Prevalence, Characteristics, and Unmet Needs of Unbefriended Residents in Alberta Long-Term Care Homes

by

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Abstract

Background: Older adults who lack decision-making capacity and a willing or able surrogate to act as their representative are defined as unbefriended. These unbefriended older adults often require a public guardian and reside in long-term care (LTC) homes. Unbefriended LTC residents are at risk of poor quality of care, yet very little is known about this vulnerable resident population.

Purpose: The purpose of this dissertation was to assess the prevalence, characteristics, and potentially unmet needs of unbefriended residents in Alberta LTC homes.

Methods: This dissertation consisted of four linked studies: (1) a scoping review of the peer-reviewed and grey literature on unbefriended older adults; (2) a qualitative interview study of LTC staff and public guardians to identity the characteristics and unmet needs of unbefriended LTC residents; (3) a prevalence survey to assess the prevalence of unbefriended residents in all 172 Alberta LTC homes; and (4) a retrospective cohort study of health administrative data to further assess the prevalence, characteristics and health outcomes of unbefriended residents from a LTC home sample from Alberta.

Findings and Conclusions: Our findings demonstrated that there is little research on unbefriended older adults and no other Canadian studies or reports. Neither the United States (US) nor Canada systematically collect information on unbefriended older adults' characteristics or quality of care. Unbefriended LTC residents are socially isolated. Compared to LTC residents with family, they had lower social engagement, worse symptoms of depression, and more aggressive behaviours. Across two of our studies (interviews and administrative data), our findings indicated that unbefriended residents had significant mental health issues including diagnoses of depression, schizophrenia, and bipolar disorder. Unbefriended residents have

limited financial resources and have significant issues accessing personal care items and services. Our findings suggest that unbefriended individuals experience poor quality of care, particularly at the end of life. Public guardians visit unbefriended residents infrequently and are often unavailable when contacted by LTC staff. The public guardians' scope of work does not reflect the needs of unbefriended LTC residents, leaving the LTC staff responsible for providing the additional care and support. Unbefriended residents accounted for over 4% of all LTC residents in Alberta. Facilities with the highest proportion of unbefriended residents had more than 135 beds and were public-not-for profit. Unbefriended residents experienced more symptoms of depression, more frequent and severe pain, and exhibited more aggressive behaviours than residents with family. The findings from this dissertation indicated the unbefriended LTC residents have complex care needs and are vulnerable to poor quality of care.

Preface

Ethical approval to conduct the studies in Chapter 2, Chapter 3, Chapter 4, and Chapter 6 was received from the University of Alberta Research Ethics Board (Pro00071410) and the Northern Alberta Clinical Trials Research (PB74409). For Chapter 6, access to the RAI-MDS data was granted by the Translating Research in Elder Care (TREC) Data Management Committee and TREC Principal Investigator (C.A Estabrooks).

A version of Chapter 2 was published in the *Canadian Journal on Aging* (Cambridge University Press) and is published as 'Chamberlain, SA, Baik, S., Estabrooks, C. A. Going it alone: a scoping review of unbefriended older adults". I was responsible for the study conceptualization, analysis, drafting the article, and integrating feedback from the co-authors and article reviewers. S Baik supported the article review and extraction. CA Estabrooks contributed to the study conceptualization, drafting the article, and provided substantive feedback on manuscript drafts. Chapter 2 is an Open Access article, distributed under the terms of the Creative Commons Attribution licence (http://creativecommons.org/licenses/by/4.0/), which permits unrestricted re-use, distribution, and reproduction in any medium, provided the original work is properly cited.

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A version of Chapter 3 was accepted for publication in *Aging & Mental Health* (Routledge: Taylor & Francis Group) and is currently in-press as "Chamberlain, S.A, Duggleby, W., Teaster, P.B., Estabrooks, C.A. Characteristics and unmet care needs of unbefriended residents in long-term care: a qualitative interview study". I was responsible for the study conceptualization. I conducted the data collection, preliminary data analysis, and drafted the manuscript. C.A. Estabrooks supervised the data collection and analysis. W. Duggleby

contributed to data analysis and to revising the final manuscript. P.B. Teaster contributed to revising the final manuscript. All authors contributed to the development and revision of the manuscript.

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A version of Chapter 4 is submitted for publication in the *International Journal of Nursing Studies* as "Chamberlain, SA, Duggleby, W., Teaster, PB, Fast, J., Estabrooks, C.A. Making invisible work visible: a qualitative study of public guardians and long-term care staff caring for unbefriended residents in long-term care homes." I was responsible for the data collection, analysis, and drafting the initial manuscript. All co-authors contributed to the manuscript conceptualization and critically reviewed manuscript drafts. The copyright notice is not available because the paper has not been accepted for publication.

A version of Chapter 5 is under review at *Sage Open* as "Chamberlain, S.A., Duggleby, W., Teaster, P.B., Fast, J., Estabrooks, C.A. Incapacitated and alone: prevalence of unbefriended residents in Alberta long-term care." S.A. Chamberlain, C.A. Estabrooks, W. Duggleby, and J. Fast planned the study. I conducted the data collection and data analysis, and drafted the manuscript. C.A. Estabrooks supervised the data collection and analysis. W. Duggelby, J. Fast, and P.B Teaster contributed to data analysis and to revising the final manuscript. The copyright notice is not available because the paper has not been accepted for publication.

A version of Chapter 6 is under review at the *Canadian Medical Association Journal* as "Chamberlain, S.A., Duggleby, W.B., Teaster, P.B., Fast, J., Estabrooks, C.A. The extreme face of social isolation: a cohort study (2008-2018) of unbefriended individuals using Resident Assessment Data (RAI-MDS 2.0) in long-term care" I conceptualized the study with C.A. Estabrooks. I conducted the data analysis and drafted the manuscript. All authors contributed to drafting and revising the final manuscript. The copyright notice is not available because the paper has not been accepted for publication.

Chapter 7 of this dissertation is in preparation for publication in *Social Science & Medicine* as "Chamberlain, S.A., Duggleby, W., Teaster, P.B., Fast, J., Estabrooks, C.A. Examining unbefriended residents in long-term care through a framework of social exclusion: Results from a mixed methods study in Alberta, Canada." I conceptualized the paper and completed the initial draft. C.A. Estabrooks supported the study conceptualization and critical reviews of manuscript drafts. All authors provided critical reviews of manuscript drafts and provided substantive feedback.

Dedication

This dissertation is dedicated to all the unbefriended ones.

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I would like to acknowledge my supervisor, Dr Carole Estabrooks. She believed I could achieve more than any goal I ever set for myself. I did not always appreciate or trust her belief in my capabilities, but I am grateful for her steadfast encouragement. Any success I achieve will be owed in large part to her supervision. I would like to thank my committee members Dr Wendy Duggleby, Dr Janet Fast, and Dr Pamela Teaster. I am thankful for their time and energy throughout this process.

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Last but not least, my parents, Dave and Lori Chamberlain. I hope to carry their tireless work ethic for the rest of my life. My mother's work as a care aide in long-term care inspired this dissertation.

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Chapter 1. Introduction and overview

Worldwide the population is aging.[1] Increases in the number of older adults means a concurrent increase in the prevalence of age-related diseases such as dementia.[2] Dementia and other cognitive impairments can reduce decision-making capacity and increase the reliance on family and friend care.[3-5] Family and friends are a crucial source of support for older adults. Even after a loved one moves to a long-term care (LTC) home (also known as a nursing home or personal care home), family members provide significant support including assistance with personal care, social support, and medical decision-making.[6] Family members often act as an advocate when a resident is not able to communicate his or her preferences verbally.[7] However, not all older adults have family member support. Literature reviews on family involvement in LTC note that while there is a significant amount of research describing the types and impact of family involvement, there is limited research on residents without family member support.[7] Individuals, who for whatever reason do not have family or friend support and are incapacitated, are known as the unbefriended.[8-10] They do not have the capacity to make their own decisions and do not have anyone who is willing or able to act as a surrogate decision-maker. As a result, they often require the assistance of a public guardian. Unbefriended individuals are perhaps the most extreme case of social isolation, yet the least is known about them.[11,12] To our knowledge, there has been no Canadian research on this vulnerable population of LTC residents. The purpose of this dissertation was to assess the prevalence, characteristics, and unmet needs of unbefriended residents in LTC homes. This dissertation was planned and is presented in manuscript based format; there are 6 manuscripts in various stages from *published* to *in preparation*. These six outputs address **four research objectives:**

1. To identify and synthesize peer-reviewed and grey literature on unbefriended older adults.

2. To examine the characteristics and unmet care needs of unbefriended LTC residents using semi-structured interviews with key stakeholders in LTC and in the Office of the Public Guardian.

3. To assess the prevalence of unbefriended LTC residents by distributing an online survey.

4. To assess the prevalence, characteristics, health and functional status of unbefriended LTC residents using routinely collected Resident Assessment Instrument-Minimum Data Set, version 2.0 (RAI-MDS) data.

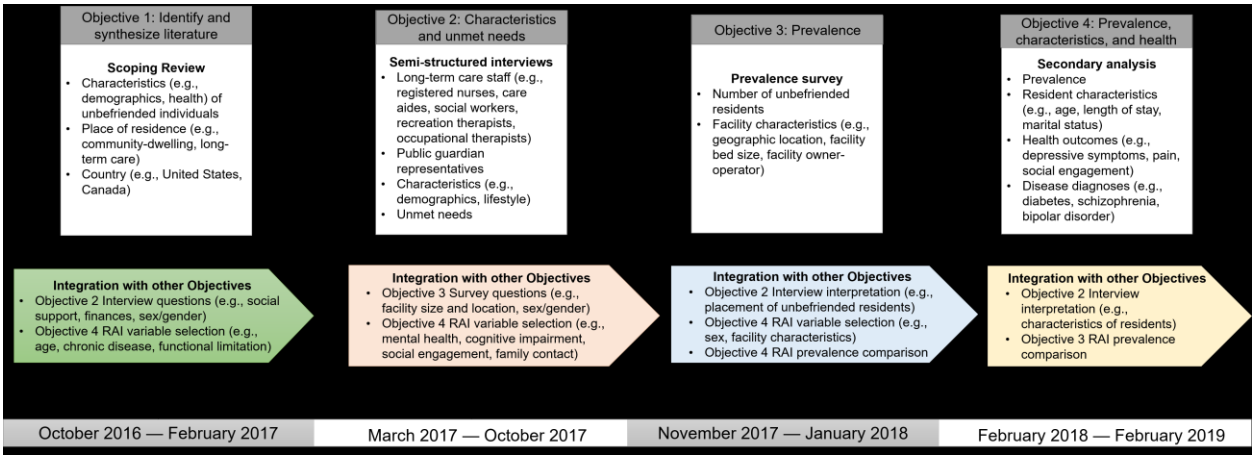

Figure 1-1 Dissertation timeline and activities

This dissertation utilized a mixed-method approach to obtain a comprehensive picture of unbefriended residents' characteristics and unmet needs. The majority of this dissertation used a convergent design, where qualitative and quantitative data were collected in a similar timeframe.[13] Integration of the qualitative and quantitative data occurred after the data collection was complete. This convergent approach allowed for the confirmation of findings from multiple methods to support the results of each other. As the data provide similar conclusions, the results have enhanced credibility.

The overall aim of this work was to contribute to theory and knowledge development regarding unbefriended older adults. This work aims to provide the first Canadian profile of unbefriended LTC residents and to demonstrate the importance of further scientific examination of this population in Canada. Furthermore, my goal was to produce research findings that would inform the development of policies that reflect the needs of this population and ultimately improve the practice of the individuals who provide care to unbefriended LTC residents. In this chapter, I begin with an overview of the concept of guardianship, gaps in current research, my

mixed-method approach, my conceptual framework, and my personal motivation for this research. I then introduce my dissertation, which is comprised of four integrated studies, each of which resulted in one or more manuscripts.

Guardianship in Canada

The legal presumption that individuals are capable of making their own decisions and therefore have the right to make decisions about their own person and property is a critical component of Canadian law.[14] However, when an individual is deemed incapable, the government must exercise their *parene patrie* role, one of legal protector of citizens unable to protect themselves. Proxy decision-making laws originated in 14th century England under the statue of *De Praerogative Regis*.[15] This law dictated that the state or sovereign was responsible for the property management of persons deemed incapable. Today, guardianship is the legal act of granting another individual, either in part or totally, responsibility for making personal or financial decisions for someone who is incapacitated.[10] In most cases, this individual who takes over legal guardianship is a family member or friend.[18,19] However, public guardians may be called upon to serve when family members or friends are unwilling or unable to assume guardianship.[8] Public guardians are employed by provincial or territorial Offices of the Public Guardian. Although intrusive, guardianship is a necessary legal mechanism to preserve rights and protect vulnerable persons from abuse and neglect.

In Canada, the responsibility for enacting laws related to adult guardianship rests with the individual provinces and territories. The first Office of the Public Guardian was established in Alberta in 1978.[14] Guardianship in Alberta is managed under the Alberta Guardianship and Trusteeship Act (AGTA), which came into effect in 2009 and replaced the Dependent Adults Act.[18] In Alberta, capacity is defined as an individual's mental ability to make decisions, and it is based on an assessment of the individual's ability to understand information that is relevant to a decision and to appreciate the foreseeable consequences of a decision. Personal decision-making legislation is assessed on a spectrum of need. A full guardianship order (i.e., public guardianship) is only invoked as a last resort. Public guardians have legal decision-making authority for incapacitated persons.[18] Public guardianship is at the intersection of the systems of legal, health, and social services.[14] Public guardianship must strike a balance between protecting individuals from harm and neglect and intruding on personal autonomy.

Research on Public Guardianship

Research on public guardianship is limited; however, what does exist points to significant issues in administrative oversight and quality of care. Public guardianship programs lack universal practice standards and the collection of robust guardianship data.[10] A national review of public guardianship programs in the United States found that education requirements for staff in public guardianship programs vary considerably, and there is enormous variability in public guardian caseloads.[19] This review suggested that the majority of individuals under public guardianship are institutionalized, either in mental health, group home, or LTC homes.[19] Yet, no research has been conducted that examines systematically the number and health outcomes of unbefriended individuals in LTC homes. Public guardianship in Canada has yet to garner significant research attention. However, it has emerged in the national media as an area of public concern. Recently, the Office of the Public Guardian in the Northwest Territories made national news for its extended waiting periods (up to a year) for guardianship applications and inadequate resources to deal with growing caseloads.[20] Reports from provincial Offices of the Public Guardian in New Brunswick and Nova Scotia indicate that they are unable to cope with any increased demand for guardianship services.[21,22] These provincial reports from Offices of the Public Guardian across Canada cited that the growing aging population is a central reason for increasing guardianship needs; however, these Offices do not systematically track the characteristics or health of their clients. Without systematic data collection on this vulnerable population there is little impetus for provincial governments to increase funding or services for Offices of the Public Guardian. This dissertation responds to the need to estimate the number of older adults under guardianship living in residential LTC settings, their characteristics, and unmet needs in order to help prepare the social service system for the growing aging population.

Theoretical framework

Just as research on unbefriended older adults is limited, so too are the theoretical frameworks with which to examine unbefriended individuals in LTC homes. To examine the health and unmet needs of unbefriended older adults I used a conceptual framework of *social exclusion*. The concept of social exclusion was first articulated in the 1970s by French sociologists to describe the responsibility of a government to its citizens.[23] Individuals working in the government were tasked with identifying groups of citizens who required, but were

excluded from social protections.[24] Social exclusion has since evolved from being solely associated with economic inequity to include the impact of inadequate social relationships. Morgan, Burns, Fitzpatrick, Pinfold, and Priebe [25] conducted a systematic review of the literature to identify a definition of social exclusion. They did not find a singular agreed upon definition. The dimensions of exclusion typically include economic exclusion, exclusion from civic participation, and exclusion from social relationships. Researching unbefriended older adults through a lens of exclusion enabled me to assess which dimensions of exclusion are relevant to unbefriended older adults in LTC homes, and if there are factors related to their exclusion that are not currently described in the literature.

There are no specific frameworks to examine unbefriended individuals; however, there are a number of conceptual frameworks developed to understand the social exclusion of older adults. Walsh, Scharf and Keating[26] conducted a scoping review of frameworks of social exclusion in older adults. Their review found that all of the frameworks reflected domains of social relationships, geographic or spatial exclusion, material or financial resources, and civic participation. Social exclusion frameworks had been used primarily in quantitative research for the development of statistical models that predict exclusion.[27] A significant limitation in the cited papers in the review is the inability to describe the linkages among the social exclusion domains. This is largely due to the lack of qualitative or mixed-method approaches.[28] Furthermore, all of the research conducted to date using the frameworks of social exclusion focused on community-dwelling older adults.[26] To my knowledge, no research has been conducted using a social exclusion framework for research focused on residents in LTC settings.

Guberman and Lavoie conceptual framework

In this dissertation I used the framework of social exclusion developed by Guberman and Lavoie.[29] Guberman and Lavoie's framework conceptualized social exclusion as including the following dimensions: economic, institutional, meaningful relations, socio-political, territorial, symbolic, identity. This framework was used to examine the care of unbefriended residents in LTC because these residents have a unique set of challenges specifically due to their guardianship status. Older adults under public guardianship lose civic responsibility for their personal and/or financial matters and thus have diminished citizenship (socio-political exclusion). Consequences of diminished citizenship specifically including the loss of personal

decision-making authority make it a central concept to unbefriended older adults. I chose Guberman and Lavoie's[29] framework because it offered a broad conceptualization of spatial exclusion, one that describes geographic freedom, confinement, or loss of control over an environment. A framework of social exclusion that includes a broad dimension of space can facilitate the exploration into location of residence (e.g., dementia unit, mental health unit, general LTC unit) for unbefriended residents in an institutional environment. Guberman and Lavoie's framework also included domains of identity and symbolic exclusion, which are not reflected in other social exclusion frameworks. Their dimensions of symbolic exclusion (negative representations of a group, or the invisibility of a group in society) and identity exclusion (dismissal or diminishment of the person or group through reduction to one identity) reflected negative representations of excluded individuals. Identifying whether, and how, unbefriended residents are represented in LTC can reveal staff representations of unbefriended residents and whether those representations influence care. My mixed-methods approach for this dissertation enabled me to articulate how the dimensions of exclusion manifested for unbefriended older adults in LTC settings, the linkages between the domains, and offer recommendations for future theoretical development of Guberman and Lavoie's framework.

Personal motivation

I was first drawn to the topic of unbefriended older adults after working as a care aide in LTC. As a care aide I witnessed firsthand the positive influence that family and friends had on resident quality of life. I worried about residents without family members but did not yet know how to address these concerns. My mother, a care aide herself, continues to work in the LTC facility where I began my training. Few weeks go by without hearing about the extra tasks the staff take on to fill in the gaps left by overburdened or unavailable family members. Although many of the staff—single mothers and women edging towards retirement—do not have excessive financial means or spare time, they share the task of buying clothes, toiletries, and treats for residents who are otherwise alone. My mother, and countless other care aides like her, are what motivate me to improve care for vulnerable residents. I am motivated by a desire to move these residents' unmet needs from individual care aide compassion to one of collective responsibility.

My decision to focus my dissertation on unbefriended LTC residents was solidified four years ago during a call with a representative from the Alberta Office of the Public Guardian and Trustee. I inquired about the number of older adults under public guardianship in Alberta and they were unable to give me a response. I asked if the Office experienced any challenges representing LTC residents, and they remarked that, on a daily basis they received calls from LTC staff requesting a guardian to drive a resident to an appointment or run an errand. When asked whose responsibility these tasks were, they had no answer. The aim of this dissertation is to answer the questions I posed four years ago and in doing so, to contribute both scientifically and practically to the care of this vulnerable population.

Dissertation objectives

The purpose of this research was to determine the prevalence, characteristics, health and unmet care needs of unbefriended older adults in LTC. I had **four objectives:**

1. To identify and synthesize peer-reviewed and grey literature on unbefriended older adults.

2. To use a social exclusion framework to identify dimensions of social exclusion that are relevant to the residents under public guardianship. I examined the challenges providing care to this resident population and described potentially unmet care needs using semi-structured interviews with key stakeholders in LTC and in the Office of the Public Guardian.

3. To assess the prevalence of unbefriended LTC residents and determine the robustness of RAI-MDS reporting by distributing an online survey to all LTC homes in Alberta.

4. To assess the prevalence (using a proxy in these data), characteristics and health. outcomes among unbefriended residents using routinely collected Resident Assessment Instrument-Minimum Data Set, version 2.0 (RAI-MDS) data from a LTC home sample in Alberta.

Objective 1

Study #1: Scoping review of the literature

The first study from this dissertation was a scoping review of the literature on unbefriended older adults. The purpose of the scoping review was to assess the scope of the available literature on unbefriended older adults. Specific objectives were to describe the characteristics (demographic and health) of unbefriended older adults, and to determine if Canadian literature existed on unbefriended older adults.

Objective 2

Study #2: Characteristics and unmet needs of unbefriended older adults

The second study from this dissertation was a qualitative study on the characteristics and unmet needs of unbefriended LTC residents. Specific objectives were to identify resident characteristics, their unmet care needs, and implications for quality of care and quality of life.

Objective 3

Study #3: Assessing the prevalence of unbefriended residents in LTC facilities

The third study from this dissertation was a prevalence study to assess the number of unbefriended residents in Alberta's LTC facilities. Specific objectives were to assess the number of unbefriended residents, if the residents were male or female, and assess characteristics of facilities with a higher prevalence of unbefriended residents.

Objective 4

Study #4: Assessing the clinical outcomes of unbefriended residents in LTC facilities

The fourth study from this dissertation was a secondary analysis of Resident Assessment Instrument, Minimum Data Set (RAI-MDS 2.0) data collected by the Translating Research in

Elder Care (TREC) program. Specific objectives were to further examine the prevalence estimates from Study #3 using routinely collected administrative data, assess the demographic characteristics, health, functional limitations, and disease diagnoses of unbefriended LTC residents in Alberta LTC facilities.

Ethics

Ethical approval for studies #2 to #4 were obtained from the University of Alberta Research Ethics Board (Pro00071410) and the Northern Alberta Clinical Trials Research (PB74409). For all of the qualitative interviews (Study #2) I obtained operational approvals from all participating LTC facilities prior to recruiting staff to participate in interviews. All LTC staff and Public Guardians completed informed consent. Access to the RAI-MDS data was granted by the Translating Research in Elder Care (TREC) Data Management Committee and Principal Investigator.

Methods and Outputs

Study #1

The method used in Study #1 was a scoping review. In Study #1, I searched 12 electronic databases for peer-reviewed and grey literature that described the characteristics (e.g., age, social support) or health of unbefriended older adults. Our search yielded 14,793 articles. We included five articles in our final sample that matched our review criteria.

Output

(Published)Chamberlain, S.A., Baik, S., Estabrooks., C.A. (2018) Going it Alone: A Scoping Review of Unbefriended Older Adults, Canadian Journal on Aging, 37(1), 1-11. doi: 10.1017/S0714980817000563

Study #2

The methods used in Study #2 were qualitative interviews. In Study #2, I conducted semi-structured interviews with 39 LTC staff and 3 public guardians. During the interviews, I asked participants to describe characteristics of unbefriended residents, challenges providing care

to this population, and if they had any unmet needs compared to residents with a family or friend guardian. I analyzed the interviews using content analysis. These interviews resulted in two papers.

Outputs

(In press) **Chamberlain, S.A**., Duggleby, W., Teaster, P.B., Estabrooks. C.A. (2019) Characteristics and unmet care needs of unbefriended residents in long term care. *Aging and Mental Health,* https://doi.org/10.1080/13607863.2019.1566812

(Submitted) **Chamberlain, S. A.,** Duggleby, W., Teaster, P.B., Fast, J., Estabrooks, C. A. (2019). Making invisible work visible: A study of public guardians and staff caring for unbefriended residents in long-term care homes. Submitted to the *International Journal of Nursing Studies*

Study #3

The method used in Study #3 was a cross-sectional online survey method. In Study #3, I distributed an online survey to senior leaders (e.g., directors of care/nursing, facility administrators) in all 172 Alberta LTC facilities. I collected information on the survey respondents' demographic characteristics, number of unbefriended residents in their facility, the sex (male/female) of unbefriended residents in their facility, and on facility characteristics (owner/operator, bed size, geographic region).

Output

(Under review) **Chamberlain, S.A.,** Duggleby, W., Teaster, P.B., Fast, J., Estabrooks. C.A. (2019). Incapacitated and alone: Prevalence of unbefriended residents in Alberta long term care. *SageOpen*

Study #4

The method used in Study #4 was a secondary analysis of resident assessment instrument data collected for the Translating Research in Elder Care (TREC) program. Data came from a sample of 24,462 residents in 34 LTC facilities in Alberta.

Output

(Submitted): **Chamberlain, S. A.,** Duggleby, W., Teaster, P.B., Fast, J., Estabrooks, C. A. (2019). The extreme face of social isolation: A cohort study (2008-2018) of unbefriended individuals using Resident Assessment Data (RAI-MDS 2.0) in long-term care. To be submitted to the *Canadian Medical Association Journal*

Tying the four studies together: theoretical paper

The purpose of this theoretical paper was to determine whether Guberman and Lavoie's framework domains of social exclusion were relevant to unbefriended LTC residents and whether new concepts were needed to understand exclusion in this resident population. Drawing on findings from all four studies, I argued that Guberman and Lavoie's framework required the addition of concepts from complex adaptive systems theory to account for and understand the organizational processes that contributed to unbefriended residents' exclusion.

Output

(In preparation) **Chamberlain, S. A.,** Duggleby, W., Teaster, P.B., Fast, J., Estabrooks, C. A. (2019). Examining unbefriended residents in long-term care through a framework of social exclusion: Results from a mixed methods study in Alberta, Canada. To be submitted to *Social Science & Medicine*

Conclusion

In this chapter, I provided background on my thesis topic, objectives, and rationale. Subsequent chapters (2-7) contain the manuscripts that represent the outputs of this dissertation. Each manuscript reflects the linked studies described in this chapter. The final chapter of this dissertation contains: a summary of the findings, main conclusions drawn from each study, main limitations, contributions this research makes to knowledge, theory, practice and policy, and the next steps in my research program to improve the quality of care for vulnerable older adults.

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Chapter 2. Paper 1- Going it alone: A scoping review of unbefriended older adults

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Background

Worldwide the population is aging with nearly 900 million people over the age of 60.[1] As the population of older adults swells so too does the prevalence of age-related diseases such as Alzheimer's disease and other dementias.[2] Advanced age and cognitive impairment result in reduced decision-making ability.[3-5] Family members or friends may intervene and act as a guardian if an older adult is deemed incapable of managing his or her personal well-being and/or finances.[6] However, not all older adults have a family member or friend available to act as their guardian. Changes in geographic mobility, family structure, childlessness [7-9] and being 'single for whatever reason'[10,11] have a negative impact on the availability of family members to act as guardians for older adults. Older adults are 'unbefriended' if they lack decision-making capacity, lack an advanced directive and the ability to execute the directive, and lack a family member or a friend to act as their representative.[12-14] The term 'unbefriended' originated in the medical ethics literature and continues to be used as a term to denote any adult who does not have decision making capacity, has no family or friends, or has family members or friends who are either unable or unwilling to assist with health decision-making.[15,16] Unbefriended older adults require a public guardian. This article synthesizes the literature regarding unbefriended older adults, that is, those under public guardianship. Specifically, our scoping review describes the scope, study methods, geographic location of available empirical literature and identifies characteristics (demographic, health) of unbefriended older adults.

Guardianship

Principles of guardianship come from the legal tradition of *parens patriae,* the duty to protect persons who cannot care for themselves.[17-20] Guardianship is a broad description of legal mechanisms that grant authority for managing personal and/or financial responsibility in the event an individual is incapacitated. Guardianship is one of the most restrictive actions that can be taken to limit legal rights.[21] It removes an individual's right to vote, travel, determine own residence, or consent to medical treatment.[22] Guardianship effectively *de-persons* the individual—removing them of all adult rights and responsibilities.[18,23,24] Adults (18+) who are under guardianship are typically older, female, have multiple chronic conditions, and are socially isolated.[25-29]

Guardianship research does not always distinguish between different types of guardians. Guardians can be either private (family member or friend) or public (government, voluntary agency, paid service).[30] Public guardianship is the legal appointment of a public official or organization to assume decision-making responsibility when a family member or friend is either unavailable or unwilling.[18] Approximately 25 to 30 percent of guardianship petitions are for public guardians, and the remainder for a family member or friend.[21,31-34] Within the guardianship literature, public guardianship has received significantly less attention.[33] As a result, much less is known about individuals under public guardianship, which is troubling given that the restriction in autonomy as a result of public guardianship places individuals at heightened risk of abuse or neglect.[35]

Public Guardianship: United States and Canada

The role of public guardian varies based on the country of origin. In the US, public guardians might be volunteers, agencies, or attorneys. In Canada, each province has their own Office of Public Guardians and/or Trustees and is typically associated with branches of provincial government. In England, the Office of the Public Guardian is an executive agency of the Ministry of Justice and will appoint panel deputies —typically lawyers and social service agencies—who act on behalf of the person who lacks capacity.[36] Although the concept of a public guardian exists in many countries, the research on public guardianship has been concentrated in the United States (US). Schmidt, Miller, Bell, New [37] conducted the first US national study of public guardianship. They found the majority of persons with a public guardian were over 65, female, low income, and living in a long term care facility or mental hospital.[37] Interest in unbefriended older adults emerged in the US in the late 1980's following an investigative reporting series by the Associated Press. At that time (1987) the Associated Press estimated that approximately 400,000 unbefriended older adults in the US. Their reporting raised substantial concerns about the quality of care provided to unbefriended older adults, highlighting rampant ageism, abuse, and neglect.[31] The Associated Press series triggered nearly 20 years of reform and scholarship into the US guardianship system. Currently, US public guardianship programs are funded through some combination of court, state office, social service agency, or local municipality/county funding.[33] In the majority of US states (n=34) public guardianship programs are managed through a social service agency. Public guardianship through a social service agency introduces significant potential for conflict of interest. When an agency or

program is both providing services and acting as a guardian and advocate, this could lead to unnecessary or undesired use of services by the person under guardianship.[33] On the other hand, it could result in the denial of necessary services when cost cutting is mandated.

Canada has a significantly different public guardianship system than the US. Since Canada's guardian and trustee system is managed at the provincial government level it is akin to the US independent state agency model. In Canada, three provincial Offices of the Public Guardian operate as special operating agencies or sole custodians (Manitoba, British Columbia, New Brunswick) under agreements with provincial departments. Operating as a special operating agency or sole custodian means that Offices function separately from the government and these Offices can sue or be sued on behalf of clients; this organizational structure is meant to facilitate external monitoring, and oversight. The purpose of this scoping review was to review the peer-reviewed and grey literature to assess the scope of the available literature on unbefriended older adults. We aimed to describe the characteristics (demographic and health) of unbefriended older adults. In this review we determine if Canadian literature exists, and discuss implications for policy and practice.

Methods

We conducted a scoping review to assess the types of evidence available and address the gaps in existing literature regarding unbefriended older adults.[38,39] A scoping review was appropriate to address the range of available research on the topic of unbefriended older adults and enabled us to address the need for future research in this field of inquiry.[40] A scoping review is a synthesis method used when the research question is broad in scope and contains a range of different study designs.[39,41,42] We conducted our scoping review based on the process developed by Arksey and O'Malley[39] and later refined by Levac, Colquhon and O'Brien[40]. The five stages of a scoping review as described by Arkey and O'Malley[39] are: (1) developing the research question, (2) searching the literature, (3) study selection, (4) data charting, and (5) data synthesis and summary. Our research question focused on a descriptive analysis of unbefriended older adults. We were unable to conduct quality assessments as was suggested by Levac et al[40] of the final included results due to highly disparate study designs and the descriptive nature of the final articles. We did include a section in our discussion describing necessary empirical directions for future research efforts and the utility of the research in policy and practice.[40]

Search Strategy

The search strategy and key words were developed in consultation with a university health sciences librarian. The research librarian assisted in developing and refining the search strategy. We conducted the search using combinations and synonyms of the core concept keywords for "unbefriended" and "older adult". We used the Boolean term "OR" when searching within core concepts, and "AND" to combine core concepts. An exemplary search strategy from the Medline database can be found in Table 2-1.

[Table 2-1 here]

Study Inclusion and Exclusion Criteria

We included studies that were focused on unbefriended older adults. The study needed to include older adults who did not have a family or friend representative. We included only those studies that were available in English and were published after 1991. We excluded studies that did not include older adults (defined here as those 60+). We excluded studies with mixed-samples where data regarding the older adults could not be isolated from the larger sample. We excluded editorials, commentaries, and opinion articles.

The review was conducted from October to November 2016. We searched 12 electronic databases: Medline, CINAHL, PsychInfo, Cochrane Library, Abstracts in Social Gerontology, Family Studies Abstracts, Scopus, Web of Science Core Collection, Pubmed, Social Work Abstracts, SocINDEX, and Legal Source. Grey literature sources included ProQuest dissertations, and relevant conference programs (e.g., Gerontological Society of America Annual Conference, Canadian Association on Gerontology Annual Conference, National Conference on Guardianship, World Congress on Adult Guardianship). We searched the grey literature with the same search terms. All search results were exported and stored in Zotero, an online citation software program. Once the searches from each database were completed and compiled all duplicates were removed. We completed ancestry searches of all the full-text paper reference lists.

Study Selection

We considered studies that described the characteristics (e.g., age, socioeconomic status, social support) or health of unbefriended older adults. We defined a person who was unbefriended (also described as a 'ward', 'conservatee' in the literature), as someone who is unable to meet their own personal health needs and/or manage the essential aspects of personal financial resources, and who has no willing or able family member or friend to act as their guardian [23]. We conducted a two-stage study selection process. In the first stage, two of the paper authors (SC and SB) reviewed study titles and abstracts to assess if the article met the identified inclusion and/or exclusion criteria, or if the full text study was needed to determine study applicability. Both reviewers labelled an abstract to include for further review as either 'Yes', 'No', 'Unsure'. Discrepancies were resolved by consensus and all titles without an abstract or abstracts labelled as 'Unsure' were carried forward to the full text review. The second stage consisted of two team members (SC and SB) independently reviewing all of the full-text articles. To begin, the reference lists from the full-text articles and grey literature were searched for articles not yet included in the review. Differences in the decision to include a study for full-text review were resolved by team discussion and consensus. Further review of the full-text articles in relation to the inclusion and exclusion criteria led additional articles to be rejected before data charting. Two team members separately charted the data from the final included studies and then came together to determine the appropriate information to be extracted from the studies. Authors SC and SB completed the data extraction and synthesis. We analyzed a final number of five articles. A summary of the collected information from the full text articles including: authorship, study design, setting/location, sample/subjects, number under guardianship in study sample, older adult characteristics, comparison group (if any), and statistical analysis, can be found in Table 2-2.

[Table 2-2 here]

Results

Our search yielded 14793 articles once duplicates were removed. After title and abstract screening we assessed 185 full text articles. We excluded 180 articles because they did not meet the review criteria. Of all the studies that we excluded, the largest number (n=62) were excluded because they focused on family and friend guardians and not public guardians. We excluded

(n=43) studies because they did not provide any description of demographic characteristics or health outcomes. Studies were excluded because they did not provide any empirical research and rather discussed the challenges and legal implications of public guardianship (n=21). We excluded (n=17) studies that described the characteristics and health outcomes of unbefriended adults, however information about the older adult participants could not be isolated from the larger sample. We excluded three studies because the full text was not available in English (Japanese=2, German=1).

Figure 1 shows the search, screening, and final selection process. Our search and review resulted in a final total of five papers that matched our review criteria.

[Fig 2-1 here]

Of the five articles included in the final sample, one study was conducted in long term care, one reported on data collected from state or county legal records, and three collected information from a state or regional office of the public guardian. All of the included studies were conducted in the US and were published between 1993 and 1999.

Discussion

Our scoping review of unbefriended older adults revealed an exceptionally small body of peer-reviewed and grey literature. Three studies used information collected from county legal records and case files, however they varied in state of origin. We found only one study that included older adults from long term care, which provided minimal description of the characteristics of those residents without a family or friend guardian.[43] Our results indicated that between 29 and 42 percent of older adults in the study samples were unbefriended.

Characteristics of Unbefriended Older Adults

Our findings suggest a grim picture of unbefriended older adults. They are more likely to be single, childless, have fewer siblings, and limited financial resources when compared to older adults with a family or friend guardian.[15,22] Unbefriended older adults often have a diagnosis of a dementia or related cognitive impairment and multiple chronic diseases.[44-46]

Our scoping review results suggest that at this time there is little value added by or adequate literature with which to conduct a systematic review on the characteristics or health of

unbefriended older adults. Empirical research is extremely limited. Studies included in the review demonstrate disparate methods and outcome measures that leave us unable to make any meaningful comparisons between the studies. Our results emphasize the erratic and sparse literature base for this population of unbefriended individuals.

Our findings reveal an alarming lack of data on those residents who are unbefriended and living in institutional settings such as long term care. Public guardianship imposes significant limitations on the older adult's ability to decide location of residence, and when coupled with mental and physical limitations, means these individuals are likely to live in a long term care facility.[44,46] Although research reports indicate that once older adults are placed under public guardianship they are more likely to be transferred to long term care.[22,44,47], we found only one study specifically examining long term care residents.[43]

Research efforts that examine the health and care provided to unbefriended older adults should be directed at long term care facilities.[30] However, since no state or provincial records indicate location of residence, we are unable to discern who is providing care to this vulnerable population and if there are gaps in quality of care. Unbefriended older adults are exceptionally vulnerable to poor quality of care due to inadequate family or friend support.[48,49] Without reliable information on the location of residence for these older adults, we are unable to identify who is providing their care and if they are receiving quality care. Farrell, Widera, Rosenberg, Rubin, Naik, Braun, Torke, Li, Vitale, Shega, the American Geriatrics Society Clinical Practice and Models of Care Committee [14] recommended that future research is needed to better quantify the number of unbefriended older adults across different care settings (e.g., community, acute, long term care). Limited empirical research and an inability to track the location of residence for unbefriended older adults reflects a significant gap in our knowledge and an opportunity for future research that would inform policy.

Our review located *no Canadian studies or reports*. Since our review found no Canadian studies or reports on the characteristics or health of unbefriended older adults, we have no idea how Canada may or may not compare to the US. Discussions with several provincial policy analysts from the Office of the Public Guardian in Alberta suggest that the Canadian population of unbefriended older adults likely does not differ substantially from those in the US. However, given our lack of reporting on these older adults in Canada, we are unable to substantiate these

claims or make meaningful comparisons. Recently, the Office of the Public Guardian in the Northwest Territories made national news for its extended waiting periods (up to a year) for guardianship applications and inadequate resources to deal with growing caseloads.[50] Reports from Offices of the Public Guardian in New Brunswick and Nova Scotia indicate that with their current budgets and staffing levels they are unable to cope with any increase in demand for guardianship services.[51,52] Further inquiry is imperative to establish the number of older adults requiring guardianship services in Canada and prepare the social service system for the growing aging population.

All of the included studies that described the characteristics or health of unbefriended older adults were cross-sectional. Future research should focus on longitudinal assessments of health and identifying unmet care needs of this population of older adults.[44] Our findings raise important questions not answered by the available literature. There is an obvious and troubling gap in the research regarding unbefriended older adults and their unmet care needs. Research in the nineteen eighties and nineties suggests that these individuals have limited contact with their public guardian.[53] In the last twenty years little insight has been gained on the frequency or quality of interactions between the public guardian and the individual under guardianship, or its influence on quality of life and quality of care. National reports in the US indicated that guardians have enormous and variable caseloads (even as high as 1 guardian for 341 persons under guardianship.[19,30] Linking information about caseload, visiting frequency, and type of guardianship activity with individual health outcomes is an essential step in determining appropriate policy and practice recommendations.

Implications for Policy and Practice in Canada

In both the US and Canada a lack of state or provincial coordination has resulted in variability in (negligible) national reporting and inconsistent regional oversight. Results of this review demonstrate that those unbefriended older adults may have a number of health and social limitations, potentially leading to poor quality of life. Given the provincial administration of public guardianship and the challenges collecting even basic demographic information, analysis of health and quality of care of unbefriended older adults could focus on those already available sources of data. Throughout most of Canada the Resident Assessment Data Minimum Data Set (RAI-MDS 2.0) is used to routinely collect personal and health information about residents living in long term care. This instrument offers an opportunity to assess the prevalence and health outcomes of residents who do not have family or friend guardians. The items that assess the presence of family or public trustee are not mandatory to complete, resulting in an underestimation of unbefriended older adults in the RAI-MDS. Although the RAI-MDS likely underestimates unbefriended long term care residents, it is collected across Canada and could allow us to examine unbefriended residents' clinical and functional status, which is currently not possible with data collected by provincial Offices of the Public Guardian.

Offices of the Public Guardian can serve in a variety of substitute decision-making roles, not only as public guardians, but also as powers of attorney, trustee, and other more limited decision-making capacity roles. Future research could examine the different types of guardianship and link it with demographic characteristics and services to determine if there are groups who are using certain services with greater or lesser intensity. This would contribute to improved organizational planning and policies that reflect the groups that are most frequently using various guardianship services.

Strengths and Limitations

Our scoping review was completed with the assistance of a health science research librarian. We conducted an ancestry analysis from the full text peer-reviewed articles and reports to ensure that all available literature was reviewed. We were limited to English language publications and as a result excluded three studies. Title assessment and abstract assessment was restricted to guardianship and older adults, which may have limited articles that were not explicit about their population. Guardianship models and terminology vary among different states and

countries.[30] If a paper did not explicitly describe the guardianship status as public or a situation where an individual did not have a family member or friend guardian, we were unable to include it in our findings. We did not report demographic characteristics for samples that were not specifically described for older adults.

Conclusion

We found limited peer-reviewed literature describing the prevalence and characteristics of unbefriended older adults. All of the literature concerning public guardianship was US based. This review reveals troubling gaps in the reporting of guardianship status. This is a population that is likely to grow and longitudinal studies on health and care needs are needed to examine the potential health impact of unbefriended older adults. Without studies of characteristics or health outcomes we are unable to adapt our continuing care to meet the needs of this unique population. Although this group of older adults – the unbefriended – arguably constitute the highest risk group of older adults, there is no population level data on this population in Canada.

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Table 2-1: Exemplary search strategy

MEDLINE (1946 to Present) via OVID: Includes MEDLINE(R) In-Process & Other Non-Indexed Citations

#	Search Terms
1	exp Aged/
2	((gerontolog* or older adult* or elder* or senior* or geriatric* or aged). af.
3	1 and 2
4	exp Legal Guardians/
5	exp Decision Making/
6	exp Third-Party Consent/
7	(advocat$ or legal$ guardian$ or surrogate$ decision maker$ or decision making$ or no surrogate$ or incapacitate$ or unrepresent$ or public guardian$ or conservator$ or unbefriend$).mp
8	4 or 5 or 6 or 7
9	3 and 8
10	exp Health Behaviour/ or exp Health Status Indicators/ or exp Health Status/ or exp Health Services/ or exp Health Services for the Aged/
11	9 and 10
12	11 and 1991:2016. (sa_year)

Table 2-2: Study characteristics

Author, Journal, Year	Study Design	Setting, Location	Sample, Subjects	Proportion of OA without Family or Friend Guardian in Total Sample	Sample Demographic Characteristics	Statistical Analysis
Janofsky, *Journal of Geriatric Psychiatry & Neurology*, 1993	Cross-sectional survey	Nursing home (*n* = 1) Country: USA	Emergency contact or family member of resident (*n* = 191 respondents)	*n* = 63 residents lacked durable power of attorney or guardian Prevalence = 33%	*n* = 46 (73%) were not considered mentally capable of decision-making *n* = 16 (25.4%) were considered mentally capable of decision-making	None
Teaster, dissertation, 1997	Qualitative interviews, document review	Qualitative interviews, document review of court petitions, and case files from older adults under public guardianship Country: USA	Case files from older adults included in qualitative interviews and observations (*n* = 19)	NA	*n* = 10 (52.6%) able to communicate verbally *n* = 9 (47.4%) unable to communicate verbally Average age = 80.7 years *n* = 13 (68.4%) lived in a nursing home, 1 (5.5%) in hospital, 1 (5.3%) in own home, 3 (15.8%) in group home, 1 (5.5%) home for adults *n* = 10 (52.6%) have a dementia All had at least one major medical diagnosis; the average number of major medical diagnoses was 3+	NA
Author, Journal, Year	**Study Design**	**Setting, Location**	**Sample, Subjects**	**Proportion of OA without family or friend guardian in total sample**	**Sample Demographic Characteristics with Comparison Groups**	**Statistical Analysis**

Reynolds, *Aging and Mental Health*, 1997*	Cross-sectional survey	Records from Los Angeles County Department of Mental Health's Office of Public Guardian Country: USA	Wards who were 70+ (*n* = 623) Total # of records: *n* = 2,151	*n* = 623 older adults under public guardianship Prevalence = 29%	**Public Conservatees vs. Nationally Representative Sample of Older Adults** Age 85+: Public = 30.2%; National = 13.6% Married: Public = 6%; National = 54.9% Single: Public = 38%; National = 2.9% Separated or divorced: Public = 19.8%; National = 5% Childless: Public = 73.2%; National = 14.9% No Siblings: Public = 71.3%; National = 23.6% High School Graduate +: Public = 65.1%; National = 55.9% Wealth (None): Public = 31.9%; National = 6.5% Real estate value (None): Public = 83.2%; National = 25.5%	Pearson chi-square $p < .05$ reported
Reynolds, *Aging and Mental Health*, 1999	Cross-sectional survey	Court records in two counties Country: USA	*n* = 406 court files	*n* = 167 had family guardians *n* = 147 had professional guardians Prevalence = 41%	**Public Conservatees vs Family Conservatees** Age (mean): Public = 74.26; Family = 63.45 With Spouse (Yes): Public = 7.60%; Family = 20.2% Number of children: Public = 0.29; Family = 0.96 Number of siblings: Public = 0.41; Family = 0.71	Pearson chi-square $p < .05$ reported

Reynolds, *Research on Aging*, 1997	Cross-sectional survey	Records from Los Angeles County Department of Mental Health's Office of Public Guardian Country: USA	Wards who were 60+ (*n* = 894) Total # of records: *n* = 2118	42.2%	**Older (60+) vs. Young (<60)** Female: Old = (0.63); Young = (0.33) Married: Old = (0.06); Young = (0.04) Single: Old = (0.39); Young = (0.74) Widowed: Old = (0.24); Young = (0.01) Divorced/Separated: Old = (0.29); Young = (0.18) Indications of Severe Disability: Old = (0.35); Young = (0.14) ADL Impairments: Old=(2.56); Young = (0.14) Diagnosis of schizophrenia or other psychosis: Old = (0.28); Young = (0.74) Diagnosis of dementia/OBS: Old = (0.46); Young = (0.05)	No tests for significant differences; Conducted regression model with age as predictor of placement in locked facility

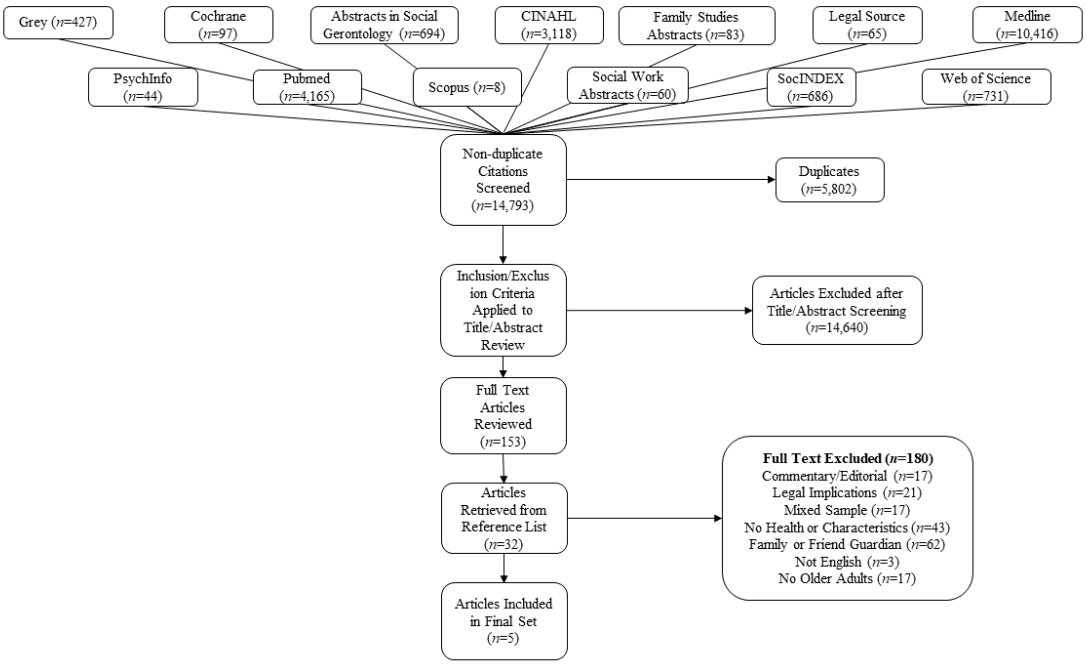

Figure 2-1. Review search strategy of included and excluded studies

Chapter 3. Paper 2- Characteristics and unmet care needs of unbefriended residents in long-term care: A qualitative interview study

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Introduction

'Unbefriended' is a term for individuals who lack decision-making capacity and a family member or friend who is a willing or available surrogate decision maker.[1,2] Although the term has negative connotations, it is used throughout the medical and bioethics literature.[3] Unbefriended individuals often require a public guardian (PG). Public guardianship is the legal mechanism of appointing a PG responsible for personal decisions (e.g., healthcare, living situation) when a family member or friend is unavailable or unwilling to become the decision maker.[4] In Canada, PGs are employees of provincial Offices of the Public Guardian and Trustee. In the United States, PGs are a mix of private and for-profit and might be employed by agencies, volunteer organizations, or law firms. Regardless of the country, PGs are the legal decision-maker for individuals who are incapacitated and alone. Unbefriended individuals are likely to live in a long-term care (LTC) facility due to physical or cognitive impairments.[5,6] US studies suggest that 3% to 4% of LTC residents are unbefriended.[3,7] Numbers and characteristics (e.g., demographics, health conditions) of unbefriended individuals living in residential LTC in Canada are difficult to obtain.[8] However, the unbefriended population will likely grow with increases in life expectancy, dementia, geographic distance of family, and decreased social networks.

Unbefriended individuals are disproportionally older adults.[3,4,9] Other groups at risk include individuals with disabilities, the homeless, and individuals with stigmatizing medical conditions (e.g., HIV/AIDS).[3] The unbefriended are the most vulnerable members of society, yet we know the least about their quality of care or quality of life.[10] Teaster [9] conducted one of the only studies that interviewed individuals under public guardianship. Unbefriended individuals expressed loneliness and social isolation. We conducted a scoping review of the public guardianship literature and were unable to identify any Canadian data on the characteristics or potentially unmet needs of unbefriended older adults.[8] Although many unbefriended individuals live in LTC facilities, we do not know the consequences of public guardianship on their quality of care or quality of life.[1] The purpose of this study was to understand the characteristics and potentially unmet needs of unbefriended LTC residents in the western province of Alberta, Canada.

Methods

Sample and Recruitment

This study is a cross-sectional qualitative descriptive study. We analyzed data from qualitative interviews conducted between March 2017 and September 2017 with 39 LTC staff and 3 PG from Alberta, Canada (Table 3-1). Using convenience and purposive sampling methods, we interviewed a variety of care provider types to examine their experiences working with residents who have a PG. Our sample included a higher number of care aides and regulated nursing staff because they are the predominant workforce in Canadian LTC facilities. We recruited 7 facilities by emailing facility chief operating officers and administrators a one-page summary of the research. These 7 facilities were located across 3 (of 5) Alberta regional health zones. The facilities were a mix of *for profit* and *not-for-profit* ownership models (5 for-profit, two not-for-profit). We recruited LTC staff by contacting directors of care in LTC facilities and asking them to circulate our project description to their staff. Once contacted by the director of care, staff gave permission to be contacted for an interview. All participants provided informed consent prior to initiating an interview. We contacted the provincial Office of the Public Guardian and Trustee to recruit PGs. To maintain the privacy of the LTC staff and PGs who chose not to participate, we did not record the names of people who were approached or who declined. LTC staff were eligible to participate if they were staff of the LTC facility (e.g., casual, part-time, full time), and had worked in the facility at least three months. Agency staff were not eligible to participate. PGs were included if they had clients in LTC facilities and had worked in their role at least three months.

Data Collection

All of the interviews were conducted by SC, she is a PhD candidate trained in qualitative research by her supervisor (CE) and members of doctoral committee (WD). Other authors (CE, WD) assisted in the interview guide development. Following informed consent, we conducted telephone and in-person interviews (17 to 45 minutes duration). Forty participants completed in-person interviews. Two participants, a director of care and a PG, completed telephone interviews. All in-person interviews with LTC staff were conducted in the LTC facility where they worked. Interviews and field notes were audiotaped and professionally transcribed.

Interview Guides

The interview guides were semi-structured, and each guide included structured questions about participant demographics (e.g., age, sex, education) and job characteristics (e.g., time in role, time in organization). Open-ended questions were focused on describing characteristics of unbefriended residents (e.g., age, medical conditions), their quality of life, their quality of care, and any unique challenges staff and public guardians experience caring for unbefriended residents.

Rigor

Data collection and analysis incorporated best practices in rigor and trustworthiness.[11,12] These practices include: pre-testing interview guides, reviewing transcripts and audio files, soliciting feedback from interview participants, developing a transcription protocol, and utilizing a rigorous coding and review process. To ensure rigor, we pre-tested the instrument to ensure the questions were appropriate and clear. We piloted the interview guide with 3 LTC staff and then made minor modifications to the order of the questions. The interviewer posed additional questions and probes for further clarification as an interview progressed. One team member (SC) reviewed all of the transcripts and audio files as they were received to ensure quality and consistency. We were unable to pilot the PG interview guide due to challenges recruiting PGs. We conducted three in-person feedback sessions in November and December 2017 with the interview participants to provide feedback on the study results and present the categories and sub-categories developed in the analysis. During our in-person feedback sessions we provided a paper copy of the one-page study summary sheet and a complete list of the categories and sub-categories from the content analysis. There were no changes to the major categories or sub-categories following these sessions.

Ethics

We received research ethics board approval from the University of Alberta (Pro00071410) and the Northern Alberta Clinical Trials and Research Centre (PB74409). We obtained operational approvals from all participating LTC facilities prior before recruiting staff to participate in interviews. All LTC staff and PGs completed informed consent prior to beginning their interview and as the interview progressed.

Analysis

We analyzed interviews using content analysis.[13] Content analysis is a method for interpreting text data through a classification process of coding and identifying categories or themes. The inductive analysis was undertaken in a series of steps during the interview process. One team member (SC) reviewed all of the transcripts and audio files as they were received to ensure quality and consistency. SC completed the initial coding of the first six interviews. CE reviewed the coding of the first six interviews, and codes were updated accordingly. SC coded the next four transcripts using the revised coding categories and CE reviewed. The coding was further refined, with sub-categories grouped under major categories. The study team reviewed the categories, sub-categories and codes. The final categories were reviewed and agreed upon by the rest of the study team. Categories were grouped under a major theme and included sub-categories (where applicable). An audit trail using memos was kept regarding the analytical decisions made. We used NVivo 11 qualitative data analysis software to organize interview transcripts, codebook, and field notes and to code.[14,15] We assessed saturation based on completed descriptions of categories and sub-categories.[16]

Results

We interviewed 39 LTC staff and 3 PG about their experience with unbefriended LTC residents. Most participants were female (93%) and over 40 years of age (54%) (Table 3-1). LTC staff had worked on average 7 years in their current position and PGs 3 years. We identified 3 themes, 5 categories and 9 sub-categories (Table 3-2). The first theme described the characteristics of unbefriended residents and was categorized based on the residents' previous lifestyle and their clinical characteristics. The second theme described unbefriended residents' unmet needs due to their guardianship status. This theme was composed of the categories social support and financial support. The third theme described unbefriended residents' quality of care. This theme was composed of the category of goals of care.

[Table 3-1 here]

Characteristics of Unbefriended Residents

Lifestyle

LTC staff and PG described most unbefriended residents as marginalized individuals who had been homeless and who lived for some time with mental health issues (e.g., schizophrenia, bipolar disorder) and alcohol or substance use. A small proportion of unbefriended residents were not marginalized and had productive careers but had never married or were childless. This latter group often lived a significant geographic distance from any remaining family. A PG described her perception of the unbefriended population in LTC:

> Traditionally, those clients [unbefriended] used to be an older individual in their late seventies, early eighties who had some form of dementia, who for whatever reason didn't have any family…Over the last 15 to 20 years, the population has changed. The acuity and the complexity of the care needs—physical, as well as psychosocial care of those individuals has increased. The clients that we represent in the continuing care centers tend to be older adults with some form of dementia. But we're getting a much higher rate of clients with mental illness as well and behavioral concerns. We're starting to get people that have used drugs earlier in their life and have reached the point where their brain is no longer functioning. (PG #1)

Unbefriended residents had limited or no social support. All LTC staff and PGs interviewed described unbefriended residents as having no known or only estranged family or friends. Estrangement often resulted from a lifetime of mental illness or substance use. LTC staff in 2 facilities described unbefriended residents who had family only at significant geographic distance. Six LTC staff (1 occupational therapist, 2 directors of care, 1 registered nurse, 1 care aide, 1 social worker) described a subset of unbefriended residents with a family member or friend in their life whose involvement negatively affected the resident. Interviewees described cases of family members removed as guardians following suspected resident abuse. One said:

> The ones that haven't burnt bridges, or have had bridges burnt for them, have often suffered elder abuse. (Occupational Therapist, Facility #4)

One director of care recently suspected that a family member was financially abusing a resident. By the time she and a social worker had initiated guardianship proceedings, the family member had removed significant amounts of money from the resident's accounts leaving the

resident unable to pay for necessary personal items. That director of care considered public guardianship an essential system to protect residents who might not have a trustworthy advocate.

Clinical Characteristics and Diagnoses

Interviewees described most unbefriended residents as having a dementia or likely having had a traumatic brain injury. We interviewed LTC staff in 1 facility that also included a young adult unit whose unbefriended residents had had brain injuries in accidents. LTC staff described notable behavioral differences between unbefriended residents and residents with family member or friend guardians. Four direct care staff (2 care aides, 2 recreational therapists) described unbefriended residents as attention-seeking and gravitating toward other residents visiting family members. Staff believed that the attention-seeking behavior was from profound loneliness and social isolation:

> Sometimes they'll just be a little bit needier, because they don't have that…they need some sort of interaction and any attention's good attention. (Care aide, Facility #3)

Care staff indicated that the combination of cognitive impairment, health and mental issues, and previous lifestyle (e.g., homelessness, substance use) resulted in unbefriended residents exhibiting paranoia and mistrust. Unbefriended residents often displayed significant responsive behaviors of dementia (e.g., physical or verbal aggression). All PGs interviewed—2 with a background in social work— speculated that LTC facilities are ill-equipped to manage unbefriended residents with complex psychosocial conditions (i.e. schizophrenia, bipolar disorder). They believed that LTC facility staff had insufficient training about how to manage residents who have lived with addiction, substance use, or mental illness. No LTC facilities in this study had support programs for residents with addiction or mental health issues:

> This group of complex clients is becoming more the norm…and… maybe some of the people that are working with these folks aren't getting paid enough. The turnover is high and they don't have the level of training. So there are more incidents and things are escalating. (PG #2)

[Table 3-2 about here]

Unbefriended Residents' Unmet Needs

Financial Support

Unbefriended residents often lacked sufficient funds or family assistance to purchase essential personal care items (e.g., clothing, shampoo, hip protectors) and services (e.g., foot care, haircuts, special meals). All had access to generic facility products, but those were often scent-free and disliked by residents or staff. Family members regularly purchase alternative products for LTC residents. Unbefriended residents had limited financial resources, often due to long-term disability or previous lifestyle. They also did not have family or friends to pay for or shop for necessary items. The PGs responsibility is to give decision-making consent to purchase items, not to acquire items. In the absence of a friend or family member, unbefriended residents required someone to acquire items. This could be a paid companion, but paid companions in Alberta cost between $20 to $30 dollars an hour, which is out of reach for most unbefriended residents. These intersecting limitations (limited finances, limited external support) meant that unbefriended residents had few options to access personal items:

> Typically, if a person gets their basic pensions, it'll cover the cost of LTC. ... So it's about 250 to 300 dollars disposable income. That doesn't leave a lot of extra money, especially when a companion say, costs $27 [an hour], then, you want to buy some clothes, or you want to pay some hygiene products. …The biggest barrier with public guardian people, is the companion. Because if they can afford one, great. If they can't, there's nothing [no services] to access for these people. (Social Worker, Facility # 5)

LTC staff from all disciplines (registered nurses, social workers, recreation staff, care aides) described picking up the slack—collecting and buying items for unbefriended residents. One care aide said:

> I can't put somebody's teeth in because they don't have Poligrip® [denture adhesive] for them. Simple thing. But it costs money. If we completely stop bringing in [things] for residents, can you imagine it? It would just be horrible. People with no teeth because we can't put them in. Raggedy clothes…we live in Canada. It makes no sense to me. (Care aide, Facility #6).

Unbefriended residents who *could* afford personal items experienced protracted wait times. LTC staff described waiting on average 2 to 3 months after a request for clothing. In the

meantime, care aides tied up residents' pants with rubber bands, scavenged the lost and found, brought in their husband's old clothing, or bought items themselves. LTC staff created this underground system to cope with wait times and get essential items to unbefriended residents:

> …lots of times we're out of shampoo, or body wash, or deodorant. Sometimes we're still waiting a month or two. Then we're borrowing from other people because we don't want our resident to smell. (Care aide, Facility # 4)

Social Support

All interviewees individually believed that unbefriended residents' quality of life suffered from limited social interaction, with limited one-on-one social interaction and no visitors. All of the facilities included in our study had recreation staff, however the recreation departments typically only had one or two full time recreation therapists per 100 residents. PGs typically visited the facility in person once a year for the resident care conference. A social worker described the difference in social support for unbefriended residents and residents with a family member guardian:

> Once they do have a guardian, it's probably not the same as people that have family members as guardians, because there's nobody coming to visit them, or take them out, so they're pretty isolated. They've got the staff here or other residents. But they don't have that support. The guardian comes and visits maybe once or twice, in a year, if needed, for a care conference. ... They [unbefriended residents] are on their own. They have no visitors, no one calls to inquire. They have no one. (Social Worker, Facility #5)

Interviewees indicated difficulty in pairing unbefriended residents with volunteers if the resident expressed challenging behaviors. Behaviors and advanced cognitive impairment meant that many unbefriended residents lived on secure units. Staff tried to compensate for lack of external social support by targeting these residents for volunteer visitor programs and—funds permitting—a paid companion. However, challenging behaviors and funding limitations created difficulties for unbefriended residents in accessing social interaction opportunities.

Unbefriended Residents' Quality of Care

Goals of Care

Interviewees were asked to describe differences in the quality of care for unbefriended residents compared to residents with family member or friend guardians. They identified resident *Goals of Care* as a significant issue for unbefriended residents. In Alberta, the *Goals of Care* is a medical order describing and communicating the aim or focus of care. It specifies preferred location and type of medical intervention desired by the individual or their legal decision maker. Regulated staff (registered nurses, licensed practical nurses) described unbefriended residents as often receive more interventionist goals of care—including resuscitation and transport to hospital—than other residents who have more comfort and palliative approaches prescribed:

> A lot of the time when they come into us with public guardian, they're an R1, which is full resuscitation, everything. It takes a lot for us to convince the public guardian that that's not necessarily in their best interest. It may seem to be…but a lot of the geriatric population you don't want to be resuscitating. It can do more harm than good to them. There are some public guardians that are dead set on making sure they're an R1 and not wanting to change. So, we've had one case where a resident was an R1 and we had to do CPR on him. And they weren't willing to change it down or anything like that. (Registered Nurse, Facility #6)

Interviewees in 4 of the 7 LTC facilities described unbefriended residents as having more aggressive goals of care than residents with a family or friend guardian. LTC staff in these facilities were unclear if the PG had specific policies that necessitated these higher (and therefore more interventionist) goals of care. LTC staff are required to call the surrogate decision maker in the event of a status change. Regulated staff (1 licensed practical nurse, 4 registered nurses, 5 directors of care) in 4 facilities indicated that the PG was more likely than a family member guardian to request a resident transfer to hospital. When asked why they thought this might be the case, LTC staff indicated that they assumed that the PGs had policies that required all possible measures are taken:

> We are dealing with an elderly patient that's 93 years old and we're putting him in and out of the hospital, when he could be palliative, that's our biggest problem…because I'm sending someone to emergency that shouldn't be. (Licensed Practical Nurse, Facility #6)

LTC staff also believed the more aggressive, interventionist approach to care also resulted from the PG's limited contact with the resident. One physician who had worked in LTC over 30 years described the PG's approach to care as more aggressive than family members. She believed their approach reflected their limited knowledge of the resident:

> They [Public Guardian] are far more knee-jerk, aggressive than not. I think it is because the person—the patient— isn't part of the formula. Because they aren't a known entity. It's an objective decision. (Physician, Facility #1)

PGs often had limited information about residents and no personal relationship with them. Unlike family member or friend guardians, PGs appeared to have limited knowledge of the resident's values or wishes beyond what they can express. Public guardians are expected to visit their clients at least four times a year. Two of the three public guardians we interviewed indicated that they attempted to visit all of their clients based on the standard. One public guardian described the challenges achieving the four times a year standard.

> It is standard that we see them 4 times a year. I am hard pressed to see them 4 times a year. Individuals in [LTC facilities], you don't go there as often because they're housed, they're safe and because they're given the basic necessities of life. They're not the squeaky wheels. The rest of my case load are squeaky wheels, they're the ones who are in and out of psych hospitals, they're in and out of the criminal justice system, and they have meetings here, there and everywhere. They have a huge team to support them and it's a lot of collaboration. Our nursing home guys kind of get put on the back burner because they are not the squeaky wheels and it's unfortunate, they are not prioritized. Which then is sad because who's going to visit them other than staff day in and day out? (Public Guardian #3)

PGs and LTC facility staff described ongoing efforts to ensure that public guardians could visit unbefriended residents more frequently. These efforts include scheduling annual case conferences for unbefriended residents during the same day so that PGs do not have to visit the facility multiple times. Over the last five years, the Office of the Public Guardian had adapted their case management system to a geographic catchment area to ensure that one guardian cared for unbefriended residents who lived in the same LTC facility. PG caseloads may also contribute to PGs inability to visit and develop a relationship with their clients. One PG indicated that the average caseload was 40 to 50 clients. In our study, the 3 PGs had caseloads of 37 to 60. The PG

with a lower caseload (37) had clients with complex care needs, and many were in the criminal justice system.

> If we're trying to look at providing quality care for residents in long term care and supportive living, then [public guardians] need to have lighter caseloads so they can provide the quality care and attention to those residents. Because I think oftentimes the residents start to begin looking just as another file…this is client A, B, C, and D. And they're so much more than that. (Social Worker, Facility #2)

In 3 facilities LTC staff perceived no discernable difference between goals of care for unbefriended residents and residents with family or friend guardians. Staff indicated that their PG was new in his or her position. They compared the new guardian to their previous experiences and described the new PGs as more 'person-centered,' more likely to solicit staff advice, and more comfortable with a less aggressive and comfort-based approach if care staff deemed it appropriate. One occupational therapist articulated the changes she observed working with the Office of the Public Guardian:

> When I started, there were 2 overriding opinions that we heard consistently from the OPG [Office of the Public Guardian] and one was that everyone must be full code, and second, safety is paramount, so we will use physical and mechanical restraints if needed. They would rush in support of that because they perceived that to be the safest way for the resident…They [unbefriended residents] were some of the last residents to be consented to trial removal of their physical restraint. They were working within a model that was really restrictive. So now they've come kind of full circle… First, they lightened up on the whole goals of care, not everyone has to be like a full code, now they're kind of coming around to the long-term care sort of philosophy around physical restraint and chemical restraint. (Occupational Therapist, Facility #3)

This occupational therapist observed this positive transition after a new PG was assigned to her facility. Our interviews with LTC indicated there was significant variability in the PG decision-making with respect to unbefriended residents' goals of care. We asked PGs to respond to the LTC staff's perception that there were differences in unbefriended resident goals of care and that these differences appeared to vary based on the individual PG. The PGs agreed that there was variability in individual PG decisions and that the variability noted by LTC staff was

an accurate reflection of the current public guardianship system. One PG described the variability in decision-making as reflecting a systemic issue within the guardianship system:

> There's mass confusion…and you know I cannot blame the facilities, I actually would hold the public guardian more responsible than anything. Simply because none of us can decide how consistent we're going to be. So, one rep will have one expectation and another rep will do something completely different. And we're not sending a clear message to facilities, and then [we differ] within regions…there is no consistency within reps, within offices, within regions. (PG #3)

PGs work within the available legislation but there are few overarching frameworks guiding their practice. Individual PGs had different levels of engagement with their clients, different frequency of interaction with LTC staff team, and different levels of medical knowledge. Two of our PG had backgrounds as social workers and the other had a background in mental health. All three of our PG participants indicated that PGs often have different professional backgrounds including social work, nursing, and corrections.

Discussion

Unbefriended residents are highly vulnerable and have many unmet needs.[4,17] They have often experienced homelessness, substance use, alcohol use, and mental health issues. This is consistent with research literature suggesting unbefriended individuals are marginalized and have stigmatizing health conditions.[18] We found that LTC staff may not have adequate time or appropriate training to provide care to unbefriended individuals. LTC staff, specifically care aides, do not have any education on how to appropriately manage or identify behaviors that result from mental illness, substance use or addiction issues.[19] Care aides, who provide the majority of direct care in LTC facilities, have limited training on dementia, the most prevalent disease in LTC facilities, let alone more comprehensive training on managing behaviours associated with other complex mental health issues or addictions.[20] LTC facility staff need sufficient time and training and support programs to care for unbefriended residents with these complex care needs.[1] Interviewees described social workers, who often have training and expertise in mental health and addictions, as a key resource for LTC facilities that have residents with complex needs. Unfortunately, most LTC facilities do not employ more than one social

worker. This suggests that all LTC facilities should have access to or employ a full-time social worker to assist in managing care for unbefriended residents.

Unbefriended Residents' Unmet Needs: Financial Support

Unbefriended LTC residents in this study had significant unmet needs that often stemmed from their limited financial resources. This is consistent with research that suggests that unbefriended residents have lower financial assets than those with a family member guardian.[21,22] The Canadian healthcare system directly funds acute, primary, and home care, but not LTC; provinces control their own LTC system and fund varying amounts of LTC health and housing services. Many of these services (e.g., medications, assistive devices) are not fully covered by provincial subsidies and require additional personal financial contributions.[23] Family and friend caregivers provide substantial financial and task-based support (e.g., booking appointments, arranging transport outside the facility) to LTC residents.[24] Services such as foot care, dental care, and eye care are either not insured or only partly insured; paid companions are an uninsured service.[25] Unbefriended residents in Canada often have basic government pensions. These pensions cover accommodation costs in LTC, leaving residents with approximately $300 per month for incidentals. Without personal financial assets, they have minimal resources for uninsured services and fees. They cannot rely on contributions from family members who are absent or severely estranged; instead they become reliant on LTC facility staff. To the best of our knowledge, no other research identifies the impact of being unbefriended on LTC residents' access to personal items or services. Our study contributes to research on unbefriended individuals by specifically identifying personal care items (e.g., lotions, clothing, hip protectors), services (e.g., dental, hearing and eye care services, foot care), and access to paid companions or a comparable service as central issues for unbefriended residents. Our finding that financial resources are a barrier to accessing items and services has implications for many LTC residents. Residents who are not unbefriended and have family member guardians may have similar challenges. Although low-income supplements can cover assistive devices and medications, they do not extend to personal care items or paid companions. Governments and LTC facilities need policies or programs that assist residents in accessing services and items, rather than relying on charitable organizations, volunteers, or their own facility staff.

One of the most profound outcomes of being unbefriended in residential LTC is being socially isolated. Unbefriended residents had no visitors and PGs rarely visited the facility. Social interaction with the resident was not the PG's mandate. Unbefriended residents, because of absence of family or friend contact and their often significant challenging behaviors, had insufficient social interaction and LTC staff were unable to provide the necessary social support. Recreation programs in the facilities did not have sufficient staff to provide one-on-one social interaction. Our study did not specifically focus on the impact of LTC facility recreation and volunteer programs for reducing unbefriended resident social isolation. Therefore, future research is needed to better understand the impact that facility recreation staff and volunteers have on unbefriended residents' social isolation. We found that LTC staff and PGs relied on paid companions to provide one-on-one social interaction and assist in shopping for personal items and social activities outside the facility. All our interviewees were positive about paid companions. This contradicts existing research on paid companions that describes tension between LTC staff and paid companions due to unclear roles in the facility.[26] Although our research did not explicitly focus on paid companions, more work is needed to critically examine the relationship between LTC facility staff and external paid companions and to explore analogous sources of support for unbefriended residents.

Paid companions fill a care gap left by chronic understaffing in LTC facilities and facilities have come to rely on them.[27] While they are an important resource for socially isolated residents, the paid companion system is fraught with issues including limited oversight and tension between companions and LTC facility staff.[26] Paid companions are *inaccessible* to lower income residents, especially for enough hours to reduce social isolation. At best they create a two-tier system where those without financial resources are further isolated. As well, they are not a sustainable solution to fill care gaps caused by understaffing. LTC facilities need adequate funding or other consistent solutions to support residents' social and personal care needs, but funders have not yet signaled that they recognize the importance of this. Government policies on hours of care per resident do not reflect the social and emotional care necessary for quality of life and quality of end of life.

Quality of Care

Our results demonstrated that a persistent issue in quality of care for unbefriended residents was inconsistent and potentially inappropriate *goals of care*. Quality of care refers to the degree to which the care and services result in desired health outcomes and are consistent with current best practices.[28] The demographics of the unbefriended population (e.g., older, multiple chronic conditions) make issues of quality of care and advance care planning critical.[29,30] Our findings are consistent with US research that suggests paid guardians or PGs take a more aggressive or interventionist treatment path than family or friend guardians.[31,32] However, given the variability in our interview findings, it is unclear to what extent unbefriended residents experience potentially inappropriate practices compared to residents with family or friend guardians. Our future work will use the routinely collected Resident Assessment Instrument, Minimum Data Set to systematically identify such potentially inappropriate practices in unbefriended residents.

Our findings indicate that PGs are inconsistent in their decision-making for unbefriended individuals. This may arise from limited policies and guidelines and on decision-making between LTC staff and PG. In Canada and the US, there is no standard framework for decision-making at end of life for unbefriended individuals.[31] Opinions and guidelines are conflicting on treatment for unbefriended individuals.[32] The American Medical Society maintains that an ethics committee should be consulted about management of unbefriended patients. The American Geriatrics Society states that the treatment team should make decisions.[10] US research on decision making for unbefriended individuals focuses primarily on hospitalized patients.[33] The LTC context has no comparable research on PG and the interdisciplinary care team. Furthermore, PGs come from a variety of professional backgrounds and may not have sufficient medical knowledge to participate actively in discussions with the care team. Developing guidelines and protocols for LTC teams and PG is essential for more consistency in decision-making and thus in resident quality of care. Recently, Teaster [34] examined the use of the 'Value History Form', a document required in the State of Virginia to aid in decision-making for individuals under public guardianship. This document is intended to encourage a discussion between the PG and the client about their goals and values and to use in decision-making. Incorporating similar documents in care plans might aid in care planning processes for PGs and care teams.

The variability in PG decision-making may relate to variability in individual PG engagement, which is a persistent issue.[1] Most PGs visit the resident once a year for the resident care conference. This is insufficient to build a relationship with the resident or the care team. PG engagement, or lack thereof, may be due to large caseloads. Teaster, Schmidt, Wood, Lawrence, Mendiondo [4] examined PG programs in each US state and found enormous variability, with caseloads ranging from 1:50 (1 PG for 50 cases) to as high as 1:173. The average caseload was 1:36 and they recommended no more than 1:20. The 3 PG we interviewed had an average of 53 cases, more than twice the US recommendation.[4] Our study reports that Alberta PG had a higher caseload than representatives in the US, but this was a small sample. Research is needed to assess the average caseloads of PGs across Canada and to determine if caseload is associated with distressing resident outcomes such as depression, social engagement, responsive behaviours, and pain.[35]

Strengths and Limitations

Strengths of this study included a robust process for rigorous and trustworthy data collection and analysis. We engaged in activities to validate our results, including participant follow-up and additional in-person feedback sessions. Limitations include low numbers of some professional groups interviewed. We aimed to interview more PG and physicians but had difficulty recruiting due to scheduling and turnover. We did not ask directors of care to document how many people they approached and ultimately declined to participate. Our findings may not be generalizable beyond Alberta due to our sample size and variation in provincial guardianship legislation. This study aimed to examine care providers' perspectives on needs of unbefriended residents. Our future work will attempt to align descriptions of unbefriended residents by care providers to resident data and to include the perspectives of unbefriended individuals themselves.

Conclusion

Our study is the first to document the unmet needs of unbefriended residents in LTC facilities. They are often aging alone, under unique circumstances that can create unmet needs. They have difficulty obtaining personal care items due to limited financial resources and external social supports. They may be more likely than residents with family member guardians to experience poor quality of care. Unbefriended residents are socially marginalized, and underfunded essential services and potentially inappropriate practices such as overtreatment are

manifestations of this. This study is a foundation for future research on ways to improve the quality of care and quality of life of this vulnerable population.

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Table 3-1. Characteristics of interview participants

Position	**N (%)**
Registered Nurse	9 (21)
Licensed Practical Nurse	2 (5)
Care Aide	6 (14)
Physician	1 (2)
Occupational Therapist	2 (7)
Recreational Therapist	4 (5)
Social Worker	4 (10)
Director of Care/Nursing	6 (14)
Facility Administrator	1 (2)
Other (Dietician, Unit Clerk, Young Adult Manager, Dementia Program Manager)	4 (10)
Public Guardian Representative	3 (7)

Sex	**N (%)**
Male	3 (7)
Female	39 (93)

Age	**N (%)**
20-29	7 (17)
30-39	12 (29)
40-49	14 (33)
50-59	6 (14)
60+	3 (7)

Years worked in facility	**Mean (SD)**
Long Term Care Staff	8 (7)
Public Guardian Representatives	8 (6)

Years worked in current position	**Mean (SD)**
Long Term Care Staff	7 (7)
Public Guardian Representatives	3 (3)

Table 3-2. Interview themes, categories, sub-categories, and codes

Theme 1. Staff and PG descriptions of unbefriended LTC residents

Category	Sub-category (if applicable)	Codes
Lifestyle	Isolation and Estrangement	Substance Use
		Alcohol Use
		Homelessness
		Career
		Abuse from a family member
Clinical Characteristics and Diagnoses	Cognitive Impairment	Alzheimer's Disease
		Korsakoff Syndrome
		Schizophrenia/Bipolar Disorder
		Down's Syndrome
		Responsive behaviours
	Physical Impairment	Traumatic Brain Injury
		Paraplegic/quadriplegic

Theme 2. Staff and PG perception of unbefriended residents' unmet needs

Category	Sub-category (if applicable)	Codes
Social Support	Social Engagement and Activities	No family visitors
		Staff must accompany to outside activities
		Needy or attention-seeking behaviour
	Personal Items	Clothing
		Shampoo
		Lotion
		Hip protectors
		External food and snacks
Financial Support	Companion	One-on-one support
		Buying clothing and personal care items
	Staff Workarounds	Facility lost and found
		Bring in personal items from home
		Items from deceased residents

Theme 3. Staff and PG perception of unbefriended residents' quality of care

Category	Sub-category (if applicable)	Codes
Goals of Care	Public guardian decision-making	Transfer to hospital
		Ordering medical tests
		Limited interaction with the resident
		Caseloads
	Public guardian policies	Risk averse

Inconsistent role and responsibility

Chapter 4. Paper 3- Making invisible work visible: A qualitative interview study of public guardians and staff caring for unbefriended residents in long-term care homes

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Introduction

By definition, unbefriended individuals are incapacitated and alone.[1-4] These individuals are alone for a number of reasons related to family: having no family; being estranged from members; and living at significant geographic distance from each other.[1,5] Unbefriended individuals are vulnerable and marginalized, having often experienced homelessness, lifelong disability, substance use, alcohol use, or mental health issues.[5,6] Because they lack a willing or able surrogate decision-maker and are adjudicated incapacitated, they often require a public guardian, a guardian of last resort. In Canada, public guardians are appointed by the provincial Office of the Public Guardian.[7] They are the substitute decision-makers for individuals over the age of 18 who have been assessed as incapable of making decisions in any and all areas of health care, living arrangements, education, social activities, whom to associate, and legal proceedings.[8] Public guardians function as surrogate decision managers for individuals who no longer having capacity due to an age-related disability, developmental disability, or a mental illness. Their job is to make decisions in the best interest of the client and situating them in the least restrictive environment possible.[9]

Unbefriended older adults with a public guardian often live in long-term care (LTC) homes (i.e., nursing homes, personal care homes) due to their physical and cognitive impairments and insufficient social support network.[10] We conducted a scoping review of the literature on unbefriended older adults and found only one study that was conducted in a LTC facility but this study did not describe the characteristics or needs of unbefriended residents.[7] In order to address this gap, we conducted interviews with LTC staff and public guardians to understand the unique needs of this resident population and the interface between the two actors. To our knowledge, this was the first paper that described the characteristics (e.g., diagnoses, life style, demographics) and unmet needs (e.g., financial resources) of unbefriended residents.[11] In addition to the description of the unbefriended residents' characteristics and unmet needs, interview participants described the organizational barriers that LTC and public guardians encountered while caring for unbefriended residents. The purpose of this paper is to describe the challenges LTC staff and public guardians experience caring for unbefriended LTC residents.

Methods

Design and Sampling

We analyzed qualitative interviews with 39 LTC staff and 3 public guardians from Alberta, Canada. We used purposive and convenience sampling methods to recruit LTC staff from 7 LTC facilities and public guardians from 2 regional offices. We obtained operational approvals from all participating LTC facilities. We conducted in-person and telephone interviews with LTC facility staff and public guardians. Chamberlain, Duggelby, Teaster and Estabrooks [5] provides additional methodological details. The majority of the interviews were conducted in person (n=40) rather than by telephone (n=2). Interviews were semi-structured and 17 to 45 minutes in duration. Interviews and field notes were audiotaped and professionally transcribed. Each interview included close-ended questions about the participant's demographics and job history (Table 4-1). Open-ended questions asked LTC staff and public guardians to describe the characteristics of unbefriended residents and their unmet needs. Participants were also asked to describe any differences providing care to unbefriended residents as compared to residents with a family member guardian. Although the interview guides were semi-structured, the interviewer posed additional questions and probes as needed. In particular, questions explored the unintended consequences of policies and practices outside staff control and the impact that the policies and practices have on the quality of life of unbefriended residents as well as staff.

Analysis

We analyzed interviews inductively using content analysis.[12] The analysis was conducted in a structured sequence. The interviewer (SC) and senior author (CE) coded the first six interviews. They met and the codes were updated. Using the revised codes, SC analyzed the next four interviews, which were then reviewed by CE. Codes were then updated, and SC proceeded to code the remaining interviews. Once all of the transcripts were coded, the researchers reviewed the codes and provided feedback. The lead author (SC) developed the initial set of categories, sub-categories, and their definitions. The team reviewed the categories and definitions with examples from the transcripts.[11] We received research ethics board approval from the University of Alberta (Pro00071410) and the Northern Alberta Clinical Trials and Research Centre (PB74409).

Results

Of the 39 LTC staff and 3 public guardian representatives whom we interviewed, the majority were female (n=39, 93%) and 40+ years of age (n=23, 54%).

[Table 4-1 here]

Our analysis indicated that LTC staff experience a number of challenges caring for unbefriended LTC residents. These challenges are often the result of organizational issues from the Office of the Public Guardian. Organizational issues included delays appointing a public guardian and LTC staff being unable to reach the public guardian. These organizational issues contributed to diminished LTC staff quality of work life. Our analysis resulted in five categories, and three sub-categories (Table 4-2). The results are organized based on the categories.

[Table 4-2 here]

Public Guardian Delays

Public guardian delays were defined as the delays LTC staff (e.g., regulated nurses, allied providers, and unregulated care aides) experienced accessing services for unbefriended residents due to delays by the Office of the Public Guardian. LTC facility staff, in most cases the social worker, applied for the resident to be appointed a public guardian. Social workers and directors of care indicated that, once the request for a public guardian was submitted to the Office of the Public Guardian, it took 6 to 12 months for the application to be approved. During the 6 to 12 month waiting period, residents remained their own legal decision-maker.

> Sometimes like it takes six to seven months to get a guardian. So that's six to seven months that that resident is in limbo, because they can't do anything. (Recreation Therapist, Facility #4)

Social workers, directors of care, and recreation therapists described the period waiting for the public guardian application to be approved as a 'limbo' period for a resident who had their freedom unnecessarily restricted. If the residents are not able to ambulate on their own, they were unable to leave the facility for outings or purchase personal items. Most, if not all, unbefriended residents did not have family members to bring in personal items while they waited for guardianship to be approved. A number of facilities indicated that their facility would no longer accept residents if the public guardian application was in-process (rather than complete) because of the additional responsibility that not having a surrogate decision-maker placed on the facility's staff. One social worker described this additional responsibility as including completing paperwork for unbefriended residents waiting for a public guardian.

> We get them [residents] to sign their own consent forms. If they don't understand the consent, we still get them to sign it because somebody has to. We are going to be audited, and they need to be signed by somebody. Usually I will write a progress note explaining that it [guardianship application] is in process. Every line has to be signed. Whether they have capacity or not. Even if it is them holding the pen and we are holding a clipboard under the pen and dragging the clipboard, somebody has to sign. (Social Worker, Facility #7)

Once a public guardian was appointed, staff experienced persistent delays. All of the staff indicated that reaching a public guardian by telephone was an ongoing challenge. For example, social workers and registered nurses— who had the most contact with the public guardians— described challenges reaching the public guardian outside of conventional business hours. Public guardians were not available after business hours or on holidays or weekends. If anything happened to the resident during those times, LTC staff had to contact an on-call guardian. On-call public guardians are not that specific resident's case manager and are unfamiliar with that resident's history and unique needs. LTC staff frustrations were amplified if a resident died.

> Provided it is during business hours, and we can get a hold of the public guardian and everything is fine and dandy. When I was on call one weekend, that was when one lady passed away. They couldn't get a hold of the public guardian. They did finally get a hold of the emergency on call public guardian. They had no idea what to do with the body. They didn't know what funeral home or anything like that. (Care Manager, Facility #4)

In this instance, the LTC staff provided input on which funeral home to send the resident based on their experience with other residents who had a public guardian. The on-call public guardian was not able to provide recommendations and was unable to find documentation in her file of the resident's preference. Two directors of care from two different facilities described instituting organizational policies for residents with a public guardian to ensure that there were instructions in the resident's chart for after death arrangements due to issues they experienced trying to reach public guardians after hours.

LTC staff felt that the effects of public guardian delays were compounded due to communication issues between care aides and regulated care staff. Care aides described that if the resident had a family member who visited frequently the family member would often notice when items needed to be refilled, or the care aides would approach the family member and ask them to purchase these items. Public guardians do not visit frequently, and it is not in their scope of work to purchase items, so care aides have to communicate the resident's needs to the regulated staff (i.e., licensed practical nurse, registered nurse) who will then communicate with the public guardian.

> Because some nurses I can report things to and they deal with it right away. And then there's other ones that just kind of forget about it. I have to report it three or four times. That frustrates me. So I'll just go above them if I have to - I'll deal with it myself. (Care aide, Facility #2)

Care aides described not knowing whether their requests to regulated staff were taken seriously or were simply forgotten. We asked the care aide participants if they attended the annual resident care conference. None of the 6 care aides we interviewed in 6 different facilities participated in annual resident care conferences. Once the care aides felt that their concerns were

not being followed through or their requests were taking too long they would 'deal with it themselves' and bring in the items for the resident.

Public Guardian Scope of Work

Scope of work refers to the processes and actions that a public guardian is authorized to perform. Public guardians are surrogate decision-makers and not surrogate family members. Most do not take on the activities of family member or friend, such as purchasing personal care items or accompanying residents to appointments outside the facility. Once the trustee (individual in charge of the resident's finances) has determined that the resident has sufficient funds, public guardians can approve that a resident have personal items purchased on their behalf. Public guardians are not responsible for purchasing items, and it is not always clear who will actually shop for the items.

> We're not actually the caregiver. We can't fulfill the role of family. I can't drive clients. I can't buy things for clients. I can't touch their money. I simply cannot do a lot of those things that family would do naturally. (Public Guardian #1)

In the absence of a family member guardian, LTC facility staff organize how the resident accesses items and services. If a resident has sufficient financial resources, the facility staff will contract a paid companion to shop for the resident. The LTC staff must do hiring and scheduling of this companion service or themselves shop for residents. There are no guidelines describing the unique role of LTC facility staff with respect to unbefriended residents and the activities that LTC staff engage in for this particular group of residents. Public guardians recognized the limitations of their work and expressed concerns about their unbefriended clients.

> We do have some compassionate representatives who will go out of their way to go pick that stuff up. With my caseload, 80% of the time I'm in court, or visiting one of my clients on a psych unit, so I do not have time to run to a convenience store for my clients. And they do not have the money for it, so then who pays for it? It's a travesty because these individuals sit there watching all these other people who do have family come in and bring them things. Something as simple as a picture frame to personalize their room. We don't do that. I don't know that person. We can't do that, we are not a service provider. And we all struggle with it because well, who does this then? (Public Guardian #3)

LTC facility ethos

LTC facility ethos is described as the character or spirit of the LTC facility and the LTC staff. It refers to the underlying sentiment of responsibility and duty that informs staff actions with respect to unbefriended residents. We found that LTC staff frequently provided additional care and emotional support to unbefriended residents due to the absence of family members or availability of public guardians.[11] Public guardians believe that LTC staff take on additional responsibilities for unbefriended residents because they feel a moral imperative to care for these residents.

> The nursing homes seem to understand or believe this is their role, that they need to step up and figure something out, and they are going to resolve this. Right or wrong, we've [Office of the Public Guardian] had that expectation of our care centers for decades, that's the nursing home model. Even as far back as the sixties and seventies, this has been that we [LTC facilities] are the last stop. And we are going to care for these people no matter what we need to do. (Public Guardian #1)

Public guardians described their reliance on LTC facility staff to support unbefriended residents. LTC staff (director of care, care manager, registered nurse) described differences in the caring approaches of staff with unbefriended residents compared to residents with family member guardians.

> One of the staff members is going to step up and do that in their own personal time. They're going to bring the receipt in and it's going to get paid out of the trust account. The frontline staff will go out and do those sorts of things. There's no expectation that they're going to bill somebody for that. They do that out of the goodness of their heart, because they see an unmet need and they step up and do it. (Public Guardian #2)

Directors of care described the care aides (who provide the majority of direct care to unbefriended residents) as highly attentive and caring towards these residents. They suggested that care aides' desire to assist unbefriended residents was due to feelings of sympathy and empathy.

> I think it is in their approach, their personality. They [LTC staff] treat them a bit differently. They show a bit more empathy. I'd say that they show up more for them. (Director of Care, Facility #4)

We asked care aides about their interactions with the unbefriended residents, and they described their caring approach reflecting their concern about the residents and that they themselves wondered how they would feel if they were in that resident's situation or if the resident were their family member.

One director of care indicated that unbefriended residents posed a unique challenge to their LTC facility because the staff were unable to call family members to get more information about the resident's history and personality. The LTC staff worked together to develop strategies to provide quality care to residents without that additional family member or friend support. One facility had recently instituted an observational tool for care aides to document the frequency of social interaction and the residents' reaction to different social activities. The LTC staff were hopeful that this tool would be beneficial to identify pleasurable activities for unbefriended residents who had communication difficulties and did not have family members to visit or provide feedback on their preferred activities.

> I think the staff become more creative in their problem-solving because they know there is no other option. They are more diligent…instead of calling the family saying, "We need help with this" (Director of Care, Facility #2)

The care and sense of responsibility of LTC staff for unbefriended residents continued even after the resident died. Two directors of care from two different facilities indicated that care aides would request time off to attend unbefriended residents' funerals. Both directors of care indicated that the care aides felt compelled to attend the funerals due to their relationship with the resident and their fear that no one else would attend.

> The clients under guardianship who've passed away, our staff are very vocal about wanting to attend the funeral services. Because they recognize that there could be nobody there. The staff are very vocal about wanting to be there. Whereas our other clients, if they have a lot of family, the staff don't develop the same relationship with them. (Director of Care, Facility #4)

Equal Care

Equal care reflected our finding that LTC staff perceived that they must provide the same care and services to unbefriended residents as they do to residents with a family or friend guardian. Although LTC staff described the unique relationships they developed with unbefriended residents and the unique support they provided to these residents (e.g., purchasing personal items, attending funerals), they conversely assured us that they provided the same care and attention to every resident. LTC staff were adamant that they treated residents the same. During the interviews LTC staff described the need for the 'same' care because LTC facilities discourage favouritism. A number of LTC staff described their belief that they are not allowed to single anyone out and that there is an expectation that what they do for one resident they must do for all residents.

> It could be looked at as favouritism towards a certain resident. If you're coming in and you're just bringing [things] for one particular person. I mean, we spread the love, so to speak. If you're going do for one, you make sure you do for everybody. (Care Aide, Facility #4)

LTC staff (typically care aides) described bringing in clothing or decorations for residents' rooms without telling any of the other staff. LTC staff had to walk a fine line between 'playing favorites' and providing care to unbefriended residents with no family support. LTC staff indicated that, although they knew that bringing in items for unbefriended residents was frowned upon or in violation of the facility's policies, they felt that the needs of the resident outweighed the repercussions. One director of care described her staff's activities as their facility's 'underground network'. Facility administrators and managers said that, while their staff might try to hide some of these activities, they often knew but did not acknowledge or penalize the staff.

LTC Staff Quality of Work Life

Quality of work life described the impact of that caring for unbefriended residents had on LTC staff. LTC staff described the potentially negative impact that caring for unbefriended residents had on their quality of work life, resulting in sadness, emotional exhaustion, and frustration. One care aide indicated that she decided to move from full-time to part-time hours due to the feelings of emotional exhaustion and stress.

> We have a lot of responsibility. Dealing with certain residents, that's why I think we get so exhausted. That's why I gave up my full time. It's just so exhausting when you have to take care of these residents. Your heart goes out, wanting to do more for those [with a public guardian]. It's hard on us. (Care aide, Facility #3)

A director of care suggested that caring for unbefriended residents was an added 'emotional burden' to the care staff because the staff felt that they could not provide the quality of care they wanted for unbefriended residents. Although care aides spend the most time with the residents, they did not describe it as quality time. They described feeling sad and guilty when they could not spend time with unbefriended residents.

> I go all day. The only time I can socialize with these [unbefriended] residents is in the dining room as I'm serving or when you're doing their care. That's the challenge, you just don't have enough time to really do what you want to do. To give the kind of care and the right attention that you know that some of them really need. (Care Aide, Facility #6)

Discussion

To our knowledge, this is the first study to examine the experiences and perceptions of staff and public guardians caring for unbefriended residents in LTC. Unfortunately, there are limited studies from which we can draw meaningful comparisons. Our results indicated that LTC staff experience a number of unique challenges providing care to unbefriended residents and that caring for these vulnerable residents had a significant impact on their quality of work life. Public guardians' scope of work does not reflect the support that is needed for unbefriended LTC residents. This results in LTC facility staff engaging in activities that are outside their own scope

of work in order to provide necessary care. Although LTC staff care for these unbefriended residents out of a deep sense of compassion, their sustained efforts could ultimately result in frustration and emotional exhaustion.

Administrative Delays: Public Guardian and LTC Facility

Our results indicated that there were significant administrative delays that impacted unbefriended resident's quality of care. These delays were due to public guardian schedules and the prolonged process to approve guardianship applications. There is no other comparable research in Canada that describes delays due to public guardian applications. However our findings are consistent with research in the United States (US) that identified administrative delays from the public guardian as negatively impacting client care.[13] Moye et al[13] interviewed officials within the state guardianship agencies, judges who preside over adult guardianship proceedings, and clinicians from acute and long-term care medical settings, about the procedures and mechanisms for addressing the needs of unbefriended individuals. This research found that the use of some guardians was associated with delays in care and an inability to meet the patient's preferences and values.

Our interviews indicated that the delays left residents 'in limbo,' and this inaction can have a negative impact on resident quality of life. LTC facility staff needs actionable strategies for how to proceed when guardianship applications are under review by the Office of the Public Guardian. Our research only examined the experience of caring for unbefriended residents from the perspective of LTC staff and public guardians. Future research will assess how these organizational barriers and procedural delays influenced residents' quality of care and quality of life. In particular, we aim to assess the impact that these delays have on the most vulnerable unbefriended residents, such as those who are at the end of life and those with acute health care crises.

Invisible Labour: Caring for unbefriended residents

Our previous and current analysis demonstrate that LTC staff engage in a number of activities for unbefriended residents (e.g., purchasing personal items, attending funerals) that they do not necessarily do for residents with available family or friend caregivers.[11] Neither the Office of the Public Guardian nor LTC facilities have legal responsibility to assist residents in accessing personal items. This leaves a distinct gap in care for unbefriended residents that would

otherwise be filled by family members.[14] Although LTC staff provide crucial support to unbefriended residents, it is rarely verbalized or acknowledged due to policies that discourage anything perceived as preferential treatment. Because the LTC staff provide this *invisible labour*, the system deficiencies that necessitated this labour are never fully resolved. The people providing much of this invisible care are care aides. Care aides are an unregulated workforce composed of older women, most of whom speak English as their second language, and who work multiple jobs.[15-17] This LTC workforce is providing care to an increasingly complex resident population yet staffing ratios have remained stagnant.[18] Perhaps more troubling is the fact that this additional support, this invisible labour, provided by LTC staff is not accounted for when considering the hours of care that staff provided to residents.[19] This has implications for the funding of LTC services. Currently, LTC staff are providing essential but unrecognized care to vulnerable LTC residents and this is not compensated by the individual facility or the health system. Provincial Offices of the Public Guardian and LTC operators must proactively develop policies and processes that address these gaps in care and reduce their reliance on the good will of LTC care staff.

Caring for unbefriended residents: Impact on LTC staff

Our interviews revealed that LTC staff tried to provide additional support to unbefriended residents. LTC staff described the care and compassion that staff show when caring for unbefriended residents. This is similar to research conducted by Andersen and Spiers [20] who interviewed care aides in four LTC facilities to explore their relational care practices. They found that care aides often felt close to, and the most dedicated to, marginalized residents who had no close relatives or have unresponsive relatives. Although the LTC staff we interviewed was dedicated to caring for these vulnerable residents, they did not feel they have sufficient time to spend with residents, particularly those without family member or friend supports. During our interviews, LTC staff described feelings of sadness and guilt due to their inability to spend time with unbefriended residents. This finding is consistent with other research that indicates LTC staff are often so rushed that they are unable to talk to residents.[21,22] LTC staff's emotional responses due to insufficient time and resources to care for unbefriended residents could contribute to staff burnout. Our findings are consistent with other research that indicates LTC staff experience a negative emotional response when they recognize the appropriate actions but cannot take them due to institutional barriers such as lack of time.[23] In this study, we did not

examine systematically the empirical relationships between caring for unbefriended residents and LTC staff burnout. Future research is needed to assess the associations between LTC staff experience with vulnerable residents, such as unbefriended residents, and the outcomes such as staff burnout, turnover, and quality of care.

Limitations

Although we interviewed a variety of LTC staff, due to recruitment challenges we were unable to interview more public guardians and physicians. We believe that these groups are critical to understanding the ways in which care is provided to unbefriended LTC residents. The purpose of the interviews with LTC staff and public guardians was to assess the characteristics and unmet needs of unbefriended residents. Although we found that LTC staff reported issues in their quality of work life, we did not assess systematically their levels of satisfaction or burnout. Future work should more rigorously assess the relationship between providing care to vulnerable and marginalized LTC residents, such as the unbefriended, and staff quality of work life. We were not able to interview residents in this study and were unable to assess the downstream impact of these organizational challenges on residents' perception of their quality of life or quality of care.

Conclusion

Unbefriended residents are incapacitated and alone. Compared to residents with family member guardians, they experience unique challenges accessing items and services. Our findings demonstrated that there are a number of organizational barriers for long-term care staff providing care to unbefriended residents. Organizational barriers include administrative delays and restrictions in public guardians' work activities. These barriers result in diminished staff quality of work life which includes profound sadness and emotional exhaustion. This study provides important insight into the ways in which organizational policies and practices can impact vulnerable LTC residents.

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Table 4-1. Interview Participants

Position	**N (%)**
Registered Nurse	9 (21)
Licensed Practical Nurse	2 (5)
Care Aide	6 (14)
Physician	1 (2)
Occupational Therapist	2 (7)
Recreational Therapist	4 (5)
Social Worker	4 (10)
Director of Care/Nursing	6 (14)
Facility Administrator	1 (2)
Other (Dietician, Unit Clerk, Young Adult Manager, Dementia Program Manager)	4 (10)
Public Guardian Representative	3 (7)
Sex	**N (%)**
Male	3 (7)
Female	39 (93)
Age	**N (%)**
20-29	7 (17)
30-39	12 (29)
40-49	14 (33)
50-59	6 (14)
60+	3 (7)
Years worked in facility	**Mean (SD)**
Long Term Care Staff	8 (7)
Public Guardian Representatives	8 (6)
Years worked in current position	**Mean (SD)**
Long Term Care Staff	7 (7)
Public Guardian Representatives	3 (3)

Table 4-2. Categories and sub-categories

Category	**Sub-category (if applicable**	**Code Examples**
Public guardian delays		Application delays Limbo Evenings and weekends Funeral arrangements
Public guardian scope of work		Purchasing items Surrogate decision-maker Visiting clients Difference between family and guardian
LTC facility ethos	Duty and responsibility	Way we do things Our job Expectation Our family Empathy Resident death
Equal care		Treat everyone the same No difference Do for one, do for all
LTC staff quality of work life	Sadness	Feeling sad Difficult to watch Feeling sorry
	Frustration	Angry Frustrated Emotional exhaustion

Chapter 5. Paper 4-Incapacitated and Alone: Prevalence of Unbefriended Residents in Alberta Long-Term Care Facilities

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Background

Canada's 2016 census noted that for the first time in history one-person households outnumbered couple households.[1] Almost 30% of Canadians live alone, a 3-fold increase in the last 50 years. Trends in living arrangements, childlessness, and shrinking social networks, coupled with the rising prevalence of age-related dementias pose significant challenges for older adults.[2,3] Insufficient social support is a problem for older adults who require assistance with managing their personal well-being and/or finances.[4] Individuals who are incapacitated and lack a willing or capable decision-maker are defined as "unbefriended" by academics and healthcare providers.[5,6] Although the term has negative connotations for some, it is used to identify individuals who are incapacitated and alone. Unbefriended individuals may require a public guardian, a public official or organization that assumes decision-making responsibility.[7] Public guardianship is among the most restrictive actions to limit a person's legal decision-making rights, yet little is known about how many individuals are under public guardianship.[8,9] The largest population of unbefriended individuals are older adults, and they often have cognitive impairments, multiple chronic conditions and limited social support.[10] The unbefriended population is expected to increase given the increasing population of older adults and prevalence of age-related dementias.[6,11,12]

Unbefriended older adults often live in long-term care (LTC) facilities, also known as nursing homes or care homes, because of their need for assistance due to cognitive and physical impairments and their limited family or friend support.[13] Research in the United States (US) estimates that unbefriended older adults comprise 3% to 4% of LTC residents.[6] This 3% to 4% estimate has been cited by a number of studies,[14,15] however, none of these studies directly assessed the prevalence of unbefriended residents in LTC facilities. Estimates are based on anecdotal reports and no primary data collection.[16] There is no research in Canada, the US or in the UK on the prevalence of unbefriended residents in LTC settings or the characteristics of LTC facilities with unbefriended residents.[17] Public guardianship in Canada and the US is managed individually by the province/state.[17,18] Most Offices of the Public Guardian (or their equivalent) do not specifically report the number of older adults under public guardianship or describe their place of residence (e.g., facility owner-operator, location).

Unbefriended individuals are at greater risk of potentially inappropriate care practices at the end of life (e.g., transfers to hospital, full resuscitation) due to limited family member support.[19,20] Limited or non-existent prevalence data means that we are unable to estimate the scope of unmet needs for unbefriended LTC residents. Alberta, one of Canada's western "prairie" provinces and was the first in 1978 to establish a provincial Office of the Public Guardian.[18] It is the province with the youngest population in Canada, however by 2035, one in five Albertans will be over the age of 65 [21]. Assessing the prevalence of unbefriended individuals in Alberta provides an early indication of the size of the population and enables us to address quality issues before the projected population increases. The purpose of this study was to identify the prevalence of unbefriended residents in LTC facilities in Alberta. Our specific aims were:

1. To determine the prevalence of unbefriended individuals living in Alberta LTC facilities.
2. To examine whether men or women were more likely to be unbefriended.
3. To assess whether certain LTC facility types (e.g., operator, bed size, geographic location) had a higher prevalence of unbefriended residents.

Methods

Data Collection

An observational prevalence study was conducted in all 172 Alberta LTC facilities. Prevalence of unbefriended residents in the LTC facilities was assessed using online survey methods. The online survey was administered to a senior leader (i.e., directors of care/nursing, facility administrators) in all Alberta LTC facilities. Senior leaders were chosen because they had access to resident information. This study was approved by the University of Alberta (Pro00071410) and the Northern Alberta Clinical Trials and Research Centre (PB74409).

The online survey was administered from November 2017 to January 2018. The survey was hosted by SimpleSurvey™, a Canadian survey vendor. Data collection consisted of six email messages (1 welcome, 4 reminder, 1 closing) and two telephone reminders. Respondents contacted during the telephone follow-up had the option to complete the survey over the phone. Email and telephone reminders were sent on varied days of the week to accommodate different schedules. A response rate of 50 to 60% is recommended for a prevalence survey.[22]

Online Survey Instrument

The survey collected senior leader demographic data including sex, age, and current position. Senior leaders indicated the number of years they had worked in their current position and the total number of years they had worked in the organization. Before using the online survey instrument it was piloted with two facility directors of care. Their suggestions were minor and were integrated into the final version of the survey. Participants provided their facility's name, location, and whether they worked in more than one facility (yes, no). If they worked in more than one facility, they indicated the name and location of the secondary facility. Participants detailed how many residents had a public guardian, and whether those individuals were male or female. Public guardians were defined in the survey for participants as legal representatives appointed by the Alberta Office of the Public Guardian and Trustee who represented residents who required assistance for personal decision-making. The online survey interface included a link to the Alberta Office of the Public Guardian and Trustee for further clarification on the guardian's roles and responsibilities.

Facility Characteristics

Facility characteristic data were obtained from the health region. Facility characteristics included operator (public not-for-profit, private for-profit, voluntary (e.g., faith based) not-for-profit), bed size, and health zone (North, Edmonton, Central, Calgary, South). Health zone was included because the highest population, and highest anticipated population growth, is concentrated in the large population centres of Edmonton and Calgary. Geographic classification was determined using Statistics Canada's Census classification methods.[23] Population centres (geographic areas) were classified as one of the following: small (1,000-29,999 people), medium (30,000-99,999 people), large (100,000+ people) or rural (<1000 people).

Analysis

Basic descriptive statistics (e.g., mean, standard deviation) were calculated for all variables. Prevalence of residents under public guardianship was calculated by dividing the total number of residents under public guardianship by the total number of beds in the facility. The proportion of individuals under public guardianship who were male was calculated by dividing

the total number who were male by the total number under public guardianship. The same calculation was conducted for females. In this paper we only present the males to limit repetition.

The entire population of Alberta LTC facilities (n=172) was surveyed. As this was a population sample, not a probability sample, reported mean percentages can be interpreted as population-based responses. Inferential statistics (e.g., Pearson chi-square test of significance, one-way analysis of variance (ANOVA)) are reported in each table for reference [24]. Non-response was examined by comparing known characteristics (operator, zone, bed size, rural/urban) for non-respondents and respondents.

Results

We received 123 survey responses, for an overall response rate of 71.51%. There were 118 unique respondents. Three respondents worked for multiple facilities and provided responses for multiple facilities. Over two-thirds of the surveys were completed online (n=82, 66.7%) and the remainder (n=41, 33.3%) by telephone. The majority of our respondents were female (88.1%) and over the age of 40 (66.9%) (Table 5-1). Respondents had worked an average of 6.4 years in their current position and an average 8.8 years with the organization. The majority of respondents were social workers (24.6%), followed by facility administrators (19.5%), directors of care (16.9%) and care managers (15.3%). Facility administrators, directors of care and care managers had nursing backgrounds.

[Table 5-1]

The overall prevalence of residents with a public guardian in Alberta LTC facilities was 4.14% (SD=6.28) (Table 5-2). Facilities that were public, not-for-profit operated had the highest prevalence (Mean=5.03%, SD=6.87). Facilities with less than 30 beds had the highest overall prevalence (Mean=5.41%, SD=8.63) followed by facilities with 31-69 beds (Mean=4.12%, SD=7.09). There were no statistically significant differences in prevalence based on facility characteristics (health zone, operator, bed size, rural/urban). Sex differences (male, female) in residents under public guardianship were examined (*see Table 1 in the supplementary data*).

Overall, the percentage of residents with a public guardian who were male is 52.98% (SD=36.70). There were 20 outliers (> 2 SD from the mean) and these are described below.

[Table 5-2 here]

Facility Outliers

There were large variations in the prevalence of residents with a public guardian in Alberta LTC facilities. We examined facilities (outliers) that were >2 Standard Deviations from the mean prevalence, of which there were 20 outside this range (Table 3). The prevalence of residents with a public guardian **in the 20 high prevalence facilities was 13.16%** (SD=9.65). High prevalence outlier facilities were: public-not-for profit operated (45%), over 135 beds (45%), and located in large population centres (55%). A total of 35 facilities (28.7%) had no unbefriended residents (Table 5-3). Facilities with no residents under public guardianship had less than 30 beds (48.6%), were public not-for-profit (54.3%), and located in the in smaller urban centers (57.1%).

[Table 5-3 here]

Non-Response bias

Response rates based on known facility characteristics (operator, bed size, health zone, rural/urban) were assessed to determine if there were systematic difference in respondents versus non-respondents.[22,25] The highest percentage of non-respondents were from the less populated North zone (30.6%). Over half (61.2%) of non-respondents were public not-for-profit facilities (*for more details see Table 2 in the supplementary data*).

Discussion

This is the first Canadian study to report the prevalence of unbefriended residents in LTC facilities. The overall prevalence of unbefriended LTC residents was 4.14%. This percentage is slightly higher than US estimates.[6,11] If we extrapolate this conservative estimate of 4.14% prevalence to all LTC residents in Alberta (approximately 20,000), there are nearly 1,000 unbefriended LTC residents.[26] However, there was wide variation in prevalence; twenty facilities had nearly 15% of their residents under public guardianship indicating that the total number of unbefriended residents is likely much higher. While Canadian provinces differ on many dimensions with respect to LTC services, 4.14% of LTC residents extrapolates to nearly 18,000 unbefriended individuals living in all Canadian LTC facilities at any point in time. Knowing the number of unbefriended residents is a crucial first step to monitoring their quality of life. Unbefriended individuals may have no family, be estranged from family and friends, or live at significant geographic distance from their families.[27] They are vulnerable to social isolation. Little research exists on social isolation, or its effects, for older adults in LTC homes.[28] To mitigate the risk of social isolation for unbefriended LTC residents, LTC facilities *and* policy makers need to be able to identify individuals at risk so that resources can be mobilized and creative solutions activated to provide social and instrumental support.

Although 4% of the LTC population can be viewed as a relatively low percentage of residents, the number of older adults in Canada is growing rapidly. Consequently, the numbers of unbefriended individuals will increase as a percentage of that larger number. Rising numbers of unbefriended individuals is a troubling trend given their vulnerability to poor quality of care due to limited family or friend support and advocacy.[11] Unbefriended LTC residents have limited financial resources or social support resulting in issues accessing basic personal items (e.g., clothing, denture adhesive, body lotion) and uninsured services (e.g., hearing and sight care, foot care).[27] These residents are at risk of experiencing inappropriate (e.g., overly aggressive) care at the end of life.[19,20,29] Coordinated efforts to improve the quality of care of unbefriended individuals are not possible without routine surveillance. Neither Canada, the US, or any European countries have a national repository of information on unbefriended older adults (e.g., characteristics, health service use) and their location of residence.[30]

Since public guardianship in Canada is managed at the provincial level, each of the 10 provinces and 3 territories have unique legislation that affects individuals under public guardianship.[17,18] It is not known how these disparate regional policies impact quality of care and quality of life of individuals who are incapacitated and alone. Comprehensive national data are critical to assess if regional policies impact resident health service use and to determine the extent to which individuals under public guardianship have unmet needs. In Canada, a large set of clinical and functional outcomes are routinely collected on a quarterly basis in most provinces and territories. This Resident Assessment Instrument-Minimum Data Set (RAI-MDS 2.0)[31] is one potential source of systematically collected guardianship status. Integrating a field in this data system to signify whether the decision-maker is a public guardian (a field already exists for public trustee) is one way to identify unbefriended individuals in administrative data. Prioritizing social relationships in public health and institutional residential settings requires comprehensive surveillance so that care needs can be assessed and needed resources allocated. Future research is needed to identify prevalence estimates to assess unbefriended individuals in other settings (e.g., community, acute care).

Our survey results indicated that LTC facilities with a high prevalence of unbefriended residents were located in large population centres, were public not-for-profit and had more than 135 beds. No other research has specifically examined the prevalence of unbefriended residents based on facility characteristics. There was only one US study that surveyed licensed LTC facilities in Tennessee to assess whether there were residents using some type of guardianship services (personal or financial). Similar to our findings, their study found that urban facilities had a higher proportion of residents using guardian services.[32] Future research is needed to across other provinces and countries to assess if there are differences in prevalence based on facility characteristics and if those characteristics have an impact on unbefriended resident quality of care.

Families are influential in the search for and selection of LTC facilities, but unbefriended residents do not have this family member support.[33] Once an unbefriended individual is eligible for LTC, public guardians select and consent for the transfer to a LTC facility.[34] Public guardians often have limited contact with unbefriended individuals and are not able to make decisions based on the individual's prior wishes or values and instead on their own substitute judgement.[6]

This undoubtedly results in differences in LTC facility placement between residents who have family member guardians and residents with a public guardian.[34] Further investigation is needed to examine the decision-making process of public guardians during the selection of LTC facilities for unbefriended residents. Research is needed to examine the amount of time public guardians spend with their clients and if it is related to resident health service use and quality of care.

Strengths and Limitations

This is the first study to examine LTC facility characteristics and the prevalence of unbefriended residents in Canada. The survey had a robust response rate. The survey was developed and tested with senior leaders in LTC to ensure that the survey questions and the online platform were understandable and accessible. Limitations included our response rate. 28.5% of Alberta LTC facilities did not respond to the survey. There was a statistically significant difference between respondents and non-respondents with respect to health zone, and rural/urban location. The survey did not capture individual characteristics (e.g., race, ethnicity, length of stay) of residents under public guardianship. This study only assessed the prevalence in one province.

Conclusion

Unbefriended residents comprised over 4% of all LTC residents in Alberta. Prevalence of unbefriended residents differs based on the facility geographic location and facility operator model. Unbefriended residents are incapacitated and alone. They are vulnerable to poor quality of care and yet they are not even systematically documented across the country. To enable cross province/state and cross-country comparisons, comparable research is needed to establish prevalence estimates in other Canadian provinces and internationally. However, acknowledging the existence of unbefriended individuals is only the first step to improving unbefriended LTC residents' quality of care. Future research is needed to address how our continuing care system, including front line staff and public guardians can meet the needs of this unique population.

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Table 5-1. Survey Respondent Characteristics (n=118)

Sex (n, %)	
Female	104 (88.1)
Missing	4 (3.4)
Age (n, %)	
20-29	6 (5.0)
30-39	17 (14.4)
40-49	28 (23.7)
50-59	31 (26.3)
60-69	20 (16.9)
Missing	16 (13.6)
Role (n, %)	
Administrative Support	5 (4.2)
Care Manager	18 (15.3)
Direct Care Staff (Registered Nurse, Licensed Practical Nurse)	3 (2.5)
Director of Care	20 (16.9)
Director of Nursing	7 (5.9)
Facility Administrator	23 (19.5)
Regional Manager, Long Term Care	2 (1.7)
Social Worker	29 (24.6)
Unit Clerk or Unit Manager	4 (3.4)
Other (Health Information Manager, Quality Best Practice and Research	2 (1.6)
Missing	5 (4.2)
Years in Position (Mean, SD)	6.4 (5.8)
Years in Organization (Mean, SD)	8.8 (8.9)

Table 5-2. Number and Prevalence of Residents under Public Guardianship in Alberta LTC Facilities (n=123)

Facility Characteristics	# Residents with a Public Guardian (Mean, SD)	P-Value*	% Residents with a Public Guardian (Mean, SD)	P-Value*
Alberta Average	3.78 (7.44)		4.14 (6.28)	
Zone		0.148		0.104
North	1.47 (2.25)		3.03 (3.10)	
Edmonton	4.32 (8.32)		2.24 (2.99)	
Central	2.63 (3.99)		4.58 (6.01)	
Calgary	6.25 (10.86)		5.14 (7.20)	
South	2.11 (2.62)		7.90 (12.92)	
Operator		0.329		0.340
Public not-for-Profit	2.84 (5.69)		5.03 (6.87)	
Private for Profit	3.97 (4.69)		3.63 (5.92)	
Voluntary not-for-Profit	5.39 (12.18)		3.08 (5.42)	
Facility Bed Size		**<0.001**		0.606
<30	0.93 (1.23)		5.41 (8.63)	
31-69	2.13 (3.80)		4.12 (7.09)	
70-135	3.16 (3.88)		3.36 (4.50)	
>135	9.03 (12.64)		3.70 (3.74)	
Rural/Urban		**0.003**		0.921
Rural (<1,000)	1.11 (1.54)		5.06 (7.27)	
Small (1,000-29,999)	1.78 (2.90)		4.17 (6.68)	
Medium (30,000-99,999)	3.67 (4.27)		2.99 (3.15)	
Large (100,000+)	6.89 (10.90)		4.15 (6.14)	

All statistical statistically differences were assessed using a one-way ANOVA. Differences observed between the following bed size categories (<30 and >135, p<0.001; 31-69 and >135, p=0.001; 70-135 and >135, p=0.007). Differences observed between small population centre and large, p=0.002

Table 5-3. Outlier Facility Characteristics

Facility Characteristics	**Low Outliers (n=35)**	**All other Facilities (n=68)**	**High Outliers (n=20)**
Overall Prevalence (Mean, SD)	0 (0.0)	3.62 (3.43)	13.16 (9.65)
Zone (N, %)			
North	6 (17.1)	11 (16.2)	2 (10.0)
Edmonton	10 (28.6)	17 (25.0)	4 (20.0)
Central	12 (34.3)	16 (23.5)	4 (20.0)
Calgary	4 (11.4)	20 (29.4)	8 (40.0)
South	3 (8.6)	4 (5.9)	2 (10.0)
Operator (N, %)			
Public not-for-Profit	19 (54.3)	28 (41.2)	9 (45.0)
Private for Profit	5 (14.3)	28 (41.2)	6 (30.0)
Voluntary not-for-Profit	11 (31.4)	12 (17.6)	5 (25.0)
Facility Bed Size (N, %)			
<30	17 (48.6)	10 (14.7)	3 (15.0)
31-69	10 (28.6)	18(26.5)	4 (20.0)
70-135	6 (17.1)	21 (30.9)	4 (20.0)
>135	2 (5.7)	19 (27.9)	9 (45.0)
Rural/Urban (N, %)			
Rural (<1,000)	5 (14.3)	4 (5.9)	0 (0.0)
Small (1,000-29,999)	20 (57.1)	32 (47.1)	7 (35.0)
Medium (30,000-99,999)	2 (5.7)	5 (7.4)	2 (10.0)
Large (100,000+)	8 (22.9)	27 (39.7)	11 (55.0)

Supplementary File

Proportion of Residents under Public Guardianship who were Male

We examined the proportion of residents with public guardians who are male (Table 3). Overall, the percentage of residents with a public guardian who are male is 52.98% (SD=36.70). We found statistically significant differences in the proportion of residents who are male based on facility bed size. Facilities with less than 30 beds have a higher percentage of males under public guardianship than facilities with 31 to 69 beds (p=0.013). Over three quarters (76.92%) of residents under public guardianship are male in facilities with less than 30 beds, compared to facilities with 31-69 beds that have 37.38% men (SD=42.28).

Supplementary Table 1. Proportion of Residents under Public Guardianship who are Male

Facility Characteristics	**Proportion who are Male (Mean, SD)**	**P-Value**
Zone		
North	55.38 (46.12)	0.386
Edmonton	61.25 (37.94)	
Central	39.04 (30.90)	
Calgary	55.99 (34.72)	
South	51.43 (35.50)	
Owner-Operator		
Public not-for-Profit	59.94 (34.86)	0.332
Private for Profit	48.04 (37.55)	
Voluntary not-for-Profit	47.83 (38.58)	
Facility Bed Size		**0.022***
<30	76.92 (23.11)	
31-69	37.38 (42.28)	
70-135	53.69 (36.92)	
>135	52.94 (32.43)	
Rural/Urban		0.905
Rural (<1,000)	54.17 (41.67)	
Small (1,000-29,999)	49.88 (40.84)	
Medium (30,000-99,999)	52.12 (33.44)	
Large (100,000+)	56.25 (33.14)	

*Statistical differences as determined by one-way ANOVA and Bonferroni post-hoc comparison. Significant differences were found between facilities with <30 beds and facilities with 31-69 beds (p=0.013)

Response Rates

The survey had an overall response rate of 71.51%, and therefore 28.5% of Alberta LTC facilities did not respond to the survey (Table 2). Table 1 describes the non-respondent and respondent characteristics. The highest percentage of non-respondents were from the North zone (30.6%). Over half (61.2%) of non-respondents were public not-for-profit facilities. The highest percentage of non-respondents were from the North zone (30.6%), and facilities located in small population centres (38.8%). Our analysis found no significant difference between respondents and non-respondents based on owner-operator model. We found a statistically significant difference between respondents and non-respondents with respect to zone, and rural/urban location. We found a marginally significant difference based on facility bed size. We are unable to complete further tests due to the limited known characteristics between the respondents and non-respondents. Based on the response rates and these tests of nonresponse bias we can conclude that there may be a chance of nonresponse bias.

Supplementary Table 2. Non-response bias: Response rates by facility characteristics

Facility Characteristics	Non Respondent (n=49)	Respondent (n=123)
Zone (n, %)		
Calgary	9 (18.4)	32 (26.0)
Central	11 (22.4)	32 (26.0)
Edmonton	5 (10.2)	31 (25.2)
North	15 (30.6)	19 (15.4)
South	9 (18.4)	9 (7.3)
Facility Bed Size (n, %)		
<30	16 (32.7)	30 (24.4)
30-69	17 (34.7)	32 (26.0)
70-135	13 (26.5)	31 (25.2)
>135	3 (6.1)	30 (24.4)
Ownership Model (n, %)		
Public not-for Profit	30 (61.2)	56 (45.5)
Private for-Profit	12 (24.5)	39 (31.7)
Voluntary not-for Profit	7 (14.3)	28 (22.8)
Rural/Urban (n, %)		
Rural (<1,000)	9 (18.4)	9 (7.3)
Small (1,000-29,999)	19 (38.8)	59 (48.0)
Medium (30,000-99,999)	8 (16.3)	9 (7.3)
Large (100,000+)	13 (26.5)	46 (37.4)

Statistically significant differences assessed using Pearson's chi-squared test of significant difference. Statistically significant differences found based on zone (p=0.011), bed size (p=0.047), and rural/urban (p=0.032).

Chapter 6. Paper 5- The extreme face of social isolation: A cohort study (2008-2018) of unbefriended individuals using Resident Assessment Data (RAI-MDS 2.0) in long-term care

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Introduction

Social isolation is a public health concern.[1-5] It increases the risk for mortality, even controlling for demographics, living arrangement, and co-morbidities.[6] Social isolation is related, although distinct, from loneliness, and describes the emotional distress and psychological pain of having insufficient social relationships.[7] Older adults are at increased risk of social isolation due to their diminished social networks and increased risk of cognitive and mobility impairment.[4] Unbefriended individuals may well be the most extreme version of social isolation, as they are incapacitated and alone.[8-10] Unbefriended older adults often live in institutional settings, such as long-term care (LTC) homes, due to their care needs and social isolation.[11] Unbefriended individuals are perhaps the most vulnerable residents in LTC homes. They have no willing or available family members to act as their surrogate decision-maker and often require a public guardian.[12] Researchers have raised significant concerns over the quality of care that unbefriended individuals receive, such as both under and over-treatment, compared to individuals who have a family or friend guardian.[11,13-15] Physicians in the United States reviewed state guardianship documents and found that most states had no guidelines for the care of unbefriended individuals.[16]

Although this population of vulnerable older adults is expected to grow, there is no Canadian research on unbefriended individuals living in LTC homes.[8] To address this gap, we undertook a mixed methods project to assess the prevalence, characteristics, and unmet needs of unbefriended individuals in Alberta LTC homes. To determine the size of this resident population, we administered an online prevalence survey to all 172 Alberta LTC facilities.[17] We found that 4.14% of Alberta LTC residents were unbefriended, although this varied based on facility location, ownership, and bed size. We also conducted 41 semi-structured interviews with LTC staff (e.g., nurses, care aides, physicians, social workers) and public guardians who described the characteristics and unmet needs of unbefriended residents.[18] Unbefriended LTC residents had no contact with their family, had no visitors, had mental health issues (e.g., schizophrenia, bipolar disorder), and previous substance and alcohol use. Our prevalence survey and interview findings indicated that while unbefriended individuals reflected a small overall proportion of LTC residents, they may be at increased risk of poor quality of care. Our scoping review of the literature on unbefriended individuals revealed that there is no Canadian research on this population and no research examining the health or functional status of this resident

population.[8] The purpose of this paper was to assess if existing items in the Resident Assessment Instrument, Minimum Data Set (RAI-MDS 2.0), which is required and routinely collected, can be used to assess the characteristics, diagnoses, and clinical and functional status of unbefriended residents.

Methods

Design

This study is a retrospective cross-sectional cohort study that assessed the demographic characteristics, clinical and functional status, and disease diagnoses of unbefriended LTC residents in Alberta, Canada. Resident data were collected in the Translating Research in Elder Care (TREC) program of research (2007-2022).[19-22] Since 2014, the TREC program has collected RAI-MDS data in nearly 100 nursing homes from British Columbia, Alberta, Saskatchewan, and Manitoba. The RAI-MDS is a comprehensive longitudinal assessment tool that collects information on clinical and functional status of residents in LTC.[23,24] The RAI-MDS is a standardized assessment tool used in LTC homes across Canada. RAI-MDS data are collected on an on-going basis by the TREC program and are housed at the University of Alberta in the Health Research Data Repository. For the descriptive analysis, we used RAI-MDS data from April 1, 2008 to March 31, 2018. For the prevalence comparisons, we used RAI-MDS data from October 1, 2017 to March 31, 2018 as this timeframe corresponded to the prevalence survey data collection.[17]

Setting and study cohort

We conducted a secondary analysis of RAI-MDS data from a sample of 34 LTC homes in Alberta from the TREC program. TREC program facilities are a representative sample of LTC facilities, stratified by region (British Columbia, Alberta, Manitoba), facility owner-operator (private for profit, public not for profit, voluntary not for profit), and bed size (small [<80 beds], medium [80-120 beds], large [>120 beds]). We only assessed residents from Alberta in order to make comparisons to our Alberta prevalence survey data. We identified the last or most recent assessment for all LTC residents in Alberta from April 1. 2008 to March 31, 2018 (n=25, 330).

Resident variables

The term unbefriended denotes an individual who lacks an available surrogate decision-maker (family or friend) and is incapacitated. In Canada, these individuals require a public guardian. The RAI-MDS does not capture public guardianship status or identify the surrogate decision-maker. Therefore, we characterized unbefriended residents as those residents who had no contact with family or friends (F2e item in the RAI-MDS) on their most recent assessment. We report on resident demographic characteristics including: sex (male, female), age (continuous), and marital status (never married, married, widowed, separated, divorced, unknown). We estimated length of resident stay based on the date of admission to the date of last assessment.

We reported on the following disease diagnoses or disorder present in the residents documented in their most recent assessment, specifically diabetes, heart disease, congestive heart failure, hypertension, arthritis, Alzheimer's disease or other dementia, cerebrovascular accident, Parkinson's disease, seizure disorder, traumatic brain injury, anxiety disorder, depression, bipolar disorder, schizophrenia, emphysema/chronic obstructive pulmonary disease, and liver disease. These diseases were chosen based on the findings from our interviews, which identified mental health illnesses, cognitive impairment, and traumatic brain injury, as resident characteristics[18] and our scoping review of the literature, which identified cognitive impairment, mental health illness, and multiple chronic conditions, as characteristics of unbefriended individuals.[8] We assessed resident clinical and functional status using outcome scales available in the RAI-MDS. Information on these scales is provided in Supplementary Files. The outcome scales assessed the following: cognitive performance, depression, activities of daily living, pain, aggressive behaviours, changes at the end of life, and social engagement.

Analysis

We analyzed the data using SAS 9.4 (SAS Institute). We calculated descriptive statistics for all scale items (mean, 95% confidence intervals). Statistical differences in the scale scores were determined using two-sample t-tests (Table 1 and 2). For ordinal and dichotomous variables, we used 95% confidence intervals for proportions. Chi-square tests were not used because the large sample size meant that even small relationships may be significant. We examined individuals who had no contact with family and a moderate-severe cognitive

impairment compared to individuals who had contact with family and had a moderate-severe cognitive impairment (Tables 3 and 4). Unbefriended individuals lack decision-making capacity. Therefore, we aimed to specifically examine those residents with moderate-severe cognitive impairment. We assessed moderate-severe cognitive impairment based on a Cognitive Performance Scale score of 4+.[25] We used binary logistic regressions to assess differences between the two groups (no family contact, contact with family). Unadjusted odds ratios from the regressions can be found in Table 6. Items were excluded from the tables if a cell had 5 or fewer cases.

We had significantly fewer residents with no family contact (n=945) than residents with family contact (n=24,385). Therefore, we conducted a sensitivity analysis to assess the potential for observed differences in disease diagnoses and scale outcomes based on sample size. Using random sampling without replacement methods, we selected 945 individuals with family and compared them to our cohort of 945 individuals without family. We repeated this process 10 times. Therefore, we compared a total of 9,450 individuals with family to our group of 945 residents without family. We found no significant differences using the results of the sensitivity analysis compared to our findings. We did not present advanced statistical tests (e.g., multivariate regression) because our intention was to describe residents with no family compared to those with family and compare these findings to the descriptions in our interviews and the scoping review.

Prevalence Comparison

We compared prevalence from the RAI-MDS sample to our online survey sample prevalence in order to assess the degree to which the findings from the RAI-MDS reflected the facility reported prevalence in our previous study.[17] We calculated the number of individuals who had no contact with family in the RAI-MDS data to assess the prevalence in our cohort. The prevalence was calculated based on the total number of individuals identified in the RAI-MDS as having no contact with family or friends and the total number of facility beds. We calculated descriptive statistics for the prevalence in the RAI-MDS data (mean, standard deviation, 95% CI). We compared our prevalence findings in the RAI-MDS data to our findings from our prevalence survey. Our online prevalence survey included prevalence data from 28 LTC facilities that were also found in our RAI-MDS facility sample.

Ethics

We received ethical approvals for this study from the University of Alberta Research Ethics Board (Pro00071410) and the Northern Alberta Clinical Trials Research (PB74409). We received approval for secondary analysis of the RAI-MDS data from the Translating Research in Elder Care (TREC) Data Management Committee.

Findings

Prevalence

In our total TREC sample of 25,330 Alberta residents (2008-2018), 945 had no contact with family. We compared the prevalence from our online prevalence survey (3.96% in the 28 Alberta sites) and the same 28 sites in the RAI-MDS data and found that using the RAI-MDS item (F2e: no contact with family), we identified fewer unbefriended individuals (2.82%) during the comparable data collection period (Table 6-1). This indicates that the RAI-MDS underestimates the total number of unbefriended individuals in LTC homes.

[Table 6-1]

Unbefriended resident characteristics

Unbefriended residents (those without family contact) had a higher proportion of men (46.5%) compared to the proportion of men in the group of residents with family contact (38%) (Table 2). Unbefriended residents were younger and had a longer length of stay in the LTC facility than did residents with family. We found significant differences in the instances of mental health issues including a diagnosis of depression (unadjusted OR: 1.21), bipolar disorder (unadjusted OR: 1.80), and schizophrenia (unadjusted OR: 3.9) (Table 6-6) in unbefriended individuals. Unbefriended individuals, defined as those who had no contact with family, had a significantly higher proportion of liver disease (3.0%) compared to individuals with family contact (1.5%).

Residents without family or friend contact had significantly higher mean scores (higher is worse) on the depression rating scale, pain, and aggressive behaviour scale (Table 6-3). They had significantly lower scores on social engagement (lower is worse). We found no differences in

cognitive performance, which is consistent with our findings that the disease diagnoses showed no difference in diagnoses of dementia or Alzheimer's disease (Table 6-2).

[Table 6-2]

[Table 6-3]

Unbefriended residents with moderate-severe cognitive impairment

Table 6-4 and Table 6-5 present the characteristics and health outcomes for residents with no family and a moderate-severe cognitive impairment relative to residents who had family and also had a moderate-severe cognitive impairment. Residents with a moderate-severe cognitive impairment and no family had higher odds of having a diagnosed seizure disorder, bipolar disorder, schizophrenia, and liver disease. Relative to residents who had family, unbefriended residents had a higher depressive rating scale scores (higher is worse), lower social engagement, and more aggressive behaviours.

[Table 6-4]

[Table 6-5]

[Table 6-6]

Interpretation

In this study, relative to individuals with family, unbefriended individuals were more likely to be younger, male, have liver disease, and have a number of mental health issues including schizophrenia and bipolar disorder. Unbefriended individuals had worse depressive symptoms, more frequent and severe pain, and lower social engagement, compared to individuals with family. One of the objectives of the study was to assess if the RAI-MDS data could be used to identify unbefriended individuals by comparing it to the results of our prevalence survey. We found that the RAI-MDS data underestimate the prevalence of unbefriendedness, specifically those with no family contact, when compared to the survey.[17] The characteristics and diagnoses of the individuals identified in the RAI-MDS data were consistent with the findings from our previous study, which indicated that unbefriended residents had lower social engagement and a history of mental illness. [18]

To our knowledge this is the first empirical paper to examine the health and functional status of unbefriended LTC residents in Canada.[8] Although there is no comparable research on this population in Canada, US research is consistent with our findings, indicating that unbefriended individuals are often male, have multiple chronic conditions, and are single or divorced.[8,26]

Unbefriended residents often had previous issues with substance and alcohol use.[10,18] These previous lifestyle factors may contribute to our finding that unbefriended individuals had a higher likelihood of having liver disease than individuals with family. Research in the US indicated that community-dwelling unbefriended individuals were often older and were more cognitively impaired than individuals with family or friends.[8,27] In contrast, we found that, compared to those with family, unbefriended individuals were younger and did not have a higher proportion of individuals with a diagnosed dementia. Assessing the reason for these differences is an important area for future study.

We stress that unbefriended individuals are lonely individuals.[28] Although we cannot assess loneliness in RAI-MDS data, we found that unbefriended individuals had lower social engagement and more symptoms of depression. LTC residents consistently report unmet needs for intimate social relationships.[29] Residents, family members, and staff agree that there is a lack of stimulating activities, insufficient visitors to sustain social engagement, and limited opportunities in the facility to make social contacts.[30,31] Unbefriended residents are perhaps the most at risk in LTC for loneliness and depression due to their severe social isolation.

This study only focused on RAI-MDS data from 34 LTC facilities in one province and therefore is not generalizable to other provinces. Because our analysis was descriptive, we are unable to make any causal claims. Our data are not linked with other administrative data (e.g., hospital discharge abstracts), and we are unable to assess transitions through the continuing care system. This study was a proof of concept to determine if using the single item in the RAI-MDS (no contact with family or friends) could be used as a proxy for unbefriended status and could complement our existing studies on unbefriended LTC residents. Given the consistencies in our findings, our future research will examine larger population data sets, including data from the Canadian Institutes for Health Information, to conduct more robust hierarchical modelling. There is no variable specifically indicating ‘unbefriended’ status in the RAI-MDS. The prevalence data indicated that the RAI-MDS data would underestimate the unbefriended population and therefore the findings in this study might actually underestimate the negative health outcomes of this population. We were unable to compare our findings to studies of related concepts, such as social vulnerability, because these studies required information on an individuals’ socio-economic status, self-esteem, and sense of control, none of which are included in RAI-MDS assessments.[2,3,32,33]

Unbefriended individuals in LTC have more depressive symptoms, more frequent and severe pain, lower social engagement, and a number of mental health issues. Compared to individuals with family, they are younger, male, and have a longer length of stay in the LTC facility. Depression, loneliness, and a lack of social engagement can have devestating health effects including increased risk of morbidity and mortality and a direct and deleterious impact on quality of life. These findings provide a foundation for future research. Our future work will include robust causal modelling and examine the influence of being unbefriended on other critical outcomes such as quality of life and mortality. Clinicians struggle with identifying these vulnerable individuals through traditional screening methods.[34] Our approach, using a single item in an already collected data source, has the potential to assist clinicians and health systems screening for these exceptionally vulnerable LTC residents.

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Table 6-1. Number and prevalence of unbefriended individuals in Alberta LTC homes from the RAI-MDS and the prevalence survey (October 1, 2017-March 31, 2018)

	Data from same 28 facilities in Alberta	
	RAI-MDS (n=123)	Prevalence Survey (n=173)
Number of unbefriended residents (Mean, SD)	4.39 (6.60)	6.18 (12.21)
Prevalence (%)	2.82%	3.96%

Table 6-2. Characteristics of individuals based on their contact with family or friends (April 1, 2008-March 31, 2018)

	Number of individuals and (%) of individuals (95% CI for %)	
	Contact with family or friends (n=24385)	**No contact with family or friends (n=945)**
Characteristics		
Female	14891 61.1 (60.5-61.7)	506 53.5 (50.36-56.73)
Age [Years] (Mean, SD)	85.6 (9.8)	81.47 (11.79)
Length of Stay [Years] (Mean, SD)	2.1 (2.8)	2.71 (3.63)
Marital Status		
Never Married	1431 5.9 (5.6-6.2)	149 15.8 (13.4-18.1)
Married	7235 29.6 (29.1-30.3)	177 18.7 (16.2-21.2)
Widowed	11631 47.7 (47.1-48.4)	365 38.6 (35.5-41.7)
Separated	385 1.6 (1.4-1.7)	33 3.5 (2.3-4.7)
Divorced	1766 7.3 (6.9-7.6)	133 14.1 (11.9-16.3)
Unknown	1914 7.9 (7.5-8.2)	88 9.3 (7.5-11.2)
Disease diagnoses		
Diabetes mellitus	5621 23.1 (22.6-23.6)	251 26.6 (23.8-29.4)
Heart disease	1239 11.2 (10.6-11.8)	44 10.6 (7.6-13.5)
Congestive heart failure	1946 17.6 (16.9-18.3)	66 15.8 (12.3-19.3)
Hypertension	6177 55.9 (54.9-56.8)	211 50.6 (45.8-55.4)
Arthritis	3713	118

	33.6 (32.7-34.5)	28.3 (24.0-32.6)
Alzheimer's Disease	1350 12.1 (11.6-12.8)	47 11.3 (8.2-14.3)
Cerebrovascular accident	4759 19.6 (19.0-20.0)	173 18.3 (15.9-20.8)
Dementia other than Alzheimer's Disease	13028 53.5 (52.9-54.1)	511 54.1 (51.0-57.3)
Parkinson's Disease	715 6.5 (6.0-6.9)	30 7.2 (4.7-9.7)
Seizure disorder	493 4.5 (4.1-4.8)	31 7.4 (4.9-10.0)
Traumatic brain injury	114 1.0 (0.8-1.2)	11 2.6 (1.1-4.2)
Anxiety disorder	1059 9.6 (9.0-10.1)	41 9.8 (7.0-12.7)
Depression	7935 32.6 (32.0-33.2)	349 37.0 (33.9-40.0)
Bipolar disorder	391 1.6 (1.4-1.8)	27 2.9 (1.8-3.9)
Schizophrenia	424 1.7 (1.6-1.9)	61 6.5 (4.9-8.0)
Emphysema/COPD	2207 20.0 (19.2-20.7)	105 25.2 (21.0-29.3)
Liver disease	363 1.5 (1.3-1.6)	28 3.0 (1.9-4.0)

Table 6-3. Outcome scales based on resident contact with family or friends (April 1, 2008-March 31, 2018)

	Mean (95% CI)		
	Contact with Family or Friends (n=24385)	**No contact with family or friends (n=945)**	P-value*
Scales^			
Cognitive Performance Scale (CPS)	3.38 (3.36-3.40)	3.37 (3.26-3.48)	0.8481
Depression Rating Scale (DRS)	2.32 (2.29-2.36)	3.34 (3.13-3.55)	<.0001
Index of Social Engagement (ISE)	2.34 (2.32-2.36)	2.16 (2.05-2.26)	0.0009
Activities of Daily Living Long Form (ADL)	20.29 (20.21-20.38)	19.21 (18.72-19.70)	<.0001
Changes in health, signs and symptoms,	1.55 (1.53-1.57)	1.55 (1.46-1.63)	0.9377

and end-stage disease (CHESS)			
Pain (PS)	0.60 (0.59-0.61)	0.70 (0.64-0.75)	0.0005
Aggressive Behaviour Scale (ABS)	1.61 (1.58-1.64)	2.30 (2.12-2.47)	<.0001

^CPS (0-6 range with higher scores indicating more cognitive impairment); DRS (0-14 range with higher scores indicating more frequent and severe depressive symptoms); ISE (0-6 range with higher scores indicating better social engagement); ADL (0-28 with higher scores indicating more impairment); CHESS (0-5 range with higher scores indicating more health instability); PS (0-3 range with higher scores indicating more frequent and intense pain); ABS (0-12) with higher scores indicating more frequent physical, verbal, and socially inappropriate behaviour; DBS
*Significant differences assessed using two-sample t-test. Statistical differences in the scale scores were determined using the Satterthwaite method because it does not assume equal variances and is a more conservative approach to assessing differences across groups with unequal variance.

Table 6-4. Characteristics of individuals based on their contact with family or friends and the presence of moderate-severe cognitive impairment (CPS 4+) (April 1, 2008-March 31, 2018)

	Number of individuals and % of individuals (95% CI for %)	
	Contact with family or friends and CPS 4+ (n=9752)	**No contact with family or friends and CPS4+ (n=365)**
Demographics		
Female	6128 62.8 (61.9-63.8)	214 58.6 (53.6-63.7)
Age [Years] (Mean, SD)	86.31(9.35)	83.89 (11.31)
LOS [Years] (Mean, SD)	2.66 (2.97)	3.66 (4.18)
Marital Status		
Never Married	446 4.6 (4.2-5.0)	50 13.7 (10.2-17.2)
Married	3216 33.0 (32.1-34.0)	74 20.3 (16.1-24.4)
Widowed	4662 47.9 (46.9-48.9)	148 40.6 (35.5-45.6)
Separated	110 1.1 (0.9-1.3)	11 3.0 (1.3-4.8)
Divorced	558 5.7 (5.3-6.2)	47 12.9 (9.4-16.3)
Unknown	744 7.6 (7.1-8.2)	35 9.6 (6.6-12.6)
Disease diagnoses		
Diabetes mellitus	1855 19.0 (18.3-19.8)	74 20.3 (16.1-24.4)
Heart disease	452 10.3 (9.4-11.2)	21 13.6 (8.2-19.1)
Congestive heart failure	557 12.8 (11.8-13.7)	15 9.7 (5.1-14.4)
Hypertension	2271 52.0 (50.5-53.4)	69 44.8 (36.9-52.7)
Arthritis	1392 31.9 (30.5-33.2)	52 33.8 (26.3-41.2)
Alzheimer's Disease	851 19.5 (18.3-20.6)	23 14.9 (9.3-20.6)
Cerebrovascular accident (stroke)	1874 19.2 (18.5-20.0)	73 20.0 (15.9-24.1)

Dementia other than Alzheimer's Disease	6535 67.0 (66.1-68.0)	259 71.0 (66.3-75.6)
Parkinson's Disease	302 6.9 (6.2-7.7)	9 5.8 (2.1-9.6)
Seizure disorder	210 4.8 (4.2-5.4)	15 9.7 (5.1-14.4)
Traumatic brain injury	52 1.2 (0.9-1.5)	6 3.9 (0.8-7.0)
Anxiety disorder	374 8.6 (7.7-9.4)	13 8.4 (4.0-12.8)
Depression	3194 32.8 (31.9-33.7)	123 33.7 (28.8-38.5)
Manic depressive (bipolar)	102 1.1 (0.8-1.2)	9 2.5 (0.9-4.1)
Schizophrenia	137 1.4 (1.2-1.6)	14 3.8 (1.9-5.8)
Emphysema/COPD	610 13.4 (12.9-15.0)	27 17.5 (11.5-23.5)
Liver disease	78 0.8 (0.6-1.0)	7 1.9 (0.5-3.3)

Table 6-5. Outcome scales based on resident contact with family or friends and CPS4+ (April 1, 2008-March 31, 2018)

	Mean (95% CI)		
	Contact with Family or Friends and CPS4+ (n=9752)	**No contact with family or friends and CPS4+ (n=365)**	P-value*
Scales			
Depression Rating Scale (DRS)	2.45 (2.40-2.50)	3.30 (2.98-3.63)	<.0001
Index of Social Engagement (ISE)	1.34 (0.32-1.37)	1.16 (1.04-1.29)	0.0054
Activities of Daily Living Long Form (ADL)	24.02 (23.93-24.11)	23.35 (22.79-23.91)	0.0212
Changes in health, signs and symptoms, and end-stage disease (CHESS)	1.88 (1.85-1.91)	1.84 (1.69-1.99)	0.6636
Pain (PS)	0.56 (0.54-0.58)	0.66 (0.57-0.75)	0.032
Aggressive Behaviour Scale (ABS)	2.37 (2.32-2.43)	3.07 (2.76-3.39)	<.0001

*Significant differences assessed using two-sample t-test. Statistical differences in the scale scores were determined using the Satterthwaite method because it does not assume equal variances and is a more conservative approach to assessing differences across groups with unequal variance.

Table 6-6. The association between resident characteristics, disease diagnosis, and functional status and having no contact with family or friends using binary logistic regression

	No contact with family or friends
	Unadjusted Odds Ratio (95% Wald Confidence Limits)
Demographics	
Female (Ref=Male)	0.74 (0.65-0.84)
Age [Years]	0.97 (0.96-0.97)
Length of Stay [Years]	1.06 (1.04-1.08)
Marital Status (Ref: Unknown)	
Never Married	1.27 (1.73-2.97)
Married	0.53 (0.41-0.69)
Widowed	0.68 (0.54-0.87)
Separated	1.86 (1.23-2.82)
Divorced	1.64 (1.24-2.16)
Disease diagnoses	
Diabetes mellitus	1.21 (1.04-1.4)
Heart disease	0.94 (0.68-1.29)
Congestive heart failure	0.88 (0.67-1.15)
Hypertension	0.81 (0.67-0.98)
Arthritis	0.78 (0.63-0.97)
Alzheimer's Disease	0.91 (0.67-1.24)
Cerebrovascular accident	0.92 (0.78-1.09)
Dementia other than Alzheimer's Disease	1.03 (0.9-1.17)
Parkinson's Disease	1.12 (0.77-1.64)
Seizure disorder	1.72 (1.18-2.51)
Traumatic brain injury	2.6 (1.39-4.87)
Anxiety disorder	1.03 (0.74-1.43)
Depression	1.21 (1.06-1.39)
Bipolar Disorder	1.80 (1.22-2.68)
Schizophrenia	3.9 (2.96-5.14)
Emphysema/COPD	1.35 (1.08-1.69)
Liver disease	2.02 (1.37-2.98)

Chapter 7. Paper 6- Examining unbefriended residents in long-term care through a framework of social exclusion: Results from a mixed methods study in Alberta, Canada

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Background

Social exclusion and older adults

Nearly 7% of Canadians 65+ live in long-term care (LTC) homes and this proportion increases to 30% for those 85^{+}.[1] LTC homes offer the highest level of support to older adults who have been assessed as having complex medical and social needs.[1-3] LTC residents have multiple chronic conditions, and over 60% have *moderate to severe* cognitive impairment.[3,4] Older adults living in LTC are disproportionately women, who are low income, and have a dementia.[3,5] LTC residents lack meaningful social engagement and experience boredom, depression and loneliness.[6-10] Individuals are entering LTC later in life and later in the trajectories of their medical conditions which means that most LTC residents (80%) will die in the facility.[11,12] Although LTC homes are increasingly responsible for providing end-of-life care, poor quality of care remains a persistent issue in LTC.[13-15] LTC residents are highly vulnerable due to their co-occurring medical and social needs.[5] It is critical that we examine social exclusion in LTC residents and the impact of exclusion on their quality of care and quality of life.

Social exclusion refers to the separation of an individual or group from society.[16-18] It is one way to describe those who are already excluded, or at risk of, exclusion from social protections.[19] Social exclusion had been used in policy development related to the inclusion of older adults in society.[20,21] Exclusion reflects the multidimensional and intersecting ways that individuals or groups experience disadvantage.[17,22] The concept first emerged in political science and sociology, and is increasingly studied in gerontology. Older adults are among the marginalized groups at significant risk of social exclusion. They are susceptible to exclusion due to their diminished participation in the workforce, their precarious health (physical and mental), and their contracting social networks.[17,23-25] Gerontologists have focused on social exclusion because of its association with negative health outcomes such as loneliness, morbidity and mortality.[24,26-29]

A number of conceptual frameworks have been developed to examine the social exclusion of older adults.[16,21,24,27,30-32] Walsh et al[17] conducted a scoping review of these frameworks and found that, in general, the exclusion domains included: social relationships, geographic or spatial considerations, material or financial resources, and civic participation. Their review highlighted several limitations in the existing research. Most frameworks described

by Walsh et al. described the dimensions of exclusion for older adults but did not identify linkages among the dimensions.[33-35] None of the frameworks had been used to examine institutionalized older adults. O'Donnell et al[36] reviewed social exclusion tools in health care settings and did not find any that had been developed or tested with older adults in institutional settings, such as LTC homes.

Socially excluded older adults in LTC: Unbefriended residents

To study social exclusion among LTC residents, we examined residents at greatest risk for exclusion—the unbefriended. Unbefriended individuals lack decision-making capacity and a willing or able family member to act as their decision-maker.[37] As a result, they often require a public guardian, who is a caseworker employed by a (Canadian) provincial Office of the Public Guardian.[38] Unbefriended individuals may have outlived family, live far away from family, or be estranged from family. Those who are estranged from family have often experienced significant challenges throughout their life, including homelessness, mental illness, and substance and alcohol use.[39,40] They are socially isolated, which can result in loneliness and depression.[41] Unbefriended individuals are exceptionally vulnerable to poor quality of care. Without an engaged family member advocate for them they are at risk of inappropriate care such as overtreatment (e.g., frequent transfers to hospital, excessive medical testing) or undertreatment.[42,43] Unbefriended LTC residents are marginalized and at risk of poor quality of care, yet little is known about the prevalence, characteristics, or health of this population. Therefore, we undertook a mixed-methods study to address these gaps.

[Figure 7-1 here]

Overall project and studies

Our project aimed to assess the prevalence, characteristics (e.g., demographics), health, and unmet needs of unbefriended LTC residents.[17,44] Using a social exclusion framework developed by Guberman and Lavoie (Table 7-1),[44] we conducted a series of four linked studies in LTC homes in Alberta, Canada (2016-2019). We used Guberman and Lavoie's framework of social exclusion because it offered a broad conceptualization of spatial exclusion, defined as geographic freedom, confinement, or loss of control over an environment, which we believed to be highly relevant to institutionalized individuals. This social exclusion framework guided the development of our interview guides, online survey, and the variable selection for our secondary

analysis of administrative data (see Figure 7-1). Following the completion of our project, we determined that in addition to Guberman and Lavoie's 7 social exclusion domains, complex adaptive system concepts were a valuable contribution to our understanding of social exclusion in institutional settings. The purpose of this conceptual paper is to use our published project findings to illustrate that a framework of social exclusion is relevant to unbefriended LTC residents. Furthermore, we argue that complex adaptive system concepts provide insight into the systems and processes that impact the care provided to socially excluded LTC residents.

[Table 7-1 here]

Structure of this paper

In this conceptual paper we will illustrate Guberman and Lavoie's framework domains using our published study findings. In addition, we present our published findings that reflect complex adaptive system principles. Below we provide a short description of the individual studies, including their purpose, methods, and results. This paper is a synthesis of our published work. It does not include all of the methodological or analytical details or individual study results, for greater detail on the individual studies see Chamberlain et al.[38,39,63-65] Where possible we have presented illustrative quotes from our studies that describe our findings in relation to the domains of exclusion. Not all domains include a direct quote, and we have cited the relevant study where additional findings can be found.

Individual study descriptions

Study 1: Scoping review of the literature

We conducted a scoping review of the literature on unbefriended older adults.[38] The purpose of the scoping review to describe the characteristics, health, and location of residence of unbefriended older adults. We reviewed the peer-reviewed and grey literature. All studies that we identified were conducted in the United States (US) and we found no Canadian research on unbefriended individuals. Research in the US with community-dwelling older adults indicated that, when compared to older adults with a family or friend decision maker, unbefriended individuals were older, had a cognitive impairment, had multiple chronic conditions, and had limited social support (they were childless or had fewer children).

Study 2: Semi-structured interviews with LTC staff and public guardians

We conducted semi-structured interviews with 39 LTC staff (e.g., registered nurses, care aides, social workers, recreational therapists) and 3 Public Guardians.[39,46] The purpose of the interviews was to identify the characteristics and potentially unmet needs of unbefriended LTC residents. See Chamberlain et al for interview participant demographics.[39] Our interview questions were developed based on Guberman and Lavoie's social exclusion framework. The interview guides included questions based on the dimensions of exclusion (e.g., social relationships/participation, financial resources, access to services). Our first paper[39] identified the characteristics of unbefriended individuals. We found that unbefriended LTC residents were socially isolated and had significant issues accessing personal care items (e.g., clothing, lotions).[39] We also identified significant quality of care issues including more aggressive and interventionist treatment (e.g., resuscitation, transfers to hospital, medical testing) for unbefriended individuals compared to individuals with family member guardians.[39] Our second paper[46] described the organizational challenges that contributed to unmet needs of unbefriended residents. Challenges included administrative delays, the limited scope of public guardians' activities, and LTC policies that emphasize equal care.

Study 3: Assessing the prevalence of unbefriended LTC residents

The number of LTC residents who are unbefriended is unknown because most provincial Offices of the Public Guardian do not systematically track, or make publicly available, unbefriended individuals' locations of residence (e.g., LTC, community). [38] The purpose of the prevalence study was to assess the number of unbefriended individuals in Alberta LTC homes. We administered an online survey to Directors of Care/Facility Administrators in all Alberta LTC facilities (n=172, 72% response rate).[63] The average prevalence was 4.14% which is consistent with the prevalence estimates in the US.[37,38,42] We examined the prevalence of unbefriended residents based on a number of facility characteristics including: rural versus urban location, bed size, owner-operator. We described the facility characteristics in detail in Chamberlain et al.[63] We found that, on average, unbefriended individuals lived in smaller (<80 bed), public-not-for profit facilities. However, the facilities with the highest prevalence rates, reached rates as high as 15%, were larger (>135 beds) and were public-not-for profit.

Study 4: Assessing characteristics and quality of care using administrative resident data

We conducted a secondary data analysis of Resident Assessment Instrument, Minimum Data Set (RA-MDS 2.0) data.[47] The purpose of this secondary analysis was to determine the prevalence, characteristics, health, and functional status of unbefriended LTC residents. We examined these administrative data to assess the demographic characteristics, clinical and functional status, and disease diagnoses of unbefriended LTC residents in Alberta (2008-2018). Unbefriended residents had lower social engagement, more frequent and severe pain, and more depressive symptoms. Compared to residents with family, unbefriended residents had a greater likelihood of a mental health diagnoses (depression, bipolar disorder, schizophrenia) and liver disease.

Synthesizing our project findings

Together, our studies described the social exclusion of unbefriended LTC residents in Alberta. Our synthesis involved examining the findings from each study with respect to Guberman and Lavoie's framework, identifying the linkages between the existing domains, and identifying additional concepts not identified by the framework that were related to the social exclusion of unbefriended LTC residents. Our syntheses are organized in three sections. **First**, we illustrated Guberman and Lavoie's domains of exclusion using examples drawn from our studies. Here we describe how Guberman and Lavoie's existing dimensions of exclusion manifested in unbefriended residents. **Second**, we identified concepts not included in Guberman and Lavoie's framework that should be used to assess exclusion in LTC settings. **Third**, we demonstrate that complex adaptive systems theory concepts are complementary to Guberman and Lavoie's framework and that these concepts enhanced our understanding of the care provided to unbefriended LTC residents.

Guberman and Lavoie's domains of exclusion

Economic exclusion

Economic exclusion was identified by LTC staff and public guardians in our qualitative interviews (Study #2).[38] Unbefriended individuals had fewer financial resources compared to individuals with family member guardians.[38] The category of '*Financial Support'* emerged from interviews with LTC staff and public guardians. Unbefriended individuals had limited pension

income and were thus unable to pay for personal items (e.g., clothing, special food), uninsured items (e.g., orthotics, hip protectors), and services (e.g., haircut, recreational activities).[39] Unbefriended residents had limited external social support and therefore relied on a paid companion to assist them with purchasing personal items and accompanying them to appointments outside of the LTC facility – *but only if they could afford it*. Private companions (different from volunteers) are care aides employed by external agencies who are paid 20 to 30 dollars per hour. They shop for the resident and accompany the resident to appointments outside the facility. Companions can offer a meaningful relationship and alleviate the challenges accessing services (institutional exclusion). However, the cost of a private companion is prohibitive for most unbefriended individuals. Unbefriended residents experienced economic exclusion, and this contributed to exclusion from services (institutional exclusion) and social support (meaningful relations).

Territorial exclusion

Territorial exclusion reflected physical isolation and lack of mobility. Unbefriended residents experienced both. They had limited control over their facility placement and, once placed, were often unable to leave their unit or facility. Our prevalence study (Study #3) found that facilities with the highest proportion of unbefriended residents had more than 135 beds and were public-not-for-profit.[45] Directors of Care indicated in interviews that unbefriended residents were placed in older, less desirable facilities, in downtown city centres. LTC staff believed that the public guardians did not advocate for a 'better' facilities (e.g., facilities with newer, specialized programs) and defaulted to the first available bed.

> The guardian's office will never refuse placement. It is never a matter of the guardian saying, "Well, it's a small room," or, "You know, it's an old facility..." If somebody is under guardianship and we call, that offer is accepted within an hour. (Director of Care, Facility #3)

Public guardians conceded that there were issues housing unbefriended individuals. From their perspective, unbefriended residents were challenging to place due to their specific characteristics, such as challenging behaviours, a history of substance and/or alcohol use, and

mental health issues. A public guardian described the placement process for unbefriended residents:

> I hate to say it, but they are a type of facility that you would never want to send your family member to. It is really quite sad because they end up in shared rooms, on a secured unit that is locked and that is basically where they stay. (Public Guardian, #3)

For unbefriended LTC residents, territorial exclusion was also related to exclusion from meaningful relations and economic exclusion. Unbefriended residents had no family to assist them in the placement process (meaningful relations). Once in the facility, unbefriended residents remained on their unit because they did not have anyone to accompany them, especially to activities off the unit or outside of the facility. Because unbefriended residents commonly lacked financial resources, which meant they were unable to pay for a private companion to assist them in leaving their unit or facility. Economic exclusion contributed to territorial exclusion for unbefriended residents.

Meaningful relations

Unbefriended residents experienced exclusion from meaningful relations. They were severely socially isolated.[39] Our interviews included a category of *'Social Support'* which described this social isolation.[39] Interview findings demonstrated that unbefriended residents had no visitors and limited contact with anyone outside of the facility. LTC staff and public guardians expressed concern over the social isolation and non-existent visitors for unbefriended residents. Our analysis of RAI-MDS data found that, compared to LTC residents with family contact, unbefriended residents had a higher likelihood of a diagnosis of depression.[47] Furthermore, we found that unbefriended residents had a higher likelihood of depressive symptoms and lower social engagement than residents with family contact.[47] Our interview findings and our analysis of the RAI-MDS data indicate that unbefriended residents experienced exclusion from meaningful relationships.

Institutional exclusion

Institutional exclusion included in organizational barriers, decreased services, and limited consultation on one's care. Our interview findings in Study #2 showed unbefriended residents experience of institutional exclusion. The category of *'Public Guardian Delays'* described how unbefriended residents experienced issues accessing services due to 6 to 9 month waits for guardianship application approval.[46] During this waiting period, unbefriended residents are unable to access any services requiring the resident to pay. Facility Directors of Care indicated that, as a result of the guardianship delays, their facility would no longer accept residents whose public guardianship application was not fully finalized (i.e. was currently under review). This category also described delays experienced once public guardianship was approved. LTC staff described persistent challenges reaching a public guardian, particularly outside of traditional office hours (e.g., 8am to 4pm) and on holidays or weekends. These delays had a profound impact if an unbefriended resident died. LTC staff were often unclear about how to proceed with after-death arrangements (e.g., funeral home arrangements). As a result, LTC Directors of Care in two facilities (of the 7) described developing documentation policies to ensure that unbefriended residents' after-death arrangements were documented on admission.

In the category '*Public Guardian Scope of Work'* we reported that the public guardians' activities were restricted to decision-making and did not include responsibility for purchasing items or accompanying residents to appointments.[46] As a result, unbefriended residents experienced delays or were simply unable to access necessary services. Unbefriended residents were unable to access services (institutional exclusion) because they did not have the financial resources (economic exclusion) to pay for uninsured services or items and/or companions to assist them to access these items and services.

Identity exclusion

Unbefriended residents experienced identity exclusion when they were identified by LTC staff only by their public guardianship status. Our interview findings indicated that having a public guardian—versus a family member guardian—contributed to the LTC staff's perception of the resident and their available resources. LTC staff perceived that, because the resident had a public guardian, he or she did not have any financial resources. Although this was often the case,

it was not always correct. A care manager described staff members' perception of unbefriended residents and the potential impact this perception had on the resident care.

> There was a perception from the staff that if somebody had a public guardian or trustee that they just had nothing. They did not have money, they did not have anything—and staff would not ask [for personal items]. They [staff] would not advocate, because there was a perception that this person just had nobody in their life and had nothing, so we could not ask. The staff went out and collected things and asked for donations. I found lots of times, residents would go without because nobody thought to ask. (Care Manager, Facility #7)

Although most unbefriended clients in LTC had limited financial resources, this was not the case for all clients. Public guardians described instances where unbefriended clients had savings that would have enabled them to pay for personal items and services—such as a paid companion— but these savings were not known about or accessed.

> Sometimes I have walked into rooms and somebody has funds to buy things, but nobody has bought it. They have got [the] basics but they have got the finances to support nice creams or nicer clothes. (Public Guardian #2)

Unbefriended residents experienced diminished access to care and services (institutional exclusion) because LTC staff made assumptions about their resources.

Socio-political exclusion

Unbefriended residents are socio-politically excluded because they have a public guardian. Public guardianship removes an individual's decision-making rights. It is the most restrictive form of surrogate decision-making. Unbefriended LTC residents are legally excluded from civic participation (i.e., they cannot vote, choose with whom to associate or choose where to live). The socio-political restrictions on unbefriended LTC residents affected all the other dimensions of exclusion. Socio-political exclusion is not a 'standalone' category from our findings but is reflective of unbefriended residents as a group. We have represented socio-political exclusion as an overarching dimension in Figure 7-2.

Symbolic exclusion

Symbolic exclusion reflected the invisibility of groups in society. Our scoping review found that neither Canada nor the United States collects national statistics on the number of unbefriended individuals, their characteristics, their place of residence, or their health. This group of individuals, who are marginalized and highly vulnerable, are not represented in any Canadian research of which we are aware.[38] Symbolic exclusion reflected the complete absence of information on unbefriended individuals. Like socio-political exclusion, this invisibility is an overarching dimension. The limited information on unbefriended residents and their lack of representation in routine reporting has the potential to affect the other exclusion dimensions.

[Figure 7-2. Social exclusion of unbefriended LTC residents]

New concepts relevant to unbefriended residents' social exclusion

We demonstrated that the existing domains of Guberman and Lavoie's framework[44] of social exclusion are relevant to unbefriended LTC residents. In addition, we described the linkages among the domains for this resident population (Figure 2). However, based on our study findings, we have identified additional concepts relevant to unbefriended resident's social exclusion. These domains are: (i) health, (ii) resident characteristics, and (iii) system factors.

Health: a predictor and outcome of exclusion

Health is a predictor of exclusion. Impairments in health and decision-making (cognition) precipitated unbefriended residents' need for a surrogate decision-maker and thus their socio-political exclusion. Unbefriended residents have mental illnesses, multiple chronic conditions, developmental disabilities, stoke or traumatic brain injuries.[39,40,48] Unbefriended individuals with a history of poor health often did not have personal income beyond a low-income pension (in Canada known as the Old Age Security Pension and Guaranteed Income Supplement), contributing to their experience of economic exclusion.

Poor health is also an outcome of social exclusion; compared to residents with family, unbefriended residents were more likely to experience less social engagement, more frequent and severe pain, more aggressive behaviours, and more symptoms of depression. Unbefriended residents experienced more interventionist care practices, including more medical testing and more frequent transfers to hospital. These more interventionist care practices are related to poor quality of care.[15] Our study findings demonstrated that health is related to exclusion, as a predictor and an outcome, for unbefriended LTC residents, and should be integrated into the framework of social exclusion.

Unbefriended resident's characteristics prior to LTC: a predictor of exclusion

An unbefriended resident's characteristics, prior to LTC entry, influenced his or her social exclusion. Many unbefriended residents had marginalized backgrounds, which included homelessness and substance and alcohol use.[39] For example, unbefriended individuals had varied work histories that contributed to their economic exclusion. In some cases, unbefriended individuals lived at significant geographic distance from family, or had outlived family, and these factors contributed to their exclusion from meaningful relationships. However, mental illness, substance and alcohol use were described by LTC staff and public guardians as a major reason for the resident's lack of meaningful relationships and need for a public guardian. Characteristics prior to LTC placement are relevant to social exclusion and therefore should be considered when examining social exclusion in LTC settings.

System factors

We identified a number of organizational factors that influenced unbefriended residents' social exclusion. These factors were identified from the LTC staff and public guardian interviews. Unbefriended residents did not have financial resources to hire a companion or have external social support (i.e., family members) to help them access personal items and services. The category of '*Public Guardian Scope of Work'* described the activities that public guardians did or did not do within their role and how this impacted unbefriended LTC residents. Public guardians are not responsible for shopping for personal items, scheduling appointments, or going with residents to appointments. As a result, unbefriended residents had persistent issues accessing these items and services. The category of '*Staff Workarounds'* described the activities that LTC staff engaged in to compensate for the public guardian's limited scope of work. LTC

staff searched the lost and found for personal items, brought in items from home, and bought items for residents.[39] LTC staff devised creative solutions to overcome limitations imposed by unbefriended residents' financial constraints. They developed cooking programs when residents could not afford to pay for special meals, and purposely did not document unbefriended residents' attendance during activities that required a fee. Most LTC facilities had holiday programs that collected items for residents during the holiday season, and unbefriended residents were the biggest recipients from these charitable programs. LTC staff attempted to reduce unbefriended residents' social isolation. Staff sat beside unbefriended residents while completing their required charting and identified unbefriended residents as priority for volunteer visits. LTC staff recognized that unbefriended residents had no visitors and required social support. They focused attention and affection on unbefriended residents because they knew that these residents had no family member support. LTC staff provided emotional care and support to unbefriended residents, thus acting to reduce their exclusion from meaningful relationships. LTC staff described providing this care and attention specifically to unbefriended residents, as opposed to residents with family members, because they felt that unbefriended residents had the greatest unmet need for social support. Although unbefriended residents experienced exclusion, LTC staff "workarounds" and often surreptitious efforts attempted to reduce the potential negative impact of resident's exclusion.

We found a '*LTC ethos'*, that is a sense of duty and the responsibility that LTC staff feel for unbefriended residents.[46] LTC staff, particularly care aides, were highly attentive and caring towards unbefriended residents. LTC staff described their feelings of sympathy and empathy towards unbefriended residents. The staff described these feelings as a result of wondering how they would feel if they (the staff) were that resident or if the resident were their loved one.

Organizational policies and practices inhibited LTC staff's ability to reduce unbefriended resident's exclusion. The workarounds that LTC staff engaged in were not always acknowledged or supported by LTC facility management. In fact they were often discouraged. Our interviews with LTC staff included the category of '*Equal Care'* that described the implicit policy in many LTC homes that that the care provided to residents must not demonstrate favouritism.[46] As a result, LTC staff did not vocalize or publicly acknowledge the additional care and services they provided to unbefriended residents. LTC staff continued to provide this care, regardless of

organizational policies, because in their minds they were "equalizing care" and providing care that reflected their individual values and beliefs.

LTC staff described communication deficits among the LTC staff that affected their ability to initiate required workarounds. We interviewed LTC staff from 7 facilities. Only one of those facilities included direct care staff (i.e., care aides) in their care conferences. Care aides and licensed practical nurses in 6 of the 7 facilities indicated that communication issues between the staff, particularly between regulated (i.e., registered nurses) and unregulated staff (i.e., care aides), inhibited their ability to provide timely and essential care to unbefriended residents. Care aides were often not informed that a resident had a public guardian. This meant that they were unaware that there might be delays receiving personal items. As a result, LTC staff waited to receive items and did not initiate workarounds right away. Poor communication among the LTC staff meant that unbefriended residents might go without necessary staff workarounds.

We identified communication and decision-making issues between the LTC staff and the public guardian. The category of '*Goals of Care'* identified potentially inappropriate practices experienced by unbefriended residents. This category had a sub-category of '*Public Guardian Decision-Making'*. Unbefriended residents experienced variable and potentially inappropriate care compared to residents with family member guardians. Individual public guardians had different levels of engagement with their clients, different frequency of interaction with LTC staff, and different levels of medical knowledge.[39] Most public guardians had limited contact with LTC staff or unbefriended residents and visited the facility once a year for the resident care conference. Public guardians had diverse professional backgrounds (e.g., nursing, social work, corrections, pastoral) which led to concerns over their ability to provide meaningful decision-making support for unbefriended residents. Unlike family member or friend guardians, public guardians had limited knowledge of the unbefriended resident's values or wishes. Collectively, these issues in public guardian decision-making contributed to issues with quality of care (e.g., health outcomes) for unbefriended residents.

Summary

Using the findings from our studies, we demonstrated that the existing domains of Guberman and Lavoie's framework of social exclusion were applicable to unbefriended LTC residents. Our findings indicated that unbefriended residents experienced exclusion from

services, relationships, financial resources, civic participation, individual identity, and representation. Furthermore, we identified linkages between Guberman and Lavoie's domains that reflect the interlinking, multidimensional nature of the domains in unbefriended LTC residents. Complex adaptive system theory, we suggest, has theoretical concepts in common with Guberman and Lavoie's framework of social exclusion, and is a natural conduit with which to examine social exclusion in institutional settings. Integrating complex adaptive systems theory concepts provides insight into institutional settings, and the processes and factors that alleviate or exacerbate exclusion.

Applicability of Guberman and Lavoie's framework of social exclusion to LTC residents

Guberman and Lavoie's framework is one of the few theoretical frameworks whose developers have described theoretical foundations in sociology and critical gerontology and their understanding of the common connections among social exclusion domains.[44] For example, they indicated that economic exclusion is closely associated with access to services.[32,44] Guberman and Lavoie have indicated that there are inherent tensions in exclusion because social position and identity (both external and internal) shape experience and access to resources. They reference intersectionality as a critical interest in their work, noting that older adults are situated at the intersections of many social positions (gender, economic status, disability, race, physical and mental health).[32,44] Guberman and Lavoie's framework for older adults aims to rectify the criticisms of social exclusion research which have argued that inequity (i.e., economic inequity, relational inequity) is less relevant to older adults because, compared to younger or middle-aged adults, they are a relatively homogenous group.[20,24,49]

Guberman and Lavoie's descriptions of the domains and their writing on exclusion is not consistent with their visual representation of their framework. Although the theoretical and conceptual underpinnings of Guberman and Lavoie's framework reference the interrelated nature of the domains, the framework is depicted as standalone domains (see Table 1). The visual representation of the framework does not reflect the proposed intersections that the authors described as inherent and critical to research on social exclusion. Walsh et al.[17] indicated that the visual presentation of social exclusion frameworks, typically represented as a table with domain definitions (see Table 1), was indicative of how social exclusion frameworks are currently being used in research. Namely, that social exclusion frameworks are descriptive and have only been

used to clarify the dimensions and not to move to higher level (i.e., causal) theoretical developments. Our study suggested potential linkages among the dimensions. These linkages may change based on the population of interest, however showing the relationship among the concepts is a critical next step in social exclusion's theoretical development. Guberman and Lavoie's framework should show potential linkages among the dimensions. This would move social exclusion research beyond simple identification and description, towards a theory that integrates relational pathways of social exclusion.

Guberman and Lavoie also point out that exclusion can change over an individual's life course.[32,44] This is consistent with research on the cumulative and co-existing disadvantages of older adults. Older adults are tipped into exclusion with age-related declines and reduced social networks.[5] Again, although Guberman and Lavoie recognize disadvantage over the life course as relevant to older adults' social exclusion, their existing framework does not reflect temporal or cumulative factors that influence an individual's current exclusion. Our study showed that pre-existing characteristics and lifestyle factors (e.g., health, resident characteristics) are critical to understanding current exclusion. Including these factors in the framework improves our understanding of the drivers of exclusion, and thus potential areas for early intervention.

Guberman and Lavoie's framework identified existing dimensions of exclusion but did not account for organization (i.e., system, contextual) factors influencing exclusion of institutionalized individuals. Complex adaptive system concepts are relevant to LTC residents' social exclusion. Complex adaptive systems thinking has been used in health care settings to understand the organizational processes that influenced quality of patient (resident) care and quality of work life of staff.[58-65] Complex adaptive systems are characterized by diverse agents who interact and adapt.[55-58] Agents are individuals who interact in a system (e.g., LTC staff, patients/residents).[57,63] Learning is a key feature of complex adaptive systems and is a result of interactions among agents and interactions of agents with the environment.[66,67] Common concepts in complex adaptive systems are non-linearity, self-organization, emergence, and co-evolution.[56-58,68] Non-linearity describes the unpredictability of systems. Agent interaction and learning result in or during processes of self-organization, emergence, and co-evolution.[56-58,62,63,69,70] Self-organization is the order that emerges from interactions among the agents.[58] Self-

organization often reflects structures and behaviours that are not related to agent position or hierarchy in a system.[58]

Linkages between complex adaptive systems theory and Guberman and Lavoie's social exclusion framework

We argue that we can link Guberman and Lavoie's framework with complex adaptive systems theory because they have ontological and epistemological commonalities. Guberman and Lavoie's framework is grounded in symbolic interactionism and critical gerontology.[44] Critical gerontology aims to identify and dismantle structural inequalities and traditional approaches to aging.[50] Symbolic interactionism is a sociological approach to studying the meaning of interaction.[51,52] Symbolic interactionism, as a foundational theoretical perspective of Guberman and Lavoie's framework, explains how interactions generate meaning, value, and group norms.[51] Complex adaptive systems examines how people in a system (agents) interact and adjust their behaviour based on those interactions.[53] Both symbolic interactionism and complex adaptive systems focus on the dialectical processes of interpretation and action among individuals in a system. However, complex adaptive systems examines the outcomes of these processes on the functioning of organizational systems (i.e., healthcare organizations). This reflects the utility of a complex adaptive system perspective to examine unbefriended LTC residents. Symbolic interactionism does not focus on input and output of a system, it is concerned with understanding how meaning is generated and how individuals and groups convey meaning through their interactions.[54] This is consistent with the complex adaptive systems concept of non-linearity. Non-linearity reflects the unpredictable and often incommensurate actions in a complex system. Systems are complex and non-linear because the outcomes are not predictable or proportional to inputs. Complex adaptive systems focus on understanding the patterns of interaction that propagate outcomes rather than just the outcomes themselves. Symbolic interactionism and complex adaptive systems theory both focus on interaction, non-linearity, and processes rather than inputs and outcomes, reflecting their compatibility.

Epistemologically, symbolic interactionism examines how individual constructions of 'meaning' give insight into the 'real' world. It reflects the belief that although individual perspectives can bring us closer to reality, no perspective reflects the true reality.[54] A fundamental question in complexity science is whether complexity is a property of a system, a

property of interactions or groups, or simply a property of any outside interpretation. Increasingly, the consensus is all of the above.[53] Cilliers's[55] foundational work on complexity and postmodernism argued that a complete understanding of a system is impossible and that our knowledge of a system is unavoidably incomplete. Symbolic interactionism (the foundation of Guberman and Lavoie's framework) and complex adaptive systems theory share the epistemological contention that there are limits to knowledge. In their own way, each perspective seeks to understand how systems are developed and function. Through rigorous and in-depth examination, we can understand how system agents create and sustain systems. The commonalities between Guberman and Lavoie's framework and complex adaptive systems means that integrating the framework and theory are possible and provide a deeper insight into the exclusion of institutionalized older adults.

Unbefriended LTC residents and complex adaptive systems theory

We argue that, in order to examine social exclusion in LTC, complex adaptive systems concepts should be adopted.[56-60] Systems theories, such as complex adaptive systems theory, are those that examine the multiple, hierarchical, and complex systems that exist in the world.[53] LTC homes are complex adaptive systems.[3,60,71] They include diverse agents (e.g., LTC staff, residents) whose interactions influence resident care. To understand the impact of social exclusion on residents in LTC, we must understand the complex adaptive system in which they receive care.[63] We organized this section of the discussion based on core complex adaptive system concepts described by McDaniel[56-58], Reuben[70], and Anderson.[59-61]

Self-Organization

Self-organization is the interaction between agents or groups in a system. It reflects how organizational structures evolve without explicit intention or intervention.[55] Self-organization is often identified when staff bend the rules.[68,72] *LTC Staff Workarounds* are an example of self-organization. Unbefriended residents were economically and socially excluded. They did not have enough resources or social support to ensure that their basic needs were met (i.e., clothing, personal care products). Public guardians are not family members and do not provide instrumental support to unbefriended residents.[39,46] As a result of system gaps and unmet needs, LTC staff undertook a variety of activities to meet unbefriended residents' needs. In our study, LTC staff self-organization occurred in response to unmet needs. LTC staff's self-organization

led to a series of adaptive processes that affected unbefriended resident's exclusion. These adaptive processes are known as emergent properties.[63] Emergence is often seen in crises—when groups rise to the occasion to organize, develop creative solutions and adapt to demands.[63] LTC staff developed programs and workarounds to care for this unique resident population. LTC staff creativity and ingenuity reflected emergent properties as they tried to alleviate the exclusion of unbefriended LTC residents.

Organizational policies and practices can alter the routines among the agents in the system.[68,72] In our study, organizational policies regarding '*Equal Care'* meant that LTC staff hid or did not openly acknowledge the routines they had devised to care for unbefriended residents. These hidden and invisible staff activities are specific to unbefriended residents. These emergent properties can reduce the negative impact of social exclusion. However, the enactment of these properties can be hindered by inadequate information flow in the system. Self-organization relies on the information flow through the system, the quality of the relationships between the agents, and the diversity of cognitive schema.[60] Higher levels of these parameters allows for higher order learning and allows for creativity and opportunities for positive evolution.[67] LTC facility staffing exhibits a rigid hierarchy between regulated (e.g., registered nurses, licensed practical nurses) and unregulated (e.g., care aides) staff which impedes the flow of information.[59,73,74] Direct care staff (i.e., care aides, licensed practical nurses) were often not included in care conferences and were not told when a resident did not have a family member guardian. Inadequate information and poor-quality relationships between the LTC staff impeded staff's ability to engage in the subroutines that supported unbefriended residents. This is consistent with findings from Anderson et al[60] who examined LTC staff using complex adaptive systems. Anderson et al[60] found that not including direct care staff in formal team meetings did not stop staff's self-organization, it simply starved the team of new information and skills.[60] We found that LTC staff still engaged in these subroutines for unbefriended residents, however they occurred later (often months later) once the staff realized the resident had no family. Insufficient information flow delayed essential care to unbefriended residents and resulted in diminished resident quality of care and quality of life.

Staff participation in decision-making is an emergent property that reflects the quality of interactions in the LTC home.[61] Decision-making is a critical factor in unbefriended residents

quality of care.[39] Public guardians have minimal interaction with LTC staff and unbefriended residents. They have varied professional backgrounds and limited engagement with the unbefriended resident and the LTC staff.[75] Care decisions differ across individual public guardians and there is significant variability in the health care decision-making, particularly at the end of life, for unbefriended residents. Although agent diversity can produce benefits for a system, in the case of unbefriended LTC residents, it can lead to inconsistent and inappropriate care. Unbefriended residents experience variability and unpredictability in their care. Care decisions are often based on an individual public guardian philosophy of care rather than their understanding of the resident. Public guardians do not have a personal relationship with the unbefriended individual and cannot go by the traditional surrogate decision-making standard of the goals and wishes of the person, and instead must rely on their perception of the 'best-interest' of the individual.[76] Care provided to unbefriended residents is often inconsistent with palliative care and comfort care approaches. A palliative care approach to care focuses on relief from pain and other distressing symptoms, and limiting unnecessary treatments experienced by people reaching the end of life.[12,77] Unbefriended residents experienced care that does not reflect a palliative approach.[39] More aggressive, interventionist approaches to end-of-life care may reflect the reluctance of substitute decision-makers to forgo potentially life-sustaining treatments and tests.[15] Although there are no agreed upon frameworks to guide decision-making for unbefriended LTC residents,[43] public guardians should rely on guidance from the interdisciplinary care team who interacts most frequently with the resident.[78] Yet, direct care staff (i.e., care aides), who have the most interaction with the resident, are the least likely to be systematically included in formal decision-making (i.e., care conferences). Quality of care provided to unbefriended residents is contingent on information flow and the relationship between the LTC staff and the public guardian. The concept of self-organization is an essential concept to understand the factors that influenced social exclusion. Our findings demonstrate that assessing information flow and relationship quality between agents influence social exclusion and the quality of care issues as a result of exclusion.

Sensemaking

LTC staff and public guardians in our study exhibited processes of sensemaking. Sensemaking is how people try to make sense of events in their environment. It influences interaction patterns and self-organization of a system. [59,79] The category of '*LTC Ethos'* reflected

the motivation of LTC staff to care for unbefriended residents. It described the duty and responsibility that LTC staff felt towards these socially excluded individuals. Public guardians used sensemaking to rationalize their reliance on LTC staff. Neither public guardians nor LTC facility staff are technically responsible for providing 'extra' care to unbefriended residents (e.g., purchasing personal items, accompanying residents to appointments). However, public guardians rationalized that LTC staff, who interact with residents most often, would take on the responsibility of caring for unbefriended residents. Public guardians' mental model (way of seeing the world) justified that LTC facilities and staff felt compelled to care for disadvantaged residents. Conversely, LTC staff rationalized their extra care based on their personal feelings of empathy and sympathy.[46] LTC staff described their actions towards unbefriended residents as a reflection of their desire to treat the resident as they hoped someone would treat them or to treat the resident as if the resident was their family member. Anderson et al.[59] offered a similar description of care aide mental models. They described care aides treating residents as they would want someone to treat them, and treating residents as if they were their own children.[59] These interpretations and sensemaking efforts that LTC constructed influenced their desire and inherent sense of responsibility for unbefriended residents.

Sensemaking does not always result in positive outcomes and can be built on an unclear and surface level rationality.[79] We found that LTC staff sensemaking contributed to unbefriended residents identity exclusion. For example, identity exclusion reflected the LTC staff's reductive reasoning that unbefriended residents were always economically or socially excluded. LTC staff held this belief about all unbefriended residents and therefore somehow enacted their subroutines without considering the resident as an individual. Care staff acted on their sensemaking for unbefriended individuals and did not assess whether the resident had resources that could alleviate their exclusion. Effective communication, between the public guardian and among the LTC staff, can improve the LTC staff's sensemaking strategies. Participating in decision-making can improve LTC staff's sensemaking and ultimately lead to improved outcomes.

Co-evolution

Co-evolution occurs when an organization's response alters both the organization and the environments.[56] It is an organization's change and response to feedback over time. LTC staff did not acknowledge their specific actions towards unbefriended residents because of implicit or

explicit policies regarding 'unequal' care. From our study we cannot determine how or when these policies were developed and instituted. However, the outcome of those policies is a series of subroutines by LTC staff that are not recognized and not compensated.

We identified co-evolution in facility policy responses to unbefriended residents. LTC staff, specifically Directors of Care, instituted policies such as not accepting individuals whose guardianship application was in process. This response (not accepting residents without a public guardian in place) at an organizational level has cascading effects. Unbefriended residents may end up being placed in facilities that do not have these policies. We found high concentrations of unbefriended residents in specific types of facilities (i.e., >135 beds, found in large urban centres, public-not-for-profit). Based on our studies we cannot determine whether these policies affected placement decisions. However, it does suggest that one facility's decision may influence other facilities in unpredictable and undetermined ways.

Complex adaptive systems and social exclusion: where do we go from here?

We have demonstrated that Guberman and Lavoie's framework of social exclusion and complex adaptive systems theory are theoretically and practically commensurate. We propose that concepts from complex adaptive systems theory should be integrated into the framework of social exclusion if social exclusion is assessed in institutional settings. Our proposition has implications for future research. First, the theoretical and conceptual linkages between social exclusion and complex adaptive systems should be further examined in the scholarly literature. Our work is a contribution to this scholarship but there must be more critical analysis of the ways in which organizational studies principles can be integrated with existing social exclusion frameworks. This may include fora and dedicated calls for papers describing the potential and pitfalls of our approach. Second, our framework should be further refined and tested in other institutionalized samples. Our work is promising but it is specific to a subgroup of institutionalized older adults. Next steps include assessing our proposed framework in a broader sample of institutionalized older adults. Continued refinement will result in a more robust framework which will enable advanced inquiry into the predictors and outcomes of exclusion.[80]

Conclusion

Unbefriended residents are socially excluded. Guberman and Lavoie's framework, although a useful tool to describe the types of exclusion that unbefriended residents experience in

LTC settings, falls short of adequately describing or explaining these residents' experience of exclusion. We demonstrated that LTC homes are hardly equitable and that exclusion is relevant to institutionalized individuals. Furthermore, we identified linkages and additional domains that improve our ability to identify and address social exclusion. We showed the complex adaptive systems theory was consistent with the underpinnings of Guberman and Lavoie's framework and could offer important insights into the dynamic interactions among residents, LTC staff, and public guardians. When caring for unbefriended residents, LTC staff and public guardians reflected the complex adaptive systems theory principles of self-organization, emergence, sensemaking, and co-evolution. Future work will refine the framework in a broader sample of institutionalized older adults. We aim to test associations between the domains of exclusion and institutional factors to assess their association with exclusion and other relevant outcomes.

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Table 7-1. Guberman and Lavoie Social Exclusion of Older Adults Framework Domains

Domain	**Definition**
Economic	Lack of access to income or material resources required to meet basic needs
Territorial	Geographic isolation, regulation to spaces with limited opportunity for social involvement, lack of geographic mobility or control over one's environment
Meaningful relations	Exclusion from the development and maintenance of meaningful social relationships through the absence of networks, lack of access to them, or rejection from them
Institutional	Exclusion from social and political institutions resulting from decreased services that negatively affect their health and well-being and/or no consultation with the individual or their caregivers regarding their care
Identity	Dismissal or diminishment of the distinctive and multiple identities of the person or group through reduction to one identity such as age
Symbolic	Negative representations afforded particular groups as well as the invisibility of each groups within society
Socio-political	Barriers to civic and political participation resulting from a lack of involvement in decision-making, collective power, limited political clout or agency

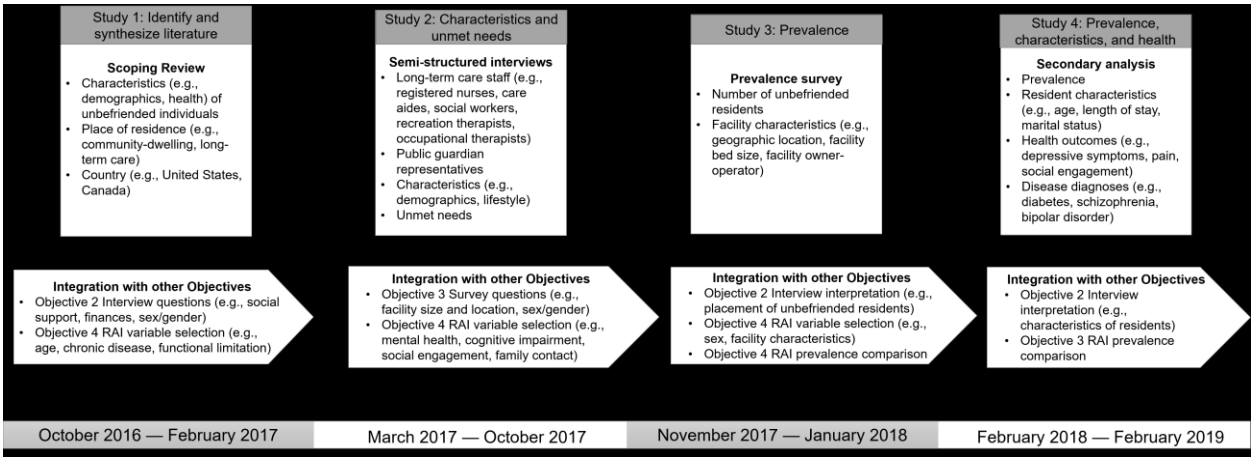

Figure 7-1. Project studies, methods, and timeline

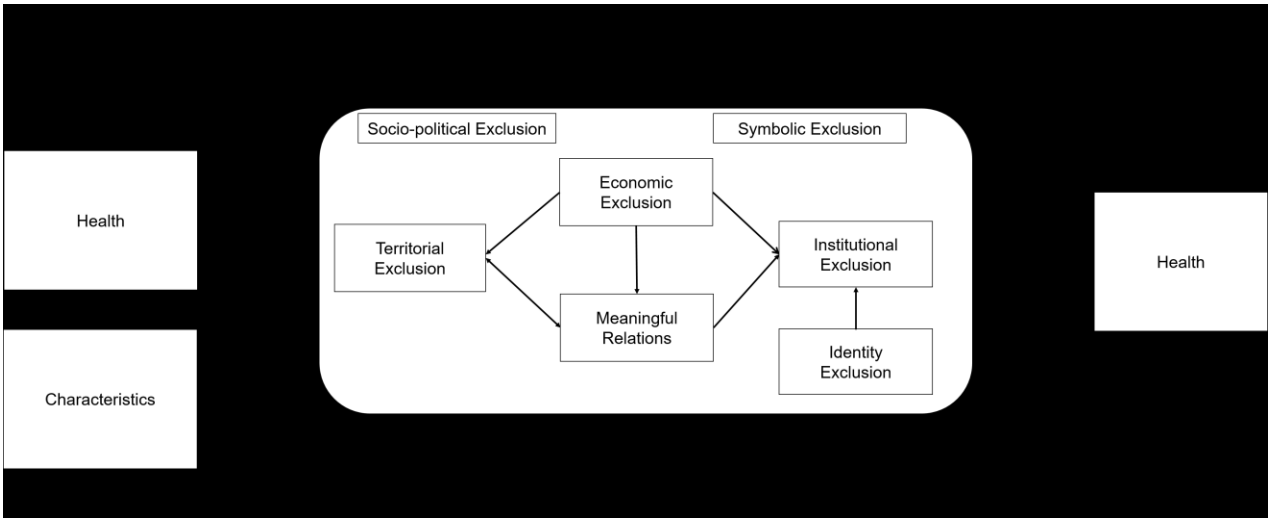

Figure 7-2. Social exclusion of unbefriended LTC residents

Chapter 8: Summary, Contributions, and Recommendations

This chapter contains a summary of my findings, contributions this dissertation makes to theory, policy and practice, limitations, and knowledge translation activities. The final section highlights my future research.

Summary of the Findings

The purpose of my dissertation was to identify the prevalence, characteristics, and unmet needs of unbefriended LTC residents. I have achieved my overall purpose and have identified several areas for future research. My dissertation contributes *internationally and specifically, to the Canadian research literature* on what is known about unbefriended residents in LTC homes. My scoping review (Paper #1) identified troubling gaps in the available research on unbefriended older adults.[1] I found no Canadian research or reports on unbefriended individuals. I found only one study conducted in LTC and this study did not provide any detail on the characteristics or unmet needs of this resident population. The papers that were available focused on community-dwelling older adults in the United States (US). These unbefriended older adults tended to have limited social support networks (i.e., childless or had fewer children), cognitive impairments, and were older than individuals with family guardians.

This dissertation contributes substantively to the research on the characteristics of unbefriended LTC residents. Using Guberman and Lavoie's social exclusion framework, I generated interview findings that described the characteristics and unmet needs of unbefriended LTC residents (Paper #2).[2] I determined that unbefriended LTC residents are often from marginalized populations and estranged from family or have no known family. Unbefriended residents have no visitors and are socially isolated. Previous to my research, most of the literature regarding the characteristics of unbefriended individuals was speculative and not based on empirical literature, therefore my qualitative research fills a critical gap in the research.[3-5] I found that unbefriended LTC residents experienced significant issues accessing personal items. As a result, LTC staff supported these residents, and this support was often hidden or unrecognized. Perhaps my most alarming finding was that unbefriended LTC residents often experienced more aggressive interventionist care (e.g., transfers to hospital, medical testing) than

residents with family member guardians. Previously, acute care research in the US hypothesized that unbefriended patients were at risk of experiencing either under-treatment or over-treatment due to the lack of a family member decision-maker.[6-8] My findings contribute substantially to the literature, describing these potentially inappropriate care practices for unbefriended residents in LTC.

My interviews with LTC staff and public guardians identified organizational barriers and facilitators to providing unbefriended resident care (Paper #4).[9] The original intention of the interviews was to identify resident characteristics and unmet needs, however I quickly discerned that there were a number of organizational factors that contributed to the care of unbefriended residents. This paper identified the cascading effects of organizational policies and practices that contribute to unbefriended resident quality of care.[9] I found that public guardians' scope of work (i.e., their job activities) did not reflect the needs of unbefriended LTC residents. Public guardians' reliance on LTC staff to provide supplemental care often conflicts with organizational policies and is unsustainable given the limited staffing resources in LTC.

In Paper #4, I identified the prevalence of unbefriended residents in Alberta LTC homes. I determined that unbefriended residents comprised a little over 4% of LTC residents in Alberta. However, I found that organizational factors (e.g., bed size, geographic location, owner-operator) were a significant driver of unbefriended residents' location of residence. Facilities with more than 120 beds that were in large urban cities had the highest prevalence (up to 15%) of unbefriended residents.

In Paper #5, I identified unbefriended residents' clinical characteristics and health outcomes using RAI-MDS 2.0 data.[10] I identified 945 individuals who had no contact with their family. I found that the resident characteristics in the RAI-MDS were consistent with the resident characteristics described by LTC staff and public guardians in my qualitative interviews. Compared to residents with family contact, unbefriended residents in the RAI-MDS had a greater likelihood of having mental health issues, more symptoms of depression, more frequent and severe pain, and lower social engagement. I compared the prevalence of unbefriended residents in the RAI-MDS to my prevalence survey and found that although RAI-MDS underestimated the overall prevalence, it may be a reasonable proxy with which to identify these individuals in administrative data.

Contributions

My dissertation has made important contributions to knowledge, theory, practice and policy.

Knowledge

My dissertation contributes substantively to the research on unbefriended LTC residents. I have contributed to what is known about the prevalence, characteristics, and unmet needs of unbefriended residents in Alberta LTC homes.[1,2,9-11] My dissertation contributes to the broader research on social isolation in LTC. Research on social isolation in older adults is abundant throughout the nursing, psychology, and gerontology literature.[12-15] Social isolation is associated with psychological concerns including depression, loneliness, cognitive decline, and increased rates of infection, falls, hospitalization, and mortality.[13,16,17] However, there is comparably little research on the isolation of institutionalized older adults.[12] Unbefriended LTC residents represent the most extreme case of social isolation. They have no willing or capable family member decision-maker. They have no visitors. They have no rights as persons under the law. My study examining the RAI-MDS data identified several troubling associations with poor health outcomes as a result of having no family contact. Health outcomes including more symptoms of depression, pain, aggressive behaviours, and lower social engagement, demonstrate the potentially negative outcomes of social isolation in LTC residents.

Theory

This dissertation advanced our understanding of social exclusion. It is the first study to examine residents in LTC through a lens of social exclusion (Paper #6). Previously, social exclusion research has not included institutionalized older adults.[18] My methodological approach addressed calls in the literature for multi-method research in social exclusion.[18] My dissertation contributes to the theoretical literature of social exclusion in several ways. *First*, I demonstrated that the dimensions of social exclusion are relevant to institutionalized individuals and can be used to describe unmet needs in this population. *Second*, I described linkages among the dimensions. The proposed linkages among the dimensions are a critical contribution to the theoretical literature. Previous to this work, the social exclusion literature has been criticized for providing a collection of dimensions and no indication of the relationships among these

dimensions.[19] These linkages among the dimensions can be tested in future empirical work to assess causal relationships between social exclusion and resident health outcomes. *Third*, I identified additional concepts relevant to the social exclusion of unbefriended LTC residents.

The most significant theoretical contribution I made was arguing for the inclusion of *complex adaptive systems* concepts. Drawing on the epistemological and ontological foundations of Guberman and Lavoie's framework[20] and complex adaptive systems theory,[21,22] I demonstrated that complex adaptive system concepts provided necessary insight into the organizational processes the affected the exclusion of unbefriended LTC residents. I identified organizational practices that were specific to unbefriended residents and how they contributed to unbefriended residents' exclusion. The inclusion of complex adaptive systems principles is an important contribution to the evolution of Guberman and Lavoie's framework, enabling a more comprehensive assessment of social exclusion in institutional settings.

Policy and Practice

My dissertation findings have implications for policy and practice. Results of LTC staff interviews identified *facilitators and challenges to providing care* to unbefriended residents in LTC. I found that LTC staff are engaging in numerous activities outside their traditional scope of practice to provide care to unbefriended residents. However, policies regarding hours of resident care do not consider this extra care that LTC staff provide for vulnerable residents. In fact, unwritten rules about "equal care" discourage staff from providing this extra, but essential, care to unbefriended residents. The extra care that staff provide in addition to their existing work activities has implications for the funding of LTC homes. Governments should measure the social vulnerability of LTC residents,[23-26] in addition to their clinical characteristics. My findings indicated that certain facilities have a higher prevalence of unbefriended residents and consequently their staff may be engaging in more of these extra activities. Therefore, funding assessments should integrate metrics that consider integrating measures of the social vulnerability of the resident population, in addition to the clinical vulnerability, when assessing facilities for funding.

My review noted the complete lack of national tracking of unbefriended individuals as a key issue in our inability to assess their characteristics and unmet needs. This is a key policy

issue because my interviews indicated that unbefriended residents experienced more aggressive care practices at the end-of-life. I found that unbefriended residents are not receiving care that is based on palliative care best practices. Without robust measurement of unbefriended individuals and the care they receive we are unable to assess these practices in routinely collected health data. I have demonstrated the potential application of RAI-MDS data to assess the prevalence and health of unbefriended LTC residents. I demonstrated the use of these data for regional and provincial health authorities to track and monitor the health of vulnerable groups in routinely collected data. My dissertation identified negative health outcomes that can be monitored for this vulnerable group. Future work is needed to link RAI-MDS data to other administrative health databases to assess vulnerable residents' use of health services. Monitoring unbefriended resident outcomes in health administrative data is a key contribution to future improvement efforts.

Unbefriended residents have a unique set of care needs, including multiple chronic conditions, mental health disorders, and histories of substance and alcohol use. LTC staff, particularly unregulated care aides, do not have training on how to manage the behaviours of unbefriended residents. My findings indicated that there is an opportunity for the development and implementation of specific education for LTC staff to learn how to care for and appropriately manage the unique care needs of these older adults. Alberta care aide competencies require that care aides demonstrate the ability to care for and communicate with clients who have a cognitive impairment, or mental health and addictions challenges.[27] However, care aide curriculum varies by educational provider,[28-30] and it is unclear whether LTC facilities offer continuing education on care practices specific to these resident challenges. My dissertation identified education needs for LTC staff on how to identify and address the needs of this unique population as an important area for practice development in LTC.

My dissertation identified a specific need to examine the impact of the staff work environment on unbefriended residents' quality of care. I identified staff communication as critical to the quality of care provided to unbefriended residents. Direct care staff (i.e., care aides), who have the most interaction with the residents, are not included in resident care conferences. As a result, they are often unaware that a resident is unbefriended and may require additional supports and services. Including care aides in care conferences is critical to providing high quality care. Care aides must work in an environment that supports the use of best practices

and high-quality communication. Future work will assess how unit and facility work environment (e.g., leadership, formal interactions) influenced the quality of care provided to unbefriended residents.

My dissertation identified specific recommendations for LTC staff and public guardians who are conducting care conferences for unbefriended residents. We proposed the introduction of a values history document to ensure that the goals and wishes of unbefriended individuals are integrated into their care plans. Research in the US indicates that there is significant variability in the decision-making processes for unbefriended older adults.[31,32] My dissertation indicated that guidelines and protocols are necessary for more consistency in care team decision-making for unbefriended LTC residents. Incorporating documents, such as a values history form, in care plans might aid in care planning processes for public guardians and care teams.[33] Developing guidelines and protocols for LTC teams and the public guardian is essential for more appropriate and consistent decision-making and thus improved resident quality of care.

My dissertation contributed to what is known about public guardians in Alberta, however it revealed several gaps that require future research. I found that in Alberta, public guardians have average caseloads that are twice the recommended average in the US.[6] It is unclear what the relative impact of caseloads is on resident outcomes. However, my qualitative findings suggest that high caseloads are related to the public guardians' lack of contact with unbefriended residents and may contribute to the issues related to decision-making and quality of care. In addition, my qualitative findings suggested that public guardians have varied professional backgrounds and may not have enough education and training on older adults, including health and age-related conditions. Further work is needed to assess comprehensively whether there is in fact a knowledge gap that is affecting public guardians' ability to provide quality decision-making support to unbefriended residents.

Directions for Future Research

My dissertation identified troubling issues in the quality of care received by unbefriended LTC residents. However, I was not able to determine the impact of caring for unbefriended residents on the broader health system. My future research will aim to assess the economic impact of potentially inappropriate practices (e.g., transfers to hospital, excessive medical

testing) experienced by unbefriended residents on the health system. Unbefriended residents experienced more frequent and severe pain and more responsive behaviours than residents with family. Next steps include examining medication administration data and determining the potential impact of behaviours on other residents and LTC staff. Caring for unbefriended residents can lead to concerns about quality of work life for LTC staff. Future work must assess the impact of caring for this vulnerable population on staff turnover, intent to leave, and absenteeism.

My career goal is to develop a program of research that identifies modifiable features of the work environments that influence the quality of care provided to vulnerable and marginalized LTC residents and to use these findings to develop and test interventions. The next phase of this work will move beyond descriptive analysis of resident health outcomes in the RAI-MDS and more towards complex causal modelling (e.g., multi-state modelling, structural equation modelling).

Findings from my dissertation signal the need for more empirical work examining unbefriended individuals in our health system. My postdoctoral project aims to assess the trajectory of care and transitions experienced by socially isolated older adults across various continuing care settings. My work will use linked administrative data and analytic techniques such as multi-state modelling to follow vulnerable older adults' transitions across continuing care using linked datasets (e.g., Discharge Abstract Database, National Ambulatory Care Reporting System). The aim of this postdoctoral fellowship is to identify how socially isolated individuals living in various complex continuing care settings access and receive health care.

Limitations

A limitation of this dissertation is the disparate operationalization of the main concept of 'unbefriended' across the studies. Our scoping review, interviews, and survey identified and described individuals under public guardianship (i.e., the unbefriended). However, the RAI-MDS does not have a variable that identifies whether a resident has a public guardian. I identified a variable (F2e) that indicated whether a resident had 'no contact with family'. This necessary choice introduces concern that the findings in Paper #5 are not reflective of unbefriended LTC residents. However, using the convergent approach in mixed-methods research, I compared the

RAI-MDS findings to my prevalence survey and my interviews with LTC staff and public guardians. Although I was unable to identify directly residents under public guardianship in the RAI-MDS data, the prevalence and characteristics described in the RAI-MDS are consistent with my other study findings.

A limitation of this dissertation is the overall representativeness of my findings. My prevalence survey had a robust response rate (72%), however this does indicate that there may be error based on non-response. We assessed non-respondents for non-response bias and found that there was a statistically significant difference between respondents and non-respondents with respect to health zone, and rural/urban location. My interviews included a variety of LTC staff, however there were low numbers of some professional groups (i.e., physicians, public guardians). Therefore, while my analytic methods were rigorous in my online survey administration and my qualitative interviews, these findings are not generalizable beyond the Alberta LTC homes included in my dissertation.

A limitation that will be examined in future work is my ability to examine empirically unbefriended residents' quality of care. My interviews indicated that unbefriended residents may experience different care practices, including more interventionist goals of care (e.g., resuscitation versus comfort care), more frequent transfers to hospital, and more medical testing. However, the RAI-MDS data that were used for secondary analysis are not linked to external databases (e.g., hospital records, prescription data). Furthermore, advanced care planning details (including goals of care) are not documented in the RAI-MDS assessments. Additional data linkage is required to further substantiate my interview findings regarding quality of care at the end of life.

I argued that social exclusion frameworks must integrate principles from complex adaptive systems when studying unbefriended LTC residents. The findings that related to complex adaptive systems came about during subsequent data analysis and were not considered in the initial conception of the study. I did not specifically ask LTC staff or public guardians for specific details that addressed complex adaptive systems properties. Had I integrated a systems approach from the beginning, I might have generated a richer understanding of the interaction patterns and organizational processes involved in the care of unbefriended LTC residents.

My research has limitations related to ethnicity, sexuality, and gender identity. My scoping review only included studies published in English. We excluded three studies that were non-English. All the studies we reviewed were conducted in the United States, a developed and high-income country. The RAI-MDS data do not include robust measures of gender or sexual identity (e.g., lesbian, gay, transgender) or ethnicity. Although research has suggested that unbefriended individuals are often members of the LGBT (lesbian, gay, bisexual, transgender) community,[4,34] I did not have access to empirical data that identified sexual identity or orientation.

Knowledge Translation Activities

Throughout this dissertation I engaged in a variety of knowledge translation activities involving academic and non-academic audiences. These activities provided me with the opportunity to share my research to the academic community and to engage with government decision-makers and frontline care staff. The discussions in these presentations provided valuable insight during the generation of the outputs that comprise this dissertation. I was fortunate to mentor two junior graduate students (S. Baik, Y.L Kang) who assisted in abstract reviews and qualitative interview data collection. I have detailed my knowledge translation activities below.

Study Participant Feedback

Individuals who participated in the semi-structured interviews (Study #2) completed a 'request for summary' form. All but one individual requested a summary of the research findings. Interview participants received a one-page summary sheet and an invitation to a webinar hosted by Brain Exchange and the Alzheimer's Society of Canada. A link to the archived presentation is included below. In addition, I completed in-person group feedback sessions at three facilities. These feedback sessions were to review the summary sheet and the qualitative interview findings (themes, categories, sub-categories). These feedback activities are described in detail in Chapter 3—Paper #2.

Published Abstracts (Peer-Reviewed) ** denotes student*

Chamberlain, S.A., Baik, S.*, Estabrooks, C. A. (2016). Going it alone: Prevalence and characteristics of unbefriended older adults in long term care. *The Gerontologist,* 56(Suppl 3), 436. doi:10.1093/geront/gnw162.1739

Conference Presentations (Peer-Reviewed)

Chamberlain, S.A., Duggleby, W., Teaster, P. B., Estabrooks, C. A (October, 2018). Invisible work: Unintended consequences of formal and informal policies for staff caring for residents with a public guardian in Alberta long-term care facilities. Canadian Association on Gerontology Annual Conference, Vancouver, CA.

Chamberlain, S.A., Duggleby, W., Teaster, P. B., Estabrooks, C. A (October, 2018). Incapacitated and Alone: Prevalence of Unbefriended Residents in Alberta Long Term Care Facilities. Canadian Association on Gerontology Annual Conference, Vancouver, CA.

Chamberlain, S.A., Duggleby, W., Estabrooks, C.A. (May, 2018). Going it alone: Quality of care and quality of life of unbefriended residents in long term care. Canadian Association for Health Services and Policy Research, Montreal, CA.

Chamberlain, S.A, Baik, S.*, Estabrooks. C.A (November, 2016). Going It Alone: Prevalence and Characteristics of Unbefriended Older Adults in Long Term Care. The Gerontological Society of America's 69th Annual Scientific Meeting, New Orleans, USA.

Chamberlain, S.A., Estabrooks, C. (October, 2015). Unbefriended Older Adults in Residential Long Term Care. 44th Annual Scientific and Educational Meeting, Canadian Association on Gerontology, Calgary, Canada.

Poster Presentations ** denotes student*

Kang, Y.L*, Chamberlain, S.A., Estabrooks, C.A. (July 2017). Connecting unbefriended older adults to their public guardian. University of Alberta Research Experience. Edmonton, Canada

Invited Presentations (Non-Academic Audience)

Chamberlain, S. A. (February 2019) Incapacitated and alone: Characteristics and unmet needs of unbefriended older adults in Alberta long-term care homes. Geriatric Grand Rounds, Glenrose Rehabilitation Hospital. Edmonton, Alberta.

Chamberlain, S.A., (May 2018). Unbefriended long-term care residents: What do we know about their quality of care? Branch Learning Session: Government of Alberta, Continuing Care Branch.

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Chamberlain, S.A (May 2017). Unbefriended older adults in long term care. Geriatric Grand Rounds, Glenrose Rehabilitation Hospital. Edmonton, Alberta.

Media Interviews

Chamberlain, S.A. Interviewed by Angela Kokott (July 11, 2018). CHQR 770 (Radio broadcast). Calgary, AB.

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Media Coverage

Chamberlain, S.A. (July 10, 2018). Who will care for the unbefriended older adults? Winnipeg Free Press. https://www.winnipegfreepress.com/opinion/analysis/who-will-care-for-the-unbefriended-older-adults-487734531.html

Chamberlain, S.A. (July 6, 2018). Will you be old and unbefriended? https://theconversation.com/will-you-be-old-and-unbefriended-98692

Conclusion

This dissertation contributed to: (a) our knowledge of the prevalence of unbefriended residents in LTC, (b) our ability to detect this group and monitor their health using routinely collected RAI-MDS data, (c) an appreciation of this resident population's experience compared to other residents, (d) and potential barriers in providing optimal care to them. This dissertation is the foundation from which future interventions will be developed and tested to improve the quality of care and quality of life for vulnerable LTC residents.

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