Mental Health. *Journal of Psychiatric and Mental Health Nursing*. 0, 1-8.

Martin, L., Poss, J. W., Hirdes, J. P., Jones, R. ., Stones, M. J., Fries, B. E., & Rabinowitz, T. (2008). Predictors of a new depression diagnosis among older adults admitted to complex continuing care: implications for the depression rathing scale (DRS). *Age and Ageing. 37, 51-56.*

Mays, N., Pope, C., & Popay, J. (2005). Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *Journal of Health.Services Research & Policy, 10(1)*, 6-20.

Mezey, M., Teresi, J., Ramsey, G., Mitty, E., & Bobrowitz, T. (2000). Decision-making capacity to execute a health care proxy: Development and testing of guidelines. *Journal of the American Geriatrics Society, 48*(2), 179-187.

Mor, V. (2004). A comprehensive clinical assessment tool to inform policy and practice - applications of the minimum data set. *Medical Care, 42*(4), 50-59.

Mor, V., Branco, K., Fleishman, J., Hawes, C., Phillips, C., Morris, J. (1995). The structure of social engagement among nursing home residents. *The Journals of Gerontology, Series B, 50*(1), 8-9.

Morris, J., Belleville-Taylor, P., Berg, K., Bjorkgren, M., Frijters, D., Fries, B., *et al*. (2008). *interRAI Clinical Assessment Protocols (CAPs) - For Use With interRAI's Community and Long-Term Care Assessment Instruments, March 2008 (Ottawa: CIHI, 2008).*

Morris, J. N., Berg, K., Bjorkgren, M. A., Frijters, D., Fries, B. E., Gilgen, R. (2006). *interRAI-community health assessment (CHA) guide for use of the interRAI CHA assessment form, Canadian version 07.*

Morris, J., Fries, B., & Morris, S. (1999). Scaling ADLs within the MDS. *Journals of Gerontology Series A-Biological Sciences and Medical Sciences, 54*(11), 546-553.

Morris, J. N., Carpenter, I., Berg, K., & Jones, R. N. (2000). Outcome measures for use with home care clients. *Canadian Journal on Aging. Special Issue: International Studies of the Minimum Data Set: The InterRAI Experience, 19*(2), 87-105.

Morris, J. N., Fries, B. E., Mehr, D. R., & Hawes, C. (1994). MDS cognitive performance scale©. *Journals of Gerontology, 49*(4), 174-182.

Mozley, C. G., Huxley, P., Sutcliffe, C., Bagley, H., Burns, A., Challis, D. (1999). 'Not knowing where I am doesn't mean I don't know what I like': Cognitive impairment and quality of life responses in elderly people, *International Journal of Geriatric Psychiatry, 14*(9), 776-783.

Murray, E., Charles, C., & Gafni, A. (2006). Shared decision-making in primary care: Tailoring the Charles *et al*. model to fit the context of general practice. *Patient Education and Counseling, 62*(2), 205-211.

Naik, A. D., Schulman-Green, D., McCorkle, R., Bradley, E. H., & Bogardus, S. T. (2005). Will older persons and their clinicians use a shared decision-making instrument? *Journal of General Internal Medicine, 20*(7), 640-643.

Perlman, C. M., & Hirdes, J. P. (2008). The aggressive behavior scale: A new scale to measure aggression based on the minimum data set. *Journal of the American Geriatrics Society, 56*(12), 2298-2303.

Poss, J. W., Jutan, N. M., Hirdes, J. P., Fries, B. E., Morris, J. N., & Teare, G. F. (2008). A review of evidence on the reliability and validity of minimum data set data. *Healthcare Management Forum / Canadian College of Health Service Executives = Forum Gestion Des Soins De Sante / College Canadien Des Directeurs De Services De Sante, 21*(1), 33-39.

QSR International Pty Ltd. (2009). *NVivo*. United States: Microsoft Corporation.

Rockwood, K., Fay, S., Jarrett, P., & Asp, E. (2007). Effect of galantamine on verbal repetition in AD: A secondary analysis of the VISTA trial. *Neurology, 68*(14), 1116-1121.

Rockwood, K., Stolee, P., & Fox, R. (1993). Use of goal attainment scaling in measuring clinically important change in the frail elderly. *Journal of Clinical Epidemiology*, (46), 1113–1118.

Rockwood, K., Stolee, P., Howard, K., & Mallery, L. (2002). Use of goal attainment scaling in a randomized, placebo-controlled trial of an anti-dementia drug. *Journal of Neurology and Neurosurgery Psychiatry*, 73(5), 500-507.

Rodriguez, K. L., & Young, A. J. (2006). Patients' and healthcare providers' understandings of life-sustaining treatment: Are perceptions of goals shared or divergent? *Social Science & Medicine, 62*(1), 125-133.

Ryden, M. B., & Feldt, K. S. (1992). Goal-directed care: Caring for aggressive nursing home residents with dementia. *Journal of Gerontological Nursing.Special Issue: Alternatives to Restraints, 18*(11), 35-42.

Sandelowski, M. (1999). Focus on qualitative methods: Time and qualitative research. *Research in Nursing & Health, 22*(1), 79-87.

SAS Institute Inc. (2003). *SAS version 9.1*. Cary, North Carolina:

Schulman-Green, D. J., Naik, A. D., Bradley, E. H., McCorkle, R., & Bogardus, S. T. (2006). Goal setting as a shared decision making strategy among clinicians and their older patients. *Patient Education and Counseling, 63*(1-2), 145-151.

Steinback, U. (1992). Social networks, institutionalization, and mortality among elderly people in the United States. *Journals of Gerontology, 47*(4), 183-191.

Stolee, P., Stadnyk, K., Myers, A. M., & Rockwood, K. (1999a). An individualized approach to outcome measurement in geriatric rehabilitation. *The Journals of Gerontology, Series A*, 641.

Stolee, P., Zaza, C., Pedlar, A., & Myers, A. M. (1999b). Clinical experience with goal attainment scaling in geriatric care. *Journal of Aging and Health, 11*(1), 96-124.

Sutcliffe, C., Burns, A., Challis, D., Mozley, C. G., Cordingley, L., Bagley, H. (2007). Depressed mood, cognitive impairment, and survival in older people admitted to care homes in England. *The American Journal of Geriatric Psychiatry, 15*(8), 708-715.

Tashakkori, A., & Teddlie, C. (1998). *Mixed methodology: Combining qualitative and quantitative approaches*. Thousand Oaks, CA, US: Sage Publications, Inc.

Uman, G. C. (1997). Where's Gertrude? *Journal of the American Geriatrics Society, 45*, 1025-1026.

Waters, D., & Sierpina, V. S. (2006). Goal-directed health care and the chronic pain patient: A new vision of the healing encounter. *Pain Physician., 9*(4), 353-360.

Waterworth, S., & Luker, K. (1990). Reluctant collaborators - do patients want to be involved in decisions concerning care. *Journal of Advanced Nursing, 15*(8), 971-976.

Yoshikawa, T., Ouslander, J. (2007). Infection management for geriatrics in long-term care facilities. *Informa Healthcare USA Inc*. 2, 94-95.

Zubialde, J. P., Eubank, D., & Fink, L. D. (2007). Cultivating engaged patients: A lesson from adult learning. *Families, Systems, & Health, 25*(4), 355-366.