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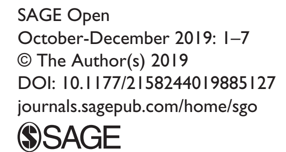

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Incapacitated and Alone: Prevalence of Unbefriended Residents in Alberta Long-Term Care Homes

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Abstract

The objective of this study was to assess the prevalence of residents who are incapacitated and have no surrogate decision maker, known as the "unbefriended" in Alberta long-term care (LTC) homes. Using cross-sectional online survey methods, data were collected from 123 staff (i.e., directors of care/nursing, administrators) from Alberta LTC homes. Information was collected on survey respondents' demographic characteristics, number of unbefriended residents, and on organizational characteristics. The overall prevalence of unbefriended residents in LTC homes was 4.14% in Alberta (SD = 6.28%, range: 0%-34.6%). Homes with the highest prevalence (nearly 15%) of unbefriended residents had >135 beds and were public not-for-profit and located in large urban centers. Fifty-three percent of unbefriended residents were male. The highest prevalence of unbefriended residents lived in homes located in large urban centers and public not-for-profit operators. Population level and LTC home level prevalence data are needed to assess the scope of unmet needs.

Keywords

unbefriended, surrogate decision maker, long-term care, prevalence, survey

Background

Canada's 2016 census noted that for the first time in history one-person households outnumbered couple households (Statistics Canada, 2017). Almost 30% of Canadians live alone, a threefold 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 (Alzheimer's Disease International, 2015; Holt-Lunstad, 2018). Insufficient social support is a problem for older adults who lose decision-making capacity and who require assistance with managing their personal well-being and/or finances (Weisensee, Anderson, & Kjervik, 1996). Individuals who are incapacitated and lack a willing or capable decision maker are defined as "unbefriended" by academics and health care providers (Farrell et al., 2016; Pope, 2017; Teaster, Wood, Schmidt, & Mendiondo, 2010). Although the term has negative connotations, it is used to identify individuals who are incapacitated and alone. Unbefriended individuals may require a public guardian. The unbefriended population is expected to increase given the increasing population of older adults and prevalence of age-related dementias (Albertini & Mencarini, 2014; Karp & Wood, 2003; Pope, 2017).

Public Guardianship

Public guardians are typically public officials, volunteers, or organizations that assumes decision-making responsibility for incapacitated individuals (Teaster, Schmidt, Abramson, & Almeida, 1999). In Canada and the United States, the responsibility for enacting laws related to adult guardianship rests with the individual provinces/states and territories. 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 (Teaster et al., 2010). In most cases, the individual who takes over legal guardianship is a family member or friend (Bayles & McCartney, 1987; Bulcroft, Kielkopf, & Tripp, 1991).

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However, public guardians may be called upon to serve when an individual has been adjudicated as incapacitated and no one is willing or able to assume guardianship (Teaster, 1997). In the Province of 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 (Government of Alberta, 2009). Personal decision-making is assessed on a spectrum of need. A full guardianship order (i.e., public guardianship) is only invoked as a last resort (Government of Alberta, 2009).

Public guardianship is at the intersection of the systems of legal, health, and social services (Chalke, 2005). It must strike a balance between protecting individuals from harm and neglect and intruding on personal autonomy. Although public guardianship is the most restrictive actions to limit a person's legal decision-making rights, little is known about how many individuals are under public guardianship (Chamberlain, Baik, Estabrooks, 2018; Lisi & Barinaga-Burch, 1995). 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., owner-operator, location).

Unbefriended older adults often live in long-term care (LTC) homes, also known as nursing homes or personal care homes, because of their need for assistance due to cognitive and physical impairments and their limited family or friend support (Reynolds, 2002). Research in the United States estimated that unbefriended older adults comprised 3% to 4% of LTC residents (Karp & Wood, 2003). This 3% to 4% estimate has been cited in a number of studies (Connor et al., 2016; Isaacs & Brody, 2010); however, the original study did not assess directly the prevalence of unbefriended residents in LTC homes. Estimates were based on anecdotal reports and not primary data collection. There is no research in Canada or the United States on the prevalence of unbefriended residents in LTC settings or the characteristics of LTC homes with unbefriended residents (Chamberlain et al., 2018). Unbefriended older adults are at risk of poor quality of life and poor quality of care. Unbefriended individuals may have no family, be estranged from family and friends, or live at significant geographic distance from their families (Chamberlain, Duggleby, Teaster, Estabrooks, 2019). They are vulnerable to social isolation and loneliness due to their limited contact with family or friends (Chamberlain et al., 2019; Teaster, 2002). Most have no known family and no visitors; they are alone. 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; Chamberlain et al., 2019).

These residents are also at risk of experiencing potentially inappropriate care practices at the end of life (e.g., transfers to hospital, full resuscitation) compared with those with family member guardians (Cohen, Wright, Cooney, & Fried, 2015; White, Jonsen, & Lo, 2012). Given their vulnerability, it is essential that we understand how many unbefriended older adults are receiving care in our health care system.

Neither Canada, the United States, nor any European countries have a national repository of information on unbefriended older adults (e.g., characteristics, health service use) and their location of residence (Schmidt, 1990). Limited or nonexistent prevalence data mean that we are unable to estimate the scope of unmet needs for unbefriended LTC residents. Assessing the prevalence of unbefriended individuals provides an early indication of the size of the population and enables us to address quality issues. The purpose of this study was to identify the prevalence of unbefriended residents in LTC homes in Alberta. Our specific aims were the following:

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

Method

Data Collection

An observational prevalence study was conducted in all 172 Alberta LTC homes. In Alberta, long-term care homes provide care and accommodation to individuals with complex medical care needs, typically older adults. Long-term care residents have access to 24-hr publicly funded nursing and personal care (Government of Alberta, 2019).

Prevalence of unbefriended residents in the LTC homes was assessed using online survey methods. The online survey was administered to a staff member in a senior leadership position (i.e., directors of care/nursing, administrators) in all Alberta LTC homes. These staff members were chosen because they had access to all 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 2-month data collection period was necessary to allow sufficient time between email reminders and complete the follow-up telephone reminders. 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 (Aschengrau & Seage, 2014).

Table 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)
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, *M* (*SD*)	6.4 (5.8)
Years in organization, *M* (*SD*)	8.8 (8.9)

Online Survey Instrument

The survey collected respondents' demographic data including sex, age, and current position. LTC staff respondents 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 LTC directors of care. Their suggestions were minor and were integrated into the final version of the survey. Participants provided their organization's name, location, and whether they worked in more than one home (yes, no). If they worked in more than one, they indicated the name and location of the second home. 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.

LTC Home Characteristics

LTC home characteristic data were obtained from the health region. LTC home 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 centers of Edmonton and Calgary. Geographic classification was determined using Statistics Canada's (2016) Census classification methods. Population centers (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 (<1,000 people).

Analysis

Basic descriptive statistics (e.g., mean, standard deviation) were calculated for all variables. Prevalence of unbefriended residents was calculated by dividing the total number of residents under public guardianship by the total number of beds in the home. The proportion of unbefriended residents who were male was calculated by dividing the total number who were male by the total number of unbefriended residents. The same calculation was conducted for females. In this article, we only present the males to limit repetition and redundancy.

The entire population of Alberta LTC homes ($n = 172$) was surveyed. Inferential statistics (e.g., Pearson chi-square test of significance, one-way analysis of variance [ANOVA]) are reported in each table (Gravetter & Wallnau, 2017). Nonresponse was examined by comparing known characteristics (operator, zone, bed size, rural/urban) for nonrespondents 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 homes and provided responses for multiple homes. Over two thirds of the surveys were completed online ($n = 82$, 66.7%) and the remainder ($n = 41$, 33.3%) by telephone. Most of our respondents were female (88.1%) and over the age of 40 (66.9%) (Table 1). Respondents had worked an average of 6.4 years in their current position and an average 8.8 years with the organization. Most respondents were social workers (24.6%), followed by administrators (19.5%), directors of care (16.9%), and care managers (15.3%). Administrators, directors of care, and care managers had nursing backgrounds.

The overall prevalence of unbefriended residents was 4.14% in Alberta LTC homes ($SD = 6.28$) (Table 2). Homes that were public, not-for-profit operated had the highest prevalence ($M = 5.03\%$, $SD = 6.87$). Those with less than 30 beds had the highest overall prevalence ($M = 5.41\%$, $SD = 8.63$) followed by homes with 31 to 69 beds ($M = 4.12\%$, $SD = 7.09$). There were no statistically significant differences in prevalence based on organizational

Table 2. Prevalence of Unbefriended Residents in Alberta LTC Facilities (n = 123).

LTC home characteristics	% Unbefriended residents, *M* (*SD*)	*P* value[a]
Alberta average	4.14 (6.28)	
Zone		.104
North	3.03 (3.10)	
Edmonton	2.24 (2.99)	
Central	4.58 (6.01)	
Calgary	5.14 (7.20)	
South	7.90 (12.92)	
Operator		.340
Public not-for-profit	5.03 (6.87)	
Private for profit	3.63 (5.92)	
Voluntary not-for-profit	3.08 (5.42)	
Bed size		.606
<30	5.41 (8.63)	
31-69	4.12 (7.09)	
70-135	3.36 (4.50)	
>135	3.70 (3.74)	
Rural/urban		.921
Rural (<1,000)	5.06 (7.27)	
Small (1,000-29,999)	4.17 (6.68)	
Medium (30,000-99,999)	2.99 (3.15)	
Large (100,000+)	4.15 (6.14)	

LTC = long-term care.
[a]Statistical statistically differences were assessed using a one-way analysis of variance.

characteristics (health zone, operator, bed size, rural/urban). Sex differences (male, female) in unbefriended residents were examined (see Table 1 in the supplementary data). Overall, the percentage of unbefriended residents who were male is 52.98% (*SD* =36.70). There were 20 outliers (> 2 *SD* from the mean) and these are described below.

Outliers

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

Nonresponse Bias

Response rates based on known organizational characteristics (operator, bed size, health zone, rural/urban) were assessed to determine whether there were systematic difference in respondents versus nonrespondents (Aschengrau & Seage, 2014; MacDonald, Newburn-Cook, Schopflocher, & Richter, 2009). The highest percentage of nonrespondents were from the less populated North zone (30.6%). Over half (61.2%) of nonrespondents 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 homes. The overall prevalence of unbefriended LTC residents was 4.14%. This percentage is slightly higher than U.S. estimates (Karp & Wood, 2003). 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 (Government of Alberta, 2017). However, there was wide variation in prevalence; 20 homes 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 is nearly 18,000 unbefriended individuals living in Canadian LTC homes at any point in time. Baseline prevalence data are crucial to inform decision-making and planning related to this vulnerable resident population in our continuing care system. Although 4% of the LTC population can be viewed as a

Table 3. LTC Home Outlier Characteristics.

LTC home characteristics	Low outliers (n = 35)	All other facilities (n = 68)	High outliers (n = 20)
Overall prevalence, *M* (*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)
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)

LTC = long-term care.

relatively low percentage of residents, the number of older adults in Canada is growing rapidly. Consequently, the numbers of unbefriended individuals may increase as a percentage of that larger number. Coordinated efforts to improve the quality of care of unbefriended individuals are not possible without routine surveillance.

As public guardianship in Canada is managed at the provincial level, each of the 10 provinces and three territories have unique legislation that affects individuals under public guardianship (Chalke, 2005). It is unclear how these disparate regional policies affect quality of care and quality of life of individuals who are incapacitated and alone. Comprehensive national data can be used to assess whether 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 database of clinical and functional outcomes is collected on a quarterly basis in most provinces and territories. This Resident Assessment Instrument–Minimum Data Set (RAI-MDS 2.0; Hutchinson et al., 2010) is one potential mechanism for systematic collection of 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) might be one way to identify unbefriended individuals in administrative data. Monitoring unbefriended residents in routinely collected data is crucial because LTC homes *and* policy makers need to be able to identify individuals at risk so that resources can be mobilized and creative solutions activated to them the necessary support.

Our survey results indicated that LTC homes with a high prevalence of unbefriended residents were in large population centers, were public not-for-profit, and had more than 135 beds. No other research has specifically examined the prevalence of unbefriended residents based on LTC home characteristics. There was only one U.S. 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 (Hightower, Heckert, & Schmidt, 1990). Our finding that a higher prevalence of unbefriended residents seem to congregate in a certain "type" of LTC home (i.e., large bed size, large population centers) suggests that placement decisions for these residents warrant more in-depth analysis. Families are often influential in the search for and selection of LTC homes, but unbefriended residents do not have this family member support (Castle, 2003). Once an unbefriended individual is eligible for LTC, public guardians select and consent to the transfer to a LTC home (Abdool et al., 2016). 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, substituting instead their own judgment (Pope, 2017). The type of guardian (e.g., family, public guardian) undoubtedly results in differences in LTC placement between residents who have family member guardians and residents with a public guardian; however, more research is needed to explore these differences in

depth (Abdool et al., 2016). In 2015, Alberta changed its continuing care practices to move away from a "first available bed" model and instead allows clients to wait for their preferred bed, resulting in increased wait times for continuing care (Alberta Health Services, 2015). Further investigation is needed to examine the decision-making process of public guardians during the selection of LTC homes for unbefriended residents and examining their transitions across the continuing care sector.

Strengths and Limitations

This is the first study to examine LTC home characteristics and the prevalence of unbefriended residents in Canada. The survey had a robust response rate. The survey was developed and tested with staff in LTC to ensure that the survey questions and the online platform were understandable and accessible. Limitations included our response rate. Nearly 30% of Alberta LTC facilities did not respond to the survey. Our data collection spanned 2 months, in part, due to the holiday season (December) which made it challenging to reach LTC staff. This timing may have contributed to an extended data collection period. There was a statistically significant difference between respondents and nonrespondents with respect to health zone and rural/urban location. These differences may reflect important features of these LTC staff and homes in rural communities (e.g., comfort with online surveys, access to high-speed Internet) that should be taken into consideration for future data collection efforts. 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 geographic location and operator model. Unbefriended residents are incapacitated and alone. They are vulnerable to poor quality of care and yet they are not 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.

Author Contributions

S.A.C., C.A.E., W.D., and J.F. planned the study. C.A.E. supervised the data collection and analysis. S.A.C. conducted the data collection and data analysis, and drafted the manuscript. W.D., J.F., and P.B.T. contributed to data analysis and to revising the final manuscript. All authors contributed to the development and revision of the manuscript.

Declaration of Conflicting Interests

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Supplemental Material

Supplemental material for this article is available online.

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