

The Impact of Prior Advance Care Planning Documentation on End-of-Life Care Provision in Long-Term Care



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ABSTRACT

Background

The impact of prior advance care planning (ACP) documentation on substitute decision-makers' (SDMs) knowledge of values for end-of-life (EOL) care, and its correlation with SDM satisfaction with EOL care provision, have not been assessed in long-term care (LTC).

Methods

A cross-sectional survey of 2,595 SDMs from 27 LTC homes assessed: 1) knowledge of pre-existing ACP documentation and values for EOL care, and 2) the importance and satisfaction of EOL care provision in LTC. Knowledge of values for EOL care was compared to administrative documentation. Importance and satisfaction were plotted on a performance-importance grid. Multiple linear regression assessed whether knowledge of pre-existing ACP documentation correlated with satisfaction.

Results

The response rate was 25% (658/2,595); 69% of LTC residents had pre-existing ACP documentation. Discordance was noted between SDMs' knowledge of values for EOL care and administrative documentation. Pre-existing knowledge of ACP documentation was not correlated with EOL care provision satisfaction. Priority areas for increasing satisfaction include illness management, SDM communication, and relationships with LTC clinicians.

Conclusions

The discordance between SDMs' knowledge of values for EOL care and formal documentation needs to be addressed. Although pre-existing ACP documentation does not impact satisfaction, EOL care provision could be improved by targeting illness management, SDM communication, and relationships with LTC clinicians.

Key words: long-term care, advance care planning, elderly, substitute decision-maker

INTRODUCTION

Advance care planning (ACP) is a process of reflection that allows individuals to define their goals and preferences for any future care in the event that one is no longer capable to direct their own care. ACPs can guide decision-making for health-care decisions at any life stage, and should not be considered synonymous with solely planning for end-of-life (EOL) care. During the ACP process, an individual is encouraged to select a substitute decision-maker (SDM), a person who they feel would best advocate on their behalf when they are not able. The individual should communicate, and ideally document, their goals and preferences for their family, SDM, and their health-care providers.⁽¹⁾ ACP documentation also needs to be reviewed and updated regularly to reflect one's current wishes and treatment choices.⁽¹⁾ It is important to note that a person with retained decisional capacity, or a SDM acting on behalf of an incapable LTC resident, can override written ACPs at any time.

Proper ACP documentation reduces emotional stress of SDMs^(2,3) when making health-care decisions on behalf of those who are not capable.⁽⁴⁾ Older adults with documentation about their treatment preferences experience more goals-congruent care (e.g., decreased use of life-sustaining therapies and hospitalization, an increased use of hospice services, decreased rate of death in hospital), as well as an increased frequency of EOL discussions around goals of care (GoC).⁽⁵⁻⁷⁾ Having proper ACP documentation would be especially important in long-term care (LTC), where a high prevalence of dementia (overall Canadian prevalence of dementia is 62%, provincial prevalence ranges from 49–64%) and decisional incapacity results in many SDMs being asked to make health-care decisions on behalf of the LTC resident.⁽⁸⁾

There are various methods of documenting treatment preferences.^(9,10) Documenting treatment preferences that arise from ACP conversations in a manner accessible to SDMs could help align care to a person's wishes.⁽¹¹⁾ Unfortunately, the existing prevalence of ACP documentation in LTC ranges from 11% to 44%.^(2,12-17) Furthermore, previous ACP documentation may be lost during the transition to LTC.^(12,18-21) As a result, LTC residents may receive EOL care that is discordant with their expressed wishes, as SDMs may not be knowledgeable about LTC residents' values and preferences for EOL care. Although the level of discordance has not been formally evaluated in LTC, a recent report in the hospital setting noted that concordance between expressed values and documentation was 30%.⁽²²⁾

Previous studies assessing the impact of ACP on EOL care in LTC have focused on system-level health utilization metrics (e.g., hospital admission, length of stay, location of death, ICU admission, hospice admission).^(6,23) The impact of ACP on the satisfaction with EOL care provision in LTC has not been assessed. Increased satisfaction with EOL care provision in various domains (e.g., the use life-sustaining therapies, communication and relationship with health-care professionals, symptom management, concordance with prior expressed wishes, and emotional support for all involved during decision-making)^(24,25) have been reported to show a positive relationship with patient quality-of-life (QOL) in advanced, life-limiting illnesses, and other populations.^(26,27)

Because there has not been a systematic attempt to assess the impact of prior ACP documentation on end-of-life care provision in LTC, the main research questions for this survey study were: 1) How does SDM knowledge of values for EOL care compare to what is recorded in a LTC resident's medical record as their prior expressed wishes?; and 2) Does knowledge of prior ACP documentation correlate to EOL care provision satisfaction in LTC? In addition, to assess the a priori hypothesis that SDMs who are more satisfied with care would perceive their loved ones to have better QOL, an exploratory analysis between satisfaction with EOL care and SDM perception of LTC resident QOL was performed.

METHODS

The Hamilton Integrated Research Ethics Board provided ethics approval (Project #2757).

Study Design and Setting

This is a multi-centre, cross-sectional survey of LTC SDMs from one LTC corporation in Ontario, Canada. At the time of this study, this LTC corporation has 46 LTC homes in Ontario representing 5,627 LTC residents.

Recruitment

Forty LTC homes were invited to a study information webinar; Table 1 presents select characteristics of these 40 LTC homes. An opt-in approach was used; 27 LTC homes expressed interest to participate. The total number of SDMs on record

was 2,651 (excluding appointed public guardians). Fifty-six SDMs could not be contacted due to address errors; the final SDM denominator was 2,595. The family council (or local equivalent) of each participating LTC home was offered a pro-rated honorarium based on site questionnaire completion rate. This honorarium was designated to support local family/resident social and educational events; the total honorarium amount available for the entire study was \$5,000.

Questionnaire Tool

The questionnaire tool (Audit of Communication, Care Planning, and Documentation in Long-Term Care, ACCEPT-LTC) consists of two sections. The first section assesses SDMs' knowledge of any pre-existing ACP documentation, knowledge about residents' values for EOL care,⁽²⁸⁾ and perception of current QOL in LTC. QOL perception was rated on a five-point scale (1=Poor, 5=Excellent). This first section was developed by adapting a primary care ACP audit tool⁽²⁹⁾ through a LTC physician focus group followed by cognitive interviews with ten SDMs using a published cognitive interview evaluation guide.^(30,31) Using this guide, the ACCEPT-LTC survey language was rated to be clear and understandable (mean 4.4 out of 5, range 4–5), and the amount of information provided within the survey to be adequate (mean 4.4 out of 5, range 3–5). The mean overall survey rating by SDMs completing the cognitive interviews was 4.4 out of 5 (range 4–5).

The second section is the CANHELP-Lite tool, a 22-item validated instrument for families of LTC residents to assess the importance and satisfaction with EOL care in LTC. The CANHELP-LITE has been validated with LTC family members, and is reported to have good content and face validity, and internally consistent (Cronbach's alpha coefficients 0.88–0.94).⁽³²⁾ CANHELP-Lite uses a five-point scale (1=Not at all important/satisfied, 5=Extremely important/completely satisfied) in five domains: 1) characteristics of the LTC staff; 2) illness management; 3) communication and decision-making; 4) relationship with doctors; and 5) involvement at the EOL. One exploratory item was added at the end of the CANHELP-Lite instrument to assess staff comfort with managing actively dying LTC residents.

Questionnaire Administration

A modified Dillman method^(33,34) was used to maximize response rates. A study invitation letter was mailed out two weeks prior to the paper questionnaire, followed by one reminder two weeks later. The mailed questionnaire included a pre-paid, return addressed envelope. A returned completed questionnaire implied consent to participate in the study. Questionnaires returned between July and November 2017 were included in the analysis.

Administrative Record Audit

Participating LTC homes use a standardized form to document LTC residents' prior expressed wishes during the study period. This form documented a "level of care" reflecting a LTC resident's wish for their treatment should they be incapable

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TABLE 1

Summary of select characteristics of the long-term care homes that were approached to participate in the ACCEPT-LTC survey study^a; LTC homes that declined to participate are listed first

LTC Home Site #	Local Health Integration Network	Number Of Beds	Response Rate (%)	Survey Item Completion Rate (Mean, SD)	Rural/Urban	Accreditation	French Language	Number of Physicians	Residents > 85y/o (%)	Residents < 65y/o (%)	Female Residents (%)	Residents With Dementia (%)
<i>LTC Homes Not Participating in the ACCEPT-LTC Study</i>												
1	A	224	–	–	Urban	Yes	No	6	47.8	6.3	67.9	60.3
2	A	391	–	–	Urban	Yes	No	0	61.0	4.4	67.7	62.4
3	B	169	–	–	Urban	Yes	No	3	44.2	13.0	56.1	46.0
4	B	107	–	–	Urban	Yes	No	4	59.4	7.1	64.7	66.2
5	C	60	–	–	Urban	Yes	No	0	43.8	4.6	62.3	52.8
6	D	66	–	–	Urban	Yes	No	0	58.9	2.2	73.3	84.7
7	D	70	–	–	Urban	Yes	Yes	2	55.8	1.8	64.6	74.5
8	I	160	–	–	Urban	Yes	No	0	61.8	2.9	70.6	71.0
9	J	116	–	–	Urban	No	No	2	35.5	9.3	61.7	58.8
10	L	247	–	–	Urban	Yes	No	0	41.5	7.3	66.0	62.8
11	L	34	–	–	Rural	Yes	No	1	41.7	6.3	39.6	68.9
12	L	243	–	–	Urban	Yes	No	0	51.1	9.4	71.1	55.8
13	L	27	–	–	Urban	Yes	No	3	51.3	2.6	48.7	60.5
<i>LTC Homes Participating In The ACCEPT-LTC Study</i>												
1	B	97	28.9	90.9 (1.72)	Urban	Yes	No	2	47.2	7.5	65.8	70.2
2	B	233	18.7	91.6 (1.94)	Urban	Yes	No	3	57.3	3.8	71.8	55.3
3	B	60	21.7	91.8 (2.05)	Urban	Yes	No	3	33.1	18.3	56.6	55.9
4	B	254	11.8	90.7 (1.66)	Urban	Yes	No	4	70.1	3.8	64.0	57.2
5	B	60	26.7	92.9 (0.95)	Urban	Yes	No	4	49.0	7.1	65.3	63.4
6	D	64	10.9	90.6 (2.11)	Urban	No	No	5	43.1	11.9	65.1	63.2
7	D	65	18.5	91.5 (1.39)	Urban	Yes	No	2	34.4	9.6	52.8	60.4
8	E	104	21.2	91.8 (1.69)	Urban	Yes	Yes	2	40.9	9.8	67.4	65.4
9	F	80	15.0	91.1 (1.61)	Urban	No	No	0	38.1	18.7	61.9	36.1
10	F	101	23.5	91.5 (2.26)	Urban	Yes	No	1	34.6	12.6	46.7	54.1
11	G	21	9.5	92.9 (1.26)	Urban	Yes	No	2	74.5	5.5	69.1	42.4
12	G	128	37.5	91.3 (1.64)	Urban	Yes	No	4	55.0	8.1	68.2	72.4
13	H	374	20.6	91.5 (1.57)	Urban	Yes	No	9	60.1	1.6	67.7	75.5
14	H	60	23.6	91.9 (1.97)	Urban	No	No	2	53.3	2.9	57.1	54.1
15	J	96	16.5	91.4 (1.69)	Urban	Yes	No	3	28.6	10.3	53.6	52.6
16	K	60	33.3	91.4 (1.86)	Urban	Yes	No	6	54.0	6.2	69.0	57.9
17	K	170	58.0	91.5 (1.77)	Urban	Yes	No	2	44.9	3.9	70.7	74.3
18	K	60	28.0	91.5 (1.51)	Urban	No	No	4	52.0	7.0	66.0	56.8
19	L	60	26.8	91.6 (1.66)	Urban	Yes	No	5	56.4	5.5	54.5	50.5
20	L	40	23.3	90.1 (1.66)	Urban	Yes	No	3	40.7	12.3	66.7	51.4
21	L	90	16.7	91.2 (1.61)	Urban	Yes	No	5	42.8	15.5	55.2	49.7
22	L	29	40.9	90.4 (1.77)	Urban	Yes	No	3	51.3	8.4	59.5	62.6
23	L	34	33.3	91.3 (1.68)	Urban	Yes	No	2	44.7	14.9	57.4	52.2
24	L	60	20.6	91.3 (1.59)	Urban	Yes	No	2	35.1	23.7	57.0	44.9
25	L	63	25.6	91.5 (1.28)	Urban	Yes	No	2	40.5	15.5	60.1	26.8
26	M	128	17.2	90.6 (1.98)	Urban	Yes	No	4	56.1	7.2	67.2	56.2
27	M	200	17.0	91.8 (1.52)	Urban	Yes	No	4	47.3	8.0	65.1	67.3

^aAt the time of the study, Ontario local health integration networks (LHINs) were organizations that planned, integrated and funded local health care for a specific geographic region. At the time of the study, there were 14 LHINs with the mandate of improving access and patient experience. Overall, LTC homes were approached in 13 out of 14 LHINs. The specific LHIN for each LTC site has been de-identified using labels “A” through “M”. Information presented in this table was derived from publically available information at <http://www.health.gov.on.ca/en/public/programs/ltc/home-finder.aspx> and <https://yourhealthsystem.cihhi.ca/>

of making a decision and the SDM was not available to make a substitute decision. This form has four levels of care: 1 = Comfort/supportive care; 2 = Active investigations and treatment, remaining in the LTC home, no CPR; 3 = Transfer to hospital for investigation, no CPR; 4 = Transfer to hospital, full code. This form is routinely completed upon LTC admission, and is reviewed and updated at annual care conferences or when a LTC resident's health status changes. Updates are recorded in the resident's paper chart and electronically in the administrative data record.

Outcome Measures

The primary outcomes are the descriptive results of the ACCEPT-LTC questionnaire, the comparison of SDMs' knowledge of LTC residents' values for EOL care with administrative data documenting prior expressed wishes, and the correlation between knowledge of pre-existing ACP and SDM EOL care satisfaction. The secondary objective is the planned exploratory analysis to assess our a priori hypothesis that SDMs who are more satisfied with care would perceive their loved ones to have better QOL.

Data Collection and Analysis

Data from completed questionnaires and corporate administrative records about prior expressed wishes were electronically collated. Administrative records were first anonymized by the LTC corporation. Categorical variables are described as counts and percentages. Results for continuous variables, such as satisfaction and importance ratings, are presented as means with 95% confidence intervals (CI).

Each item from the CANHELP-Lite questionnaire tool was plotted on a performance-importance grid, which compared importance versus satisfaction.^(35,36) The median importance and satisfaction ratings were used to divide this grid into four quadrants. Items plotting in the upper left quadrant were rated by SDMs to be important, but had the lowest satisfaction ratings. These items represent the greatest potential care gaps and highest priority clinical targets for future improvement.^(35,36)

Multiple linear regression was used to assess whether: 1) SDM knowledge of pre-existing ACP impacted each CANHELP-Lite item, the domain-specific, and the overall satisfaction ratings, and 2) the domain-specific and overall satisfaction ratings were correlated with SDMs' perception of QOL. The adjusted mean difference and the regression coefficients are reported with 95% CI and *p* values for the two analyses, respectively. Domain-specific and overall SDM satisfaction ratings were calculated as previously described.⁽³²⁾ Statistical analyses were performed using the software R⁽³⁷⁾ (The R Foundation, Vienna, Austria), and were adjusted for potential confounders including respondent's age, education, religion, and ethnicity, as well as the number of physicians and by LTC home. The primary outcome analysis was not corrected for multiple comparisons as only one statistical test was performed. As our secondary outcome analysis was solely exploratory, a correction for multiple comparisons is

not required.⁽³⁸⁾ All statistical tests were two-sided, with a level of significance of 0.05.

RESULTS

The overall response rate was 25% (658/2,595); response rates for individual LTC homes ranged from 10–58% (Table 1). Survey item completion rates were over 90% at all 27 LTC homes. Table 2 describes the respondent cohort. The demographics of the corresponding LTC residents were: 71% (467/658) female, 50% (330/658) had high school education or higher, and 74% (485/658) have resided in LTC for over one year. Ninety per cent (2,330/2,595) of residents in the participating LTC homes had an electronic medical record where a "level of care" designation could be extracted by central administration.

SDM Knowledge of Pre-Existing ACP

Sixty-nine per cent (456/658) of SDMs endorsed knowledge of pre-existing ACP documentation for their loved one; Table 3 presents their responses. Sixty per cent (272/456) indicated that ACP documentation occurred over one year prior to LTC admission. In the majority of cases, the LTC resident, their SDM or their family initiated ACP discussions; physicians initiated ACP discussions much less frequently (10%, 44/456), and were less involved (17%, 114/456) than lawyers and other allied health professionals (22% and 26%, respectively). Amongst LTC residents with no ACP documentation (24%, 160/658), respondents indicated that the main reasons for this were: the LTC resident "feels that his/her family will know what to do" (52%, 83/160); "did not know about advance care planning" (33%, 52/160); or "did not see this (ACP) as necessary" (24%, 38/160).

End-of-Life Values of LTC Residents

When SDMs were asked about their loved one's values regarding EOL care, 97% (635/658) and 88% (577/658), respectively, indicated that comfort and minimizing suffering, and avoiding a prolonged death, were very or extremely important. Only 25% (166/658) reported that living as long as possible would be a very or extremely important value (Table 4). Upon reviewing administrative records, 43% (1,010/2,330) of LTC residents had a documented "level of care" designation consistent with supportive care (i.e., Level 1 or Level 2). Twenty-five per cent (558/2,330) and 12% (286/2330) had a Level 3 or Level 4, respectively, which would be consistent with transfer to acute care for more intensive investigations and treatment. Twenty per cent (464/2330) of residents only had "Do not resuscitate, DNR" documentation in their record, and not a "level of care". Less than 1% (12/2330) of electronic records contained no documentation of a "level of care" or DNR.

SDM Satisfaction with End-of-Life Care Provision

The relationship between importance and satisfaction ratings is shown in Figure 1. Items localizing to the top left quadrant

represent priority clinical areas for improvement. Table 5 presents the mean satisfaction and importance ratings for all CANHELP-Lite items. SDMs indicated that priority clinical areas for improvement include better illness management (item 4), better cooperation amongst LTC staff providing care (item 8), and receiving more consistent information about the

resident's condition from LTC staff (item 13). SDMs also indicated that the therapeutic relationship with LTC staff and physicians needed attention; specifically SDMs want to feel heard when speaking with LTC staff (item 14), and that SDMs currently lack trust and confidence in the LTC physician looking after their loved one (item 18). Although other items in the "Relationship with doctor" domain had low satisfaction ratings (items 16 and 17), these were deemed relatively less important overall (i.e., bottom left quadrant). Items in the bottom left quadrant would still be important to address, but would have lower priority than items in the upper left quadrant. The EOL care areas being done well include LTC staff providing residents with excellent personal (item 6), compassionate and supportive care (item 1), even when the SDM is not present (item 7).

No statistically significant adjusted mean difference was observed in satisfaction ratings for any CANHELP-Lite items between those SDMs with pre-existing knowledge and those that did not (Table 6). A positive adjusted mean difference was observed for each domain-specific and the overall satisfaction ratings, but none were statistically significant.

TABLE 2.

Demographics of the 658 ACCEPT-LTC questionnaire respondents

Category	N (%)
Gender	
Male	212 (32%)
Female	439 (67%)
Prefer not to answer	7 (1%)
Age (mean, yrs)	63.5 ± 0.8
Relationship to LTC Resident	
Child (son/daughter)	450 (68%)
Spouse/partner	83 (13%)
Sister/Brother	36 (6%)
Other (e.g., parent, friend, etc)	83 (13%)
Prefer not to answer	6 (1%)
Formal Education	
Post-graduate degree	87 (13%)
University Degree	145 (22%)
College diploma or Trade School	125 (19%)
Some post-secondary education	147 (22%)
High school graduate	97 (15%)
Less than high school graduate	57 (9%)
Substitute decision-maker's overall perception of current quality of life currently of their loved one?	23 (3%)
Excellent	94 (14%)
Very Good	195 (30%)
Good	208 (32%)
Fair	131 (20%)
Poor	7 (1%)
Missing/Declined to answer	
Substitute decision-maker's perception of their loved one's life expectancy	
> 5 yrs	83 (13%)
3–5 yrs	109 (17%)
2–3 yrs	179 (27%)
< 1 yr	74 (11%)
< 6 months	21 (3%)
Unsure/don't know	180 (27%)
Missing/Declined to answer	12 (2%)
SDM knowledge of any pre-existing form of advance care plan for their loved one	
Yes	456 (69%)
No/Unsure	192 (29%)
Missing	10 (2%)

TABLE 3.

Information from the substitute decision-maker (SDM) about their loved one's pre-existing advance care plan (N = 456, 100%)

When was your loved one's advance care plan created?	
> 1 yr prior to admission	272 (60%)
< 1 yr prior to admission	33 (7%)
At LTC admission	106 (23%)
After LTC admission	40 (9%)
Missing/Declined	5 (1%)
Who initially brought up the conversation about advance care planning with your loved one?	
I or a family member brought it up	136 (30%)
My loved one brought it up	103 (23%)
Came up in a family conversation	63 (14%)
Doctor	44 (10%)
Lawyer	34 (7%)
Other	69 (15%)
Missing/Declined	7 (1%)
Who else has been involved in the conversation? ^a	
Other family members	325 (49%)
Lawyer	147 (22%)
Family doctor	114 (17%)
Other doctors (e.g., hospital, LTC)	84 (13%)
Allied health professionals (e.g., nurse, social worker, spiritual care worker)	120 (26%)
Friends	31 (5%)
Other	48 (7%)
Missing/Declined	23 (4%)

^aSDMs were allowed to choose all responses that applied; the reported percentages represent the proportion of SDMs choosing each particular response.

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TABLE 4.

Long-term care substitute decision-maker's proxy rating, in order of importance, for their loved ones to the following statements regarding values for end-of-life care with an adapted version of a published end-of-life values scale

Item	Not At All Important N (%)	Not Very Important N (%)	Somewhat Important N (%)	Very Important N (%)	Extremely Important N (%)	Unsure/ Undecided N (%)	Missing/ Declined N (%)
To be comfortable and suffer as little as possible?	2 (0.3)	2 (0.3)	15 (2.3)	119 (18.1)	516 (78.4)	0 (0.0)	4 (0.6)
That their death is not prolonged?	9 (1.4)	9 (1.4)	34 (5.2)	143 (21.7)	434 (66.0)	22 (3.3)	7 (1.1)
To avoid being attached to machines and tubes?	14 (2.1)	16 (2.4)	61 (9.3)	148 (22.5)	399 (60.6)	12 (1.8)	8 (1.2)
That no further actions are taken to slow or stop the process of their death?	16 (2.4)	20 (3.0)	74 (11.2)	159 (24.2)	339 (51.5)	42 (6.4)	8 (1.2)
That they avoid feeling like a burden on their family or others?	45 (6.8)	50 (7.6)	106 (16.1)	173 (26.3)	246 (37.4)	35 (5.3)	3 (0.5)
That you respect the wishes of other family members regarding your loved one's care?	73 (11.1)	70 (10.6)	105 (16.0)	138 (21.0)	247 (37.5)	21 (3.2)	4 (0.6)
To have more time with their family?	53 (8.1)	92 (14.0)	164 (24.9)	149 (22.6)	160 (24.3)	23 (3.5)	17 (2.6)
To live as long as possible?	141 (21.4)	156 (23.7)	160 (24.3)	74 (11.2)	92 (14.0)	27 (4.1)	8 (1.2)

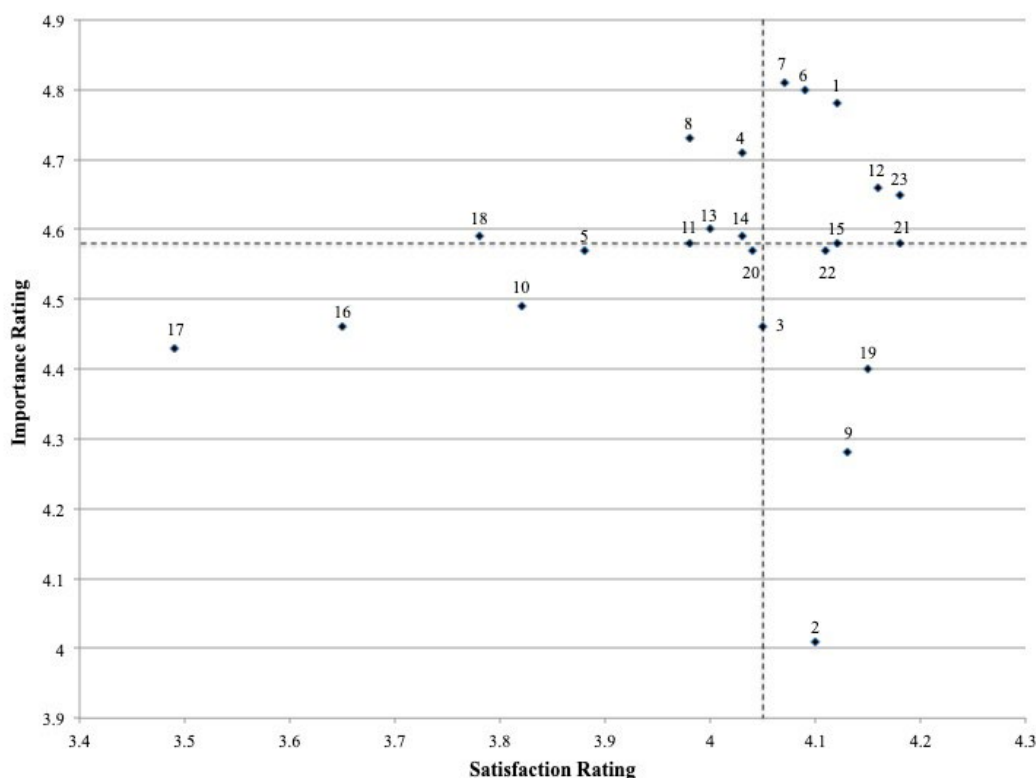


FIGURE 1. The performance–importance grid derived from a plot of the mean importance vs. mean satisfaction score for each item on the CANHELP-Lite questionnaire. The horizontal gridline corresponds to the median of the mean importance ratings (4.58), and the vertical gridline corresponds to the median of the mean satisfaction ratings (4.03). The number closest to the point on the chart corresponds to the CANHELP-Lite item number.

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TABLE 5

Substitute decision-makers' mean ratings (N=658) of importance and satisfaction with the care issues impacting the quality of end-of-life care in long-term care in order of most to least satisfied

<i>Survey Item (Domain^a)</i>	<i>Item</i>	<i>Satisfaction^b (mean, 95% CI)</i>	<i>Importance^b (mean, 95% CI)</i>
21 (YI)	Your role in decision-making regarding your loved one's medical care in the long-term care home.	4.18 (4.11-4.24)	4.58 (4.53-4.63)
23 (SC)	The long-term care staff are comfortable managing any long-term care residents that are actively dying.	4.18 (4.09-4.27)	4.65 (4.60-4.69)
12 (DM)	The long-term care staff explains things related to your loved one's illness in a straightforward, honest manner.	4.16 (4.09-4.23)	4.66 (4.61-4.70)
19 (YI)	You discuss options with the long-term care nurse about the use of life sustaining technologies (for example: CPR or cardiopulmonary resuscitation, breathing machines, dialysis).	4.15 (4.07-4.22)	4.40 (4.33-4.46)
9 (IM)	You are able to manage the financial costs associated with your loved one's long-term care.	4.13 (4.06-4.20)	4.28 (4.22-4.35)
1 (CS)	The long-term care staff looking after your loved one are compassionate and supportive of him or her.	4.12 (4.06-4.18)	4.78 (4.75-4.82)
15 (DM)	You discuss options with the nursing staff about whether your loved one would be transferred to hospital or cared for in the long-term care home if he or she were to get worse.	4.12 (4.04-4.20)	4.58 (4.54-4.63)
22 (YI)	You discuss options with the long-term care nurse about your loved one's end-of-life care wishes.	4.11 (4.03-4.20)	4.57 (4.52-4.63)
2 (CS)	The long-term care staff looking after your loved one are compassionate and supportive of you.	4.10 (4.03-4.16)	4.01 (3.94-4.09)
6 (IM)	Your loved one receives help with personal care (for example: bathing, toileting, dressing, eating) when needed.	4.09 (4.02-4.17)	4.80 (4.76-4.83)
7 (IM)	Your loved one received good care when you were not able to be with him/her.	4.07 (4.00-4.14)	4.81 (4.78-4.84)
3 (IM)	The tests are done and the treatments are given for your loved one's medical problems in the long-term care home.	4.05 (3.98-4.13)	4.46 (4.41-4.51)
20 (YI)	You discuss options with the nursing staff about initiating palliative care or comfort care measures of your loved one.	4.04 (3.95-4.13)	4.57 (4.52-4.62)
4 (IM)	The physical symptoms (for example: pain, shortness of breath, nausea) your loved one has are adequately assessed and controlled.	4.03 (3.96-4.10)	4.71 (4.67-4.75)
14 (DM)	The long-term care staff listen to what you say.	4.03 (3.96-4.22)	4.59 (4.55-4.64)
13 (DM)	You receive consistent information about your loved one's condition from all the long-term care staff looking after him or her.	4.00 (3.92-4.08)	4.60 (4.55-4.64)
11 (IM)	The care and treatment your loved one receives is consistent with his or her wishes.	3.98 (3.91-4.05)	4.58 (4.53-4.62)
8 (IM)	The health care workers worked together as a team to look after your loved one.	3.98 (3.91-4.06)	4.73 (4.69-4.77)
5 (IM)	The emotional problems (for example: depression, anxiety) your loved one has are adequately assessed and controlled.	3.88 (3.80-3.95)	4.57 (4.52-4.62)
10 (IM)	The environment or the surroundings in which your loved one receives care is calm and restful.	3.82 (3.74-3.90)	4.49 (4.44-4.54)
18 (RD)	You have trust and confidence in the doctor(s) who look after your loved one.	3.78 (3.69-3.86)	4.59 (4.54-4.64)
16 (RD)	The long-term care home doctor(s) takes a personal interest in your loved one.	3.65 (3.57-3.74)	4.46 (4.40-4.51)
17 (RD)	The long-term care home doctor(s) are available when you or your loved one needs them (by phone or in person).	3.49 (3.40-3.59)	4.43 (4.38-4.49)

^aThe five main domains in the CANHELP-Lite survey are: Characteristics of the long-term care home staff (CS); Illness management (IM); Communication and decision-making (DM); Relationship with doctors (RD); Your (*Substitute decision-maker*) involvement (YI); a sixth exploratory domain, Staff comfort (SC), was added to the end of the survey tool.

^bResponses are rated on a five-point Likert scale; 1=Not at all important, 5=Extremely important.

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TABLE 6

The adjusted mean difference for satisfaction ratings of each CANHELP-Lite item between substitute decision-makers (SDMs) with knowledge of LTC residents' pre-existing ACP and SDMs of LTC residents who did not have this knowledge;^a the adjusted mean difference for overall and domain-specific satisfaction ratings on the CANHELP-Lite are presented at the end of the table

<i>Item</i>	<i>Adjusted Mean Difference</i>	<i>95% Confidence Interval</i>	<i>P value</i>
1) The long-term care staff looking after your loved one are compassionate and supportive of him or her.	0.005	-0.137, 0.146	.95
2) The long-term care staff looking after your loved one are compassionate and supportive of you.	0.002	-0.140, 0.143	.98
3) The tests are done and the treatments are given for your loved one's medical problems in the long-term care home.	-0.013	-0.178, 0.152	.88
4) The physical symptoms (for example: pain, shortness of breath, nausea) your loved one has are adequately assessed and controlled.	-0.012	-0.174, 0.150	.89
5) The emotional problems (for example: depression, anxiety) your loved one has are adequately assessed and controlled.	-0.065	-0.239, 0.109	.47
6) Your loved one receives help with personal care (for example: bathing, toileting, dressing, eating) when needed.	0.044	-0.122, 0.211	.60
7) Your loved one received good care when you were not able to be with him/her.	0.035	-0.121, 0.191	.66
8) The health care workers work together as a team to look after your loved one.	-0.022	-0.189, 0.149	.80
9) You are able to manage the financial costs associated with your loved one's long-term care.	0.028	-0.134, 0.190	.73
10) The environment or the surroundings in which your loved one receives care is calm and restful.	-0.018	-0.198, 0.162	.85
11) The care and treatment your loved one receives are consistent with his or her wishes.	0.028	-0.139, 0.195	.75
12) The long-term care staff explains things related to your loved one's illness in a straightforward, honest manner.	-0.009	-0.166, 0.146	.90
13) You receive consistent information about your loved one's condition from all the long-term care staff looking after him or her.	-0.045	-0.224, 0.133	.62
14) The long-term care staff listen to what you say.	-0.059	-0.220, 0.101	.47
15) You discuss options with the nursing staff about whether your loved one would be transferred to hospital or cared for in the long-term care home if he or she were to get worse.	-0.019	-0.199, 0.159	.83
16) The long-term care home doctor(s) takes a personal interest in your loved one.	-0.053	-0.245, 0.139	.59
17) The long-term care home doctor(s) are available when you or your loved one needs them (by phone or in person).	-0.138	-0.352, 0.076	.21
18) You have trust and confidence in the doctor(s) who look after your loved one.	-0.108	-0.305, 0.089	.29
19) You discuss options with the long-term care nurse about the use of life sustaining technologies (for example: CPR or cardiopulmonary resuscitation, breathing machines, dialysis).	-0.044	-0.216, 0.128	.62
20) You discuss options with the nursing staff about initiating palliative care or comfort care measures of your loved one.	0.029	-0.171, 0.230	.77
21) Your role in decision-making regarding your loved one's medical care in the long-term care home.	-0.037	-0.182, 0.109	.62
22) You discuss options with the long-term care Nurse about your loved one's end-of-life care wishes.	-0.012	-0.209, 0.186	.91
23) The LTC staff are comfortable managing any LTC residents that are actively dying.	0.014	-0.202, 0.229	.90

TABLE 6

Continued

<i>Item</i>	<i>Adjusted Mean Difference</i>	<i>95% Confidence Interval</i>	<i>P value</i>
<i>Overall</i>	1.811	-1.630, 5.253	.30
DOMAIN: Characteristics of LTC staff	0.015	-0.339, 0.368	.94
DOMAIN: Illness management	0.637	-0.814, 2.089	.39
DOMAIN: Communication and decision making	0.321	-0.433, 1.075	.41
DOMAIN: Relationship with doctors	0.371	-0.367, 1.109	.33
DOMAIN: Your involvement	0.468	-0.633, 1.568	.41

^aAdjusted for age, education, religion, ethnicity, number of physicians, and by LTC home.

SDM Perception of Quality of Life

Fifty-two per cent (339/658) of SDMs felt that their loved one's QOL was fair or poor, while 18% (117/658) indicated that QOL was very good or excellent (Table 2). Table 7 presents the results of the exploratory analysis of the impact of SDMs' satisfaction on the perception of LTC resident QOL. There were statistically significant associations between the domain-specific and overall satisfaction ratings and QOL perception. Satisfaction in the "Characteristics of LTC staff" domain was most strongly associated with QOL perception.

DISCUSSION

In this multi-centre survey of 658 SDMs in LTC, although 69% of SDMs indicated that their loved one had some form of pre-existing ACP documentation, this documentation was not being routinely shared with the physician. Other key findings reveal that the main reasons for LTC residents not to have ACP documentation include lack of knowledge and interest, and the belief that this decision should be made by family or

clinicians. These findings build on previous knowledge from other countries.⁽³⁹⁻⁴²⁾

This study reports several novel insights into ACP in LTC. First, we report discordance between SDMs' knowledge of LTC residents' values for EOL care and what is documented in administrative records. Second, most ACP in LTC residents were occurring over one year prior to LTC admission without significant input and engagement from physicians. Third, knowledge of pre-existing ACP was not significantly correlated with SDM satisfaction with EOL care provision. This last finding is clinically significant and meaningful, as it could highlight the diligence of LTC staff to ensure proper EOL care provision regardless of prior ACP documentation. Lastly, key areas in EOL care that should be prioritized for improvement were identified, including improving LTC staff teamwork, the sense of being heard by LTC staff, and improving the trust and confidence a SDM has for their LTC physician.

SDMs overwhelmingly indicated that their loved one would value comfort and minimizing suffering at EOL. However, in the event of resident incapacity and an ill-prepared or unavailable SDM, almost 40% of LTC residents have documentation that could result in unwanted care. This discordance highlights a potential care gap and reinforces the inadequacies of selecting a "level of care" designation. Selecting a designation does not represent, document, nor summarize prior ACP discussions or values for EOL care. This documentation could be wrongly mistaken for prior consent, leading to inappropriate transfers to hospital.⁽⁴³⁾ Further, the "level of care" designation forms may be more easily accessible and visible than other forms of ACP documentation within the medical record. As a result, SDMs and LTC clinicians may preferentially use the "level of care" designation during times of acute clinical decline instead of actual information regarding LTC resident wishes.

Although knowledge of a pre-existing ACP did not significantly impact the satisfaction with EOL care provision, SDMs indicated the need for improvement in several EOL care provision domains. Improving the quality of LTC physician and staff engagement with SDMs could improve satisfaction with EOL care provision and should be prioritized.

TABLE 7.

Results of multiple regression analysis^a to assess the impact of substitute decision-maker (SDM) satisfaction ratings (overall and by domain) on SDM perception of a LTC resident's quality of life

<i>CANHELP-Lite Care Domain</i>	<i>Regression Co-efficient</i>	<i>95% Confidence Interval</i>	<i>P value</i>
Overall	0.011	0.007, 0.016	<.001
Characteristics of LTC staff	0.102	0.059, 0.145	<.001
Illness management	0.031	0.021, 0.041	<.001
Communication and decision making	0.034	0.014, 0.055	.001
Relationship with doctors	0.029	0.008, 0.049	.007
Your involvement	0.015	0.001, 0.029	.035

^aAdjusted for age, education, religion, ethnicity, number of physicians, and by LTC home.

Promoting regular engagement with the resident and the SDM by encouraging physicians to be more proactive in initiating and mediating ACP and GoC discussions in LTC could be one way to foster increased satisfaction with the therapeutic relationship. This would require prioritization of clinical time and the support of administration to ensure adequate time is provided. Additionally, training LTC clinicians in serious illness conversations, shared decision-making, and elder mediation⁽⁴⁴⁾ could help all LTC clinicians feel more confident with in-depth ACP and GoC conversations with the LTC resident, SDM, and other family members.

This study highlights the need for ongoing work in ensuring that older adults and their SDMs understand what ACP involves, ways to improve the quality and documentation of ACP discussion up-stream of LTC admission, and ways to increase physician engagement and competence. Prior ACP documentation also needs to consistently accompany the older adult during any health-care transition to ensure this information is shared across the health-care system. ACP documentation needs to be readily available and easily accessible by LTC clinicians, LTC residents, and SDMs in order to inform conversations and treatment decisions in LTC. Lastly, system-level policy changes would be required to support the restructuring of LTC clinical time to build clinician capacity and competence to better engage in ACP in LTC.

Limitations

There are several limitations to this study. Responses were specific to LTC homes affiliated with a single corporation in Ontario, Canada. Therefore, some responses may be influenced by administrative structure and policies that may not be more broadly applicable. The questionnaire did not define a specific type of ACP documentation; some respondents may have incorrectly indicated a lack of knowledge about pre-existing ACP documentation. Further, because our study had a suboptimal response rate, despite using a modified Dillman method, and respondents were required to take the additional action of mailing the survey, we cannot be certain of representativeness of our SDM population. Compared to other informal caregiver statistics,⁽⁴⁵⁻⁴⁷⁾ our respondent SDM population has a similar gender proportion and education level, but were older and more often children rather spouse or partner. Therefore the associations and results from the survey may not be generalizable to the whole population. Lastly, matching SDM responses to their specific LTC resident was not possible, as creating unique survey identifiers was deemed to pose an unnecessary potential risk to SDMs and their residents in the event of a confidentiality breach. Therefore, we were limited to performing an audit on aggregated “Level of care” designations as a proxy for documented resident values for EOL care. Because of this, we are unable to report congruence between an SDM’s understanding a LTC resident’s values for EOL care, and what is actually documented, and we were unable to control for specific individual LTC resident indicators of health (e.g., functional status, presence or absence of dementia, comorbidity measures) in our statistical analysis.

CONCLUSIONS

In this study, LTC SDMs’ knowledge of LTC residents’ values for EOL care and their satisfaction with EOL care were systematically assessed. A discordance between knowledge of values for EOL care and what is documented supports the need for increased physician engagement in ACP prior to LTC admission, and for ongoing work in promoting accurate, timely, and accessible ACP documentation in LTC. Although pre-existing knowledge of ACP documentation does not impact satisfaction with EOL care provision, this study has identified key areas for improvement, namely relationship with LTC staff and physicians, communication with the SDM, and illness management. Lastly, an in-depth investigation to assess the relationship between EOL care satisfaction and QOL, as measured by a standardized tool, would be warranted. Developing and evaluating the interventions that address SDM-identified areas for care improvement could inform local quality initiatives and influence corporate policies to improve the provision of EOL care for LTC residents.

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CONFLICT OF INTEREST DISCLOSURES

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