



# Evaluating the Implementation of the Conversation Starter Kit in Long Term Care

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## Abstract

**Introduction:** Advance care planning can improve the quality of life for residents in long-term care homes and reduce stress for families. However, care home staff and families often lack knowledge about advance care planning, making it especially difficult for residents with dementia to communicate their care plan wishes. A Conversation Starter Kit may increase advance care planning awareness among staff and families.

**Objectives:** This study evaluated an advance care planning intervention, the Conversation Starter Kit booklet, for use in long term care homes.

**Methods:** Data were collected at three long-term care homes in southern Ontario. We collected data from 55 residents who were able to make decisions on their own paired with 11 family members of these residents. We also collected data from 24 family members of residents who were unable to make decisions on their own. This study used a quasi-experimental, one group pre/post design. Quantitative surveys were administered before and after a three-month advance care planning intervention. An additional structured interview was completed at the end of the intervention period, which included both closed and open-ended questions to assess perceptions about the booklet's use or non-use.

**Results:** Residents reported more engagement in advance care planning after completing the Conversation Starter Kit booklet, particularly related to asking questions to health care providers about health care decisions. Family members reported feeling very certain that they would be able to make decisions on behalf of the resident but felt less certain after completing the booklet, implying the booklet raised their awareness of the types of decisions they might need to make, hopefully prompting them to be more prepared for decisions in the future.

**Conclusions:** An advance care planning intervention – The Conversation Starter Kit booklet - appears acceptable and easy to use for residents and family members/friends in long-term care and can improve resident engagement in advance care planning. Although using the booklet may decrease efficacy for decision making among family members of long-term care residents, it may highlight the importance of more actionable engagement in advance care planning among residents, their families/friends, and staff.

## Keywords

palliative approach, advance care planning, end-of-life care, long-term care, dementia

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## Introduction

As the population ages, more people will die in long-term care (LTC) homes (Hirdes et al., 2011). Annual mortality rates of residents in LTC homes range from 27–52.3% (Canadian Institute for Health Information, 2020). Yet research has shown that LTC homes do not support residents and their families well within a palliative approach to care, with lack of attention given to advance care planning (ACP) that can lead to inappropriate hospitalizations and lingering issues during grief and bereavement (Kaasalainen et al., 2020; Martin et al., 2016; Stewart et al., 2011; Thompson et al., 2012).

ACP is defined as a process that supports adults of any age to understand and share their personal values, life goals, and preferences regarding their future health care. Ultimately, the goal of ACP is to provide goal-concordant care during serious and chronic illness (Sudore et al., 2017). An ACP tool, called the Conversation Starter Kit (CSK) booklet, provides a structured way for older adults to engage in ACP. It is an evidence-informed workbook aimed at supporting ACP uptake through interactive exercises, prompting questions, and information (Institute for Healthcare Improvement, 2020). However, little research, if any, has been conducted to evaluate its use in LTC homes. Hence, the **goal of this study** was to evaluate the implementation of the CSK booklet in LTC homes.

## Review of the Literature

ACP can positively impact end-of-life care by promoting residents' autonomy; facilitating communication between residents, families and health care teams; and encouraging shared decision-making within a resident-focused approach (Brinkman-Stoppelenburg et al., 2014; Houben et al., 2014; Jimenez et al., 2018; Martin et al., 2016; Stewart et al., 2011). A palliative approach promotes a seamless transition from admission to LTC to end-of-life, beginning with ACP to activate critical communication early with residents and families so that options for end-of-life care can be discussed (Stewart et al., 2011).

However, many barriers exist related to implementing ACP in LTC, including staff discomfort and uncertainty about when and how to earlier initiate discussions about future care, lack of training and capacity building for staff, high rates of cognitive impairment among residents, and failure to identify impending death (Flo et al., 2016; Siu et al., 2020; Stewart et al., 2011; Strudwick et al., 2017). ACP for people with dementia is further complicated in long term care (LTC) homes where care providers lack the skills and knowledge about how to best support residents and their families in the process. Unfortunately, if people do not engage in ACP in the early stages of dementia, then they will lose the opportunity to share their wishes and preferences for their own end-of-life planning with their substitute decision maker (Mignani et al., 2017). This can lead to family and care providers not being adequately prepared to

make end-of-life decisions for the resident, contributing to added stress and burden while decisions are being made in 'crisis mode' (De Gendt et al., 2013; Heckman et al., 2021).

Most of these challenges stem from a lack of awareness and engagement in ACP, as well as a poor understanding of a palliative approach. As such, there is a need to educate residents and families/friends about how to engage in ACP activities and provide tools to facilitate their learning (Siu et al., 2020). Therefore, the following research questions were addressed in this study:

1. Did the use of the CSK booklet improve residents' engagement in ACP?
2. Did the use of the CSK booklet improve family members' (a) self-efficacy regarding decision-making, and (b) satisfaction with quality care (i.e., characteristics of LTC staff, illness management, communication and decision-making, relationship with doctors, family/friend involvement)?
3. To what extent did residents and family members use the CSK booklet (i.e., read, complete, and discuss content) for decision-making (DM) residents, family of DM residents, family of non-DM residents?
4. What are the impacts of using the CSK, and what adaptations are needed to make it easier to use as reported by residents and family/friends'?

The current study was embedded within the Strengthening a Palliative Approach in Long Term Care (SPA-LTC) program ([www.spaltc.ca](http://www.spaltc.ca)), which aims to improve the quality of living and dying for older adults living with frailty, and their friends/family who support them.

## Methods

### Design

This study used a quasi-experimental, one group pre/post design (Woo, 2019). Despite the lack of randomization and a control group, this design offers a practical way to evaluate intervention in a real-world setting (Woo, 2019). Quantitative surveys were administered before and after the three-month intervention (CSK Booklet). In addition to the quasi-experiment, a structured interview was completed at the end of the intervention period, which included both closed and open-ended questions to assess perceptions about the CSK booklet's use or non-use. Given the open-ended questions did not produce rich, in-depth information from participants, we did not label it as a qualitative component, nor use qualitative thematic analysis to yield conceptual categories. Each of these components are described in more detail below.

### Advance Care Planning Intervention

The CSK booklet was selected because of several features that support its usability in LTC, including; (a) a self-directed

paper-based format; (b) information on the role of family/friends in decisional-support; (c) a companion workbook for family/friends of persons with dementia, and (d) a moderate 12-page length (Sussman et al., 2020). Two versions of the Conversation Starter Kit (CSK) booklet developed for LTC were used; one version was designed for self-use, which was given to all LTC residents who had capacity to complete it. The second version was given to families/friends whose relative lacked capacity; this version was designed for use by families/friends of residents who have advanced dementia (Institute for Healthcare Improvement, 2020). Both versions include the following components: Step 1: Get Ready, Step 2: Get Set, Step 3: Go, and Step 4: Keep Going. The first two steps (Get Ready & Get Set) help promote reflection and learning about how to engage with a family member in ACP discussion through tips, prompts, and both closed- and open-ended questions that focus on values, wishes, concerns, and preferences for future care. The last two components (Go & Keep Going) focus on moving forward to future discussions with family/friends and health care providers.

We used a multifaceted approach to implementing the intervention. First, we held an educational workshop for staff about ACP and effective communication with families and residents within a palliative approach (Kaasalainen et al., 2021). After the educational workshop was delivered, we met regularly with the palliative champion team at each site to make them aware of the study's progress and to help answer any questions they might have had about the intervention. A research assistant gave the CSK booklet to each resident or family member once they were enrolled in the study. Given we were evaluating the potential for residents to use the booklet themselves, we did not include LTC staff in a formal role to help implement the ACP booklet. Rather, participants were invited to share their reflections, questions, or concerns with staff if they chose to do so.

## Study Setting

Data was collected from three LTC homes in southern Ontario from June 2018–July 2019. We selected these three LTC homes to reflect a mix of contexts found in LTC homes including for-profit and not-for-profit; large (over 200 beds) and small (less than 100 beds); high-turnover and low-turnover; and religious-based and secular to promote transferability of findings. These contexts impact the successful implementation and adoption of change efforts within smaller, not-for-profit, and low-turnover homes identified as better conditions to support change (Miller et al., 2010).

## Sampling and Recruitment

We worked with LTC staff to recruit residents who had dementia and were considered to have at most moderate

health instability, determined by the Changes in Health, End-stage disease, and Signs and Symptoms scale (CHESS) using a score of 0–3. Staff informed us of residents that either: a) were able to consent themselves or, b) required proxy consent to participate in the study. Once these residents were identified, a staff member approached either the resident (if able) or the family to inform them about the study and asked for permission to share their name and contact information with a research assistant. If agreeable, a research assistant approached potential participants to further inform them about the study and obtain written consent. If the resident could provide consent themselves, we asked them if they were agreeable to their family member also being invited to participate in the study. If they agreed, then we approached their family member to participate in the study as well. For residents who were not able to consent, we asked their family member to participate in the study on behalf of the resident as their proxy. All participants were informed about the possible risks and benefits of participating, the confidentiality of the data collected, and that they could refuse to participate at any point during the study. We used a rolling recruitment strategy so that we could recruit residents who moved into the LTC home after our initial recruitment period to increase the sample size of residents given the relatively low number of residents that met our eligibility criteria (i.e., CHESS score of 0–3).

Once participants consented, we grouped them in the following manner: (a) decision making residents (DMRs) or residents who consented and could complete both the CSK booklet and the study questionnaires themselves; (b) family members paired with DMRs; and (c) family members paired with non-decision-making residents (non DMRs). All participants received a \$25 gift card as a token of appreciation for their time and effort in the study.

## Institutional Review Board Approval

Ethics approval was obtained from the Research Ethics Boards at McGill University (#16-0617) and McMaster University (#3484).

## Data Collection Tools

### Residents

Once consent was obtained, we asked DMRs to complete a baseline survey, which consisted of the ACP Engagement Survey that assessed Action Measures of behaviours related to ACP. The Action Measures assessed concrete actions taken towards ACP uptake, using a 5-point Likert scale (1 = strongly disagree, 5 = strongly agree) for each of the 18 questions on the questionnaire. Questions were grouped into four subscales: (a) Decision Maker (e.g., whether they had asked someone to be a substitute decision maker), (b) Quality of Life (e.g., whether they had discussed

their quality of life with a health care provider), (c) Flexibility (e.g., whether they wanted to give their substitute decision maker flexibility in decision making, and (d) Ask Questions (e.g., whether they had asked health care providers question to make a good medical decision) (Sudore et al., 2013). The Action Measures have good internal consistency ( $\alpha = 0.94$ ) and good test-retest reliability (0.87) and showed good discriminant validity compared to a young college student population ( $p < .001$ ).

Demographic information was collected using resident charts (e.g., age, diagnoses, frailty [CHESS score], length of stay, gender identity, marital status, ethnicity, religion, sexual orientation). Using the list of diagnoses, we calculated the Charlson Comorbidity Index (a measure that aims to categorize comorbid medical conditions that can alter mortality risk) (Charlson et al., 1987).

### Family Members

Family members who were paired with both DMRs and non DMRs were asked them to complete a survey that included a demographics form and two questionnaires, including the Family Decision-Making Self-Efficacy scale (FDM-SE) (Nolan et al., 2009) and the CANHELP-LTC lite questionnaire (Nadin et al., 2017). The FDM-SE scale measures family members' confidence in making decisions for a terminally ill relative. It is a 13-item scale with each item ranging from 1 (cannot do at all) to 5 (certainly can do). The scale has good internal consistency (Cronbach of .91 and .95) and test-retest reliability ( $r = .96$ ,  $p = .002$ ;  $r = .92$ ,  $p = .009$ ) for families of both conscious and unconscious patients respectively (Nolan et al., 2009).

CANHELP-LTC lite is a 22-item questionnaire, scored from 1 (not at all) to 5 (extremely), that measures both level of importance of and satisfaction with aspects of quality care within a palliative approach. It includes five subscales: a) Characteristics of LTC staff, b) Illness Management, c) Communication and Decision-Making, d) Relationships with Doctors, and e) Family/friend Involvement. These subscales and the overall satisfaction score had good internal consistency (Cronbach alphas range: .88–.94) (Nadin et al., 2017).

### Post Implementation Data Collection

Within three months of receiving CSK booklet, participating residents and/or their family/friends were asked to complete the same questionnaires as before in addition to a structured interview. The structured interview was used to gather information about residents' and family/friends' use and perceptions of the CSK booklet; and for those who did not complete it, what their reasons were. The questions that were included in the structured interview questionnaire were chosen based on previous studies (Kaasalainen et al., 2021; Sussman et al., 2020). Final decisions about the

content of the questionnaire were made through deliberations among the study team.

### Data Analysis

Quantitative data was summarized using descriptive statistics (i.e., frequencies, percentages, means, standard deviations [SD]). We conducted paired t-tests for the pre-post measures to examine change within each participant after using the CSK booklet. All quantitative data analysis was conducted using the statistical software program SPSS 22.0.

## RESULTS

### Characteristics of Resident Participants

An initial sample of 58 DMRs were enrolled in the study but three formally withdrew reporting they were no longer interested in participating, leaving a final sample of 55 residents. The average age of participating residents was 77.30 (SD: 11.87) with an average length of stay in LTC 3.11 (SD: 4.62) years (Table 1). Over half of the residents (53%) identified as female, many of whom were widowed (42%), as well White (63%). The average Charlson Comorbidity Index score was 5.4 (SD: 1.89; Table 1) with the majority having a CHESS score of 0 (55%), indicating low to no health instability (Hirdes et al., 2003).

### Characteristics of Family Member Participants

Of the 11 family members who were paired with DMRs, the average age was 62.82 (SD: 14.91) with an average length of stay for the resident being 1.76 years (SD: 2.04). Most identified as female (64%) and were children of the residents (64%). The majority of whom were married (82%), White (92%) and were straight or heterosexual (100%).

### Pre-Post Measurements

#### Resident Engagement in Advance Care Planning

Of the 55 residents who completed the ACP Engagement Survey at baseline, 44 completed the post survey after receiving a CSK booklet. Residents reported higher engagement scores after completing the booklet than before on all four subscales (see Table 2) and these scores were significantly higher for two subscales; Ask Questions ( $t = 2.15$ ,  $p = 0.04$ ) and Flexibility ( $t = 2.01$ ,  $p = 0.05$ ).

#### Family Decision-Making Self-Efficacy

At baseline, family members paired with DMRs reported feeling very certain that they will be able to make decisions on behalf of the resident, with an average score of 4.88 (SD: 0.22, possible range 1–5). Of the 11 family members paired with DMRs who completed a baseline survey, nine completed

**Table 1.** Characteristics of Residents and Family Members.

	Decision-Making Residents (DMR) (n = 55)		Family Members Paired with Decision-Making Residents (FAM-DM) (n = 11)		Family Members Paired with Non-Decision-Making Residents (FAM-NDM) (n = 24)	
	N	%	N	%	N	%
<b>Gender Identity</b>	<b>55</b>	<b>100%</b>	<b>11</b>	<b>100%</b>	<b>24</b>	<b>100%</b>
Male	26	47%	4	36%	8	33%
Female	29	53%	7	64%	16	67%
Other or Prefer Not to Say	0	0%	0	0%	0	0%
<b>Relationship to Resident</b>		N/A	<b>11</b>	<b>100%</b>	<b>24</b>	<b>100%</b>
Spouse			2	18%	6	25%
Child			7	64%	16	67%
Niece/nephew			0	0%	1	4%
Sibling			2	18%	0	0%
Friend			0	0%	1	4%
<b>Marital Status</b>	<b>55</b>	<b>100%</b>	<b>11</b>	<b>100%</b>	<b>24</b>	<b>100%</b>
Never Married	10	18%	1	9%	4	17%
Married/Common-law	12	22%	9	82%	13	54%
Widowed	23	42%	0	0%	0	0%
Divorced/separated	9	16%	1	9%	7	29%
Prefer not to answer	1	2%	0	0%	0	0%
<b>Education</b>	<b>55</b>	<b>100%</b>	<b>11</b>	<b>100%</b>	<b>24</b>	<b>100%</b>
No high school	19	35%	1	9%	4	17%
High school	7	13%	3	27%	3	13%
Trade/Apprenticeship	3	5%	0	0%	0	0%
College	8	15%	1	9%	2	8%
Bachelor's	11	20%	3	27%	11	46%
Post-Grad/Professional Degree	7	13%	3	27%	4	17%
<b>Ethnicity</b>	<b>60<sup>a</sup></b>	<b>100%</b>	<b>12<sup>b</sup></b>	<b>100%</b>	<b>26<sup>c</sup></b>	<b>100%</b>
White	38	63%	11	92%	21	88%
Chinese	3	5%	0	0%	0	0%
South Asian	0	0%	0	0%	2	8%
Black	1	2%	0	0%	0	0%
Filipino	1	2%	0	0%	2	8%
North American Indian	3	5%	0	0%	0	0%
Jewish	3	5%	0	0%	0	0%
Other	11 <sup>d</sup>	18%	1 <sup>e</sup>	8%	1 <sup>f</sup>	4%
<b>Religion</b>	<b>54<sup>g</sup></b>	<b>100%</b>	<b>11</b>	<b>100%</b>	<b>25<sup>g h</sup></b>	<b>100%</b>
Roman Catholic	12	22%	2	18%	12	48%
United Church	5	9%	1	9%	3	12%
Anglican	2	4%	0	0%	0	0%
Protestant <sup>h</sup>	16	30%	3	27%	5	20%
Presbyterian	2	4%	0	0%	0	0%
Lutheran	0	0%	0	0%	2	8%
Baptist	2	4%	1	9%	0	0%
Eastern Orthodox	0	0%	0	0%	1	4%
Jewish	7	13%	2	18%	3	12%
Jehovah's Witness	1	2%	0	0%	0	0%
No Religion	10	19%	4	36%	3	12%
Christian	3	5%	0	0%	1	4%
Other	6 <sup>i</sup>	11%	0	0%	1 <sup>j</sup>	4%
<b>Sexual Orientation</b>	<b>55</b>	<b>100%</b>	<b>11</b>	<b>100%</b>	<b>24</b>	<b>100%</b>
Straight or Heterosexual	53	96%	11	100%	24	100%
Other	1	2%	0	0%	0	0%
Prefer Not to Answer	1	2%	0	0%	0	0%

(continued)

Table 1. Continued.

	Decision-Making Residents (DMR) (n = 55)		Family Members Paired with Decision-Making Residents (FAM-DM) (n = 11)		Family Members Paired with Non-Decision-Making Residents (FAM-NDM) (n = 24)	
	N	%	N	%	N	%
<b>CHES Score</b>	<b>55</b>	<b>100%</b>	N/A		N/A	
0	30	55%				
1	22	40%				
2	2	4%				
3	1	2%				

<sup>a</sup>5 of 55 participants entered 2 ethnicities.

<sup>b</sup>1 of 11 individuals entered 2 ethnicities.

<sup>c</sup>2 of 24 individuals entered 2 ethnicities.

<sup>d</sup>African, Creole, East Indian, Eastern European, Egyptian, French, German/Canadian, Iran, Israel, Trinidad, West Indian.

<sup>e</sup>North African Spanish.

<sup>f</sup>Jewish/Polish.

<sup>g</sup>1 of 55 individuals has missing data, 1 entered 2 religions, and 1 entered 3 religions.

<sup>h</sup>1 of 24 individuals entered 2 religions.

<sup>i</sup>Protestant Religions: Anglican, Associated Gospel, Baptist, Lutheran, Presbyterian, United Church.

<sup>j</sup>Associated Gospel, Catholic, Christian Orthodox, Jehovah's Witness, Longhouse, Mormon Latter-Day Saints, Self-realization fellowship, Zoroastrianism.

<sup>k</sup>Eastern Orthodox.

Table 2. Change in Resident's Scores of Their Level of Engagement in Advance Care Planning at Baseline and Post-Implementation, N = 44.

Scale	Baseline (T1) Mean (SD)	Post (T2) Mean (SD)	Baseline to Post (T2-T1)		95% Confidence Interval	
			Mean difference (SD)	t (p)	Lower	Upper
Decision Maker	3.85 (1.04)	4.07 (0.84)	0.22 (0.96)	1.51 (0.14)	-0.07	0.51
Quality of Life	2.95 (1.13)	3.03 (1.11)	0.07 (1.25)	0.39 (0.70)	-0.31	0.45
Ask Questions	2.76 (0.90)	3.18 (1.17)	0.41 (1.28)	2.15 ( <b>0.04</b> )*	0.02	0.80
Flexibility	3.51 (1.42)	3.98 (1.42)	0.47 (1.52)	2.01 ( <b>0.05</b> )*	0.00	0.93
<b>TOTAL</b>	<b>3.36 (0.93)</b>	<b>3.59 (0.81)</b>	<b>0.23 (0.88)</b>	<b>1.69 (0.09)</b>	<b>-0.04</b>	<b>0.49</b>

\* = p < 0.05.

SD = Standard Deviation.

a post survey. Interestingly, the average self-efficacy score decreased to 4.58 (SD: 0.47) after having completed the CSK booklet, however this was not statistically significant (Table 2).

At baseline, family members paired with nonDMRs reported feeling very certain that they will be able to make decisions on behalf of the resident with an average score of 4.89 (SD: 0.23, possible range 1–5). Of the 24 family members paired with nonDMRs who completed a baseline survey, 17 completed a post survey. Interestingly, the average self-efficacy score decreased to 4.74 (SD: 0.49) after having completed the CSK booklet. This decrease was statistically significant at the p < 0.05 level (Table 2).

### Perceived Importance and Satisfaction with Quality Care (CANHELP)

Similarly, family members reported high baseline scores on the CANHELP for both perceived importance and satisfaction for all subscales and total scores (see Table 3). The highest

subscale score for perceived importance was for Communication and Decision-Making for both families paired with DMRs (M: 4.81, SD: 0.35) and non DMRs (M: 4.94, SD: 0.25). Family members rated their satisfaction with Relationship with Doctors as the lowest at baseline who were paired with both DMRs (M: 3.43, SD: 1.08) and non DMRs (M: 3.93, SD: 0.91). These satisfaction scores remained the lowest post implementation. Family members of DMRs reported significantly higher perceived importance (t = 3.41, p = 0.01) of Characteristics of LTC Staff (e.g., staff are compassionate and supportive) and family of non DMRs reported significantly lower satisfaction (t = 2.07, p = 0.05) of Characteristics of LTC Staff after having completed the CSK booklet.

### Post Implementation Structured Interview

#### Use of the CSK Booklet

Twenty-seven residents and 26 family members (nine of DMRs, 17 of non DMRs) completed a structured interview after having

**Table 3.** Change in Families' Scores of Self-Efficacy in Decision-Making and CANHELP From Baseline to Post-Intervention.

Scale	Baseline (T1) Mean (SD)	Post (T2) Mean (SD)	Baseline to Post (T2-T1) Mean difference (SD)	t (p)	95% Confidence Interval	
					Lower	Upper
<b>Self-Efficacy in Decision-Making</b>						
Families Paired with DM Residents (n = 9)	63.44 (2.92)	59.56 (6.13)	3.89 (7.39)	-1.58 (0.15)	-1.79	9.57
Families Paired with Non-DM Residents (n = 17)	63.59 (3.00)	61.41 (7.01)	2.18 (4.32)	2.08 (0.05)*	0.04	4.40
<b>CANHELP</b>						
Families Paired with DM Residents (n = 9)						
<b>Importance</b>						
Characteristics of LTC Staff	4.44 (0.39)	4.89 (0.22)	0.44 (0.39)	3.41 (0.01)*	0.14	0.74
Illness Management	4.62 (0.40)	4.79 (0.35)	0.17 (0.35)	1.49 (0.17)	-0.09	0.44
Communication & Decision-Making	4.81 (0.35)	4.89 (0.33)	0.08 (0.18)	1.41 (0.20)	-0.05	0.22
Relationship with Doctors	4.78 (0.37)	4.78 (0.37)	0	<sup>a</sup> NA	<sup>a</sup> NA	<sup>a</sup> NA
Your Involvement	4.66 (0.78)	4.78 (0.36)	0.13 (0.46)	1.76 (0.47)	-0.26	0.51
TOTAL	4.66 (0.39)	4.82 (0.31)	0.16 (0.17)	2.76 (0.03)*	0.03	0.29
<b>Satisfaction</b>						
Characteristics of LTC Staff	4.06 (0.73)	4.00 (0.56)	-0.06 (0.98)	-0.17 (0.87)	-0.81	0.70
Illness Management	3.87 (0.36)	3.98 (0.60)	0.12 (0.74)	0.47 (0.65)	-0.45	0.69
Communication & Decision-Making	3.93 (0.47)	4.05 (0.62)	0.12 (0.89)	0.36 (0.74)	-0.70	0.94
Relationship with Doctors	3.43 (1.08)	3.71 (0.89)	0.29 (1.08)	0.70 (0.51)	-0.71	1.28
Your Involvement	3.88 (0.67)	4.32 (0.56)	0.44 (0.84)	1.29 (0.25)	-0.44	1.33
TOTAL	3.85 (0.47)	3.97 (0.56)	0.12 (0.77)	0.47 (0.65)	-0.47	0.71
Families Paired with Non-DM Residents (n = 17)						
<b>Importance</b>						
Characteristics of LTC Staff	4.68 (0.43)	4.59 (0.62)	-0.09 (0.51)	-0.72 (0.48)	-0.35	0.17
Illness Management	4.90 (0.18)	4.83 (0.37)	-0.08 (0.31)	-1.02 (0.32)	-0.24	0.083
Communication & Decision-Making	4.94 (0.24)	4.85 (0.34)	-0.09 (0.36)	-1.00 (0.33)	-0.28	0.10
Relationship with Doctors	4.94 (0.25)	4.85 (0.40)	-0.08 (0.26)	-1.29 (0.22)	-0.22	0.05
Your Involvement	4.85 (0.42)	4.81 (0.43)	-0.04 (0.49)	-0.37 (0.71)	-0.29	0.21
TOTAL	4.89 (0.21)	4.81 (0.38)	-0.08 (0.30)	-1.11 (0.29)	-0.23	0.07
<b>Satisfaction</b>						
Characteristics of LTC Staff	4.50 (0.59)	4.32 (0.50)	-0.18 (0.35)	-2.07 (0.05)*	0.36	0.00
Illness Management	4.31 (0.57)	4.30 (0.53)	-0.01 (0.33)	-0.16 (0.87)	-0.18	0.16
Communication & Decision-Making	4.33 (0.71)	4.17 (0.72)	-0.17 (0.43)	-1.61 (0.13)	-0.39	0.05
Relationship with Doctors	3.93 (0.91)	3.76 (1.01)	-0.18 (0.64)	-1.07 (0.30)	-0.53	0.18
Your Involvement	4.36 (0.62)	4.38 (0.70)	0.02 (0.68)	0.12 (0.91)	-0.33	0.37
TOTAL	4.30 (0.58)	4.22 (0.56)	-0.08 (0.33)	-0.98 (0.34)	-0.25	0.09

**Notes:**

<sup>a</sup>Since the difference between the Pre and Post scores was 0 neither a t-test nor confidence intervals can be calculated because the standard error of the difference is 0.

\* = p < 0.05.

SD = Standard Deviation.

**Table 4.** Reported Use of CSK Booklet.

Which of the following sections of the toolkit did you:		Decision-Making Residents (DMR)		Family Members Paired with Decision-Making Residents (FAM-DM)		Family Members Paired with Non-Decision-Making Residents (FAM-NDM)	
		n	%	n	%	n	%
<b>Read?</b>	Step 1: Get Ready	41	98	9	100	17	100
	Step 2: Get Set	42	100	9	100	17	100
	Step 3: Go	41	98	9	100	17	100
	Step 4: Keep Going	33	79	8	89	17	100
<b>Complete?</b>	Step 1: Get Ready	39	93	7	78	14	82
	Step 2: Get Set	40	95	7	78	16	94
	Step 3: Go	39	93	7	78	15	88
	Step 4: Keep Going	25	60	6	67	16	94
<b>Discuss?</b>	Step 1: Get Ready	17	43	9	100	10	59
	Step 2: Get Set	17	43	9	100	13	76
	Step 3: Go	17	43	9	100	12	71
	Step 4: Keep Going	15	38	8	89	10	59
	Missing	2	5				

completed the CSK booklet. The majority (56%) of residents who completed an interview stated that they completed the booklet with research staff. Other residents stated they completed it by themselves (15%), with family (18%), or with LTC staff (8%), and one did not respond.

Most residents (79%) and almost all the family members (89%) stated that they read all sections of the booklet. Of those, not all completed every sections of the booklet (60% and 67% respectively) with more residents completing it than family members (see Table 4). Fewer residents (43%) stated that they discussed the booklet with others (e.g., family, staff etc.) whereas all the family members of DMRs reported discussing the first three sections with residents and 89% of them discussing the last section (Step 4: Keep Going). Residents spent on average 56 (SD: 35) minutes completing the booklet and 34 (SD: 30) minutes discussing it with their family members and/or LTC staff.

### Perceived Impact of Using the CSK Booklet

Residents and family members mostly agreed the information and guidance in the booklet was presented clearly and was easy to understand (4.11–4.59/5; see Table 5). As a whole, residents rated each item lower than family members with the lowest rated items for residents being: feeling more reassured (3.41/5) and satisfied with end-of-life care that they are receiving/expect to receive in the future (3.59/5). Family members of non DMRs generally rated each item higher than both residents and family members of DMRs, with their lowest scored item (3.94/5) being: “After using this tool, I feel more aware of their ACP goals and wishes”.

### Suggestions to Adapt the CSK Booklet for Easier Use

**Residents.** When asked about how the CSK booklet could be adapted for easier use, residents stated that the language and

terms used were “too wordy”, “need to just get to the point”, and would prefer more scale questions over those posed in paragraph form. Terms, such as ‘home’ and ‘health care facility’ were confusing and they did not know what they meant specifically in the LTC context. Other terms like ‘intervention survey’, ‘tools’, ‘starter kit’ made it “sound like some information was for a scientific study rather than a personal happening in a person’s life”. One participant recommended residents be paired with family and complete it together. Another participant stated that it “should be completed as soon as possible because you don’t know what’s going to happen”.

**Families.** Similarly, when families were asked how the CSK booklet could be adapted for easier use, suggestions were made to optimize technology (e.g., Skype call with resident) to accommodate for a distant living arrangement: “I live across the country so it would have been nice to see [the resident]” when completing it. A family member of a DMR stated they were unsure what was expected of them in answering the questions.

Alternatively, five family members of non DMRs stated that it should be used earlier on, “when a family member is considering LTC placement/prior to LTC placement”, earlier on in the dementia process, or even “years before this stage so it could have been discussed with my husband before the end of his life”.

### Perceptions About Not Using the CSK Booklet

When we followed up with the 11 DMRs who did not complete the post survey, five stated that they decided to not complete the booklet but that they would be willing to be interviewed to share their reasoning behind their decision. All five residents stated that they no longer wanted to



**Table 5.** Perceived Impact of Using the Tool.

	<b>Decision-Making Residents (DMR) (N=42)</b> Mean (SD)	<b>Family Members paired with Decision-Making Residents (FAM-DM) (N=9)</b> Mean (SD)	<b>Family Members paired with Non-Decision-Making Residents (FAM-NDM) (n = 17)</b> Mean (SD)
The information and guidance in this tool is presented clearly.	4.27 (0.62)	4.11 (0.93)	4.59 (0.51)
The information and guidance in this tool is easy to understand, without additional assistance.	4.09 (0.94)	4.11 (0.93)	4.35 (0.86)
This tool was useful to me and/or my family member.	3.75 (0.89)	4.00 (0.50)	4.12 (1.05)
After using this tool, I and/or my family member have a better understanding of the concept of advance care planning.	3.77 (0.89)	4.22 (0.67)	4.13 (0.92)
After using this tool, I and/or my family member feel(s) that I/they are more aware of my/their advance care planning goals and wishes.	3.75 (0.97)	4.33 (0.71)	3.94 (1.03)
After using this tool, I and/or my family member feel(s) more reassured.	3.41 (0.90)	4.00 (0.71)	3.94 (0.83)
After using this tool, I feel more confident that I or my family member will continue to receive care that is consistent with my/their goals.	3.98 (0.85)	4.22 (0.67)	4.35 (0.61)
I am satisfied with the End-of-Life care that I or my family member is currently receiving, and/or with the EOL care that I/they expect to receive in future.	3.59* (1.00)	4.22 (0.44)	4.41 (0.71)
This tool helped clarify the healthcare resources and choices available to me and/or to my family member.	3.57 (1.07)	3.78 (0.67)	4.06 (0.97)
After using this tool, I feel more comfortable discussing my advance care planning wishes and concerns with my family and caregiving staff.	3.59 (0.87)	4.00 (0.71)	4.12 (0.86)

Note. Each item is scored on a Likert scale from 1 (strongly disagree) to 5 (strongly agree).

participate because they felt that the CSK booklet was not useful ( $n=3$ ), did not agree with or enjoy the content ( $n=1$ ), or circumstances no longer enabled them to participate ( $n=1$ ). One family member did not complete the booklet because they found it too difficult to understand, it was not clear how to use it, and it was “too much”.

## DISCUSSION

These study findings add to our knowledge about the usefulness and impact that engaging in ACP discussions can have early on for LTC residents who have dementia and their family members. After completing the CSK booklet, residents were more engaged in ACP, specifically related to asking questions about topics such as choosing a substitute decision maker and about their health care decisions. This is an important finding given the evidence suggests that residents are generally well prepared for their death (e.g., funeral arrangements) but not necessarily for the dying process (Mignani et al., 2017). Given the CSK booklet addresses topics for discussion about the dying process and values and preferences relating to it, it has potential to facilitate conversations that often do not occur. It is critically important that residents' questions are asked while they are still able to respond, before dementia advances and precludes the opportunity for important discussions to occur. If not, this opportunity will likely be missed and may result in a lack of alignment between residents' actual wishes and the care provided to them (Jeong et al., 2010; Mignani et al., 2017).

The study findings also highlight the importance of residents and families completing the CSK booklet together to promote discussion. Completing the booklet together enables families to be more aware of a residents' values and preferences in advance of having to make end of life decisions on their behalf. We found that if residents reported completing the CSK booklet with someone, it was often with a research staff as opposed to a family member or even a health care provider. Our study findings showed that when families were paired with DMRs, they were more apt to engage in discussion together while completing the CSK booklet. It is important to promote discussion beyond simple ‘yes/no’ answers as the conversation needs to address a variety of situations and contexts for future decision making. Tools such as the CSK booklet are needed to recognize trade-offs in resident and family member's values, and to facilitate conversation in light of these trade-offs within ACP (Sunner & Howard, 2018).

However, it was interesting to note that family members' self-efficacy in decision-making scores decreased after using the booklet, which is consistent with other work in this area (Sudore et al., 2014). Perhaps once families learned about the types of decisions that would need to be made in the future, they realized that the CSK is just the beginning; in terms of the knowledge and understanding, more would be necessary to address the complexities of ACP for residents; that it

cannot be ignored, and these discussions are important. As such, using the CSK booklet could serve as a teaching tool to educate families and residents about what is involved in ACP and what decisions will need to be made at end of life, in addition to the commonly known and planned for decision about funeral arrangements etc. (Mignani et al., 2017). Nolan et al. (2009) found that family members who had experience making decisions for an ill person had higher levels of decision-making self-efficacy than those without this experience. Using the CSK booklet promoted reflection and contemplation among families, which gave them time to think about what they may need to know (beyond making funeral arrangements) in order to make difficult decisions later on when needed (Sussman et al., in press). Hence, although our findings showed a poorer sense of self-efficacy, we see these findings as being positive. Using the CSK booklet could help prompt the need for additional conversations between the resident and family earlier so that families can be better prepared to make these decisions and experience less guilt and stress. Unfortunately, if residents with dementia and their families wait too long to have ACP conversations, then opportunity for discussions together will be lost. Although the CSK booklet helped ‘prime’ families for these important discussions, additional support from health care providers is needed to move families from reflecting on potential topics that need to be discussed to more actionable directions in having these discussions with residents (Howard et al., 2021). In light of previous work and these study findings, it is recommended that the CSK booklet should be introduced early, and that staff need to support families and residents to have these discussions together.

### *Implications for Practice*

Our study findings indicate that families were the least satisfied with their relationship with the doctor (e.g., doctor takes a personal interest and is available to resident and/or family when needed, family has trust and confidence in doctor). Perhaps the CSK booklet could be completed prior to a care conference. The booklet could be used as a mechanism with which to frame some discussion about ACP during a care conference when the doctor is present and available to answer questions and provide additional information to meet the needs of residents and families. Care conferences allow for shared decision-making and improve family satisfaction (Durepos et al., 2018; Kaasalainen et al., 2020). Future research is needed to evaluate the effectiveness of using the CSK booklet to help prepare families better for discussions during a care conference with the health care team, including the doctor.

Finally, although residents and families were somewhat positive about using the CSK booklet, they did highlight some changes that need to be made for it to be more relevant to the LTC sector. As far as we know, this was one of the first

studies to evaluate the CSK in LTC. As suggested by families, terms such as ‘home’ and ‘health care facility’ are ambiguous and take on different meaning for residents living in LTC.

### Study Limitations

This study has limitations. First, given the design did not include a control group, we cannot conclude the CSK is effective in improving study outcomes. Secondly, the sample was not randomized nor large, therefore we are not able to generalize our sample to other regions, etc. Moreover, the inclusion of open-ended questions on the structured interview precluded our ability to both gather and analyze rich, in-depth data for our final analysis.

Hence, there is a chance that the participants were systematically different from non-participants in ways that might be associated with our outcomes of interest, introducing a risk of bias into our finding. Another limitation is that most of the DMRs did not participate along with a family member, which may prevent us from seeing the maximum benefit/impact of the CSK as an ACP tool. Finally, the reliance on research staff (over half) to complete the CSK with DMRs in the study raises the issue about sustainability of this intervention.

### Conclusions

CSK appears acceptable, easy to use for residents and family members/friends in LTC and can improve resident engagement in ACP. Although using the CSK may decrease efficacy for decision making among family members of LTC residents, it may highlight the importance of engaging further in ACP and prompt to more actionable engagement in ACP among residents, their families/friends and LTC staff.

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### Declaration of Conflicting Interests

The authors declare that there is no conflict of interest.

### Brief Summary

An ACP intervention improved resident engagement in their care, though reduced the efficacy of family member decision making, implying increased awareness. This may highlight the importance of ACP.

### Declaration of Conflicting Interests

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### Supplemental material

Supplemental material for this article is available online.

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