

Exploring the Acceptability and Relevance of Tool-supported Advance Care Planning (ACP) for a Long-term Care (LTC) Home Environment

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Research article

Keywords: end-of-life communication, death and dying, assisted living, palliative care, advance directive, nursing homes

DOI: <https://doi.org/10.21203/rs.3.rs-76248/v1>

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Abstract

Objectives: Despite known benefits, advance care planning (ACP) is rarely a component of usual practice in long-term care (LTC). A series of tools and workbooks have been developed to support ACP uptake. Yet, their acceptability and relevance for LTC has yet to be examined. This study explored the extent to which available ACP materials hold promise in improving ACP engagement in LTC by (1) exploring LTC home staff's reactions to tool supported ACP and (2) examining if available ACP tools include content of relevance to LTC.

Methods: A combination of focus group deliberations with LTC home staff (N=32) and content analysis of publicly available ACP workbooks (N=32) were used to meet the study aims.

Results: Focus group deliberations suggested that tool-directed ACP is a promising approach for LTC, provided tools include psychosocial elements and are paper-based. Content analysis of available tools revealed that only a handful of paper-based ACP tools (32/611, 5%) include, psychosocial content, with most encouraging psychosocially-oriented reflections (30/32, 84%), and far fewer providing direction around other elements of ACP such as communicating psychosocial preferences (14/32, 44%) or transforming preferences into a documented plan (7/32, 22%).

Conclusions: Tool-supported ACP appears acceptable to LTC staff. To improve ACP uptake in LTC selected tools should include psychosocial content that can be supported by a range of clinical and non-clinical staff. Available ACP tools may require infusion of scenarios pertinent to frail older persons, and a better balance between psychosocial content that elicits reflections and psychosocial content that supports communication.

Introduction

Long-Term-Care (LTC) homes are becoming a major site of death for older adults globally (Flo, Husebo, Bruusgaard, Gjerberg & Thoresen, 2016; Frey, Boyd, Foster, Robinson, & Gott, 2016). Yet, many LTC facilities still lack formalized palliative care programs, resulting in sub-optimal end-of-life care (Cable-Williams & Wilson, 2017; Davis, Morgans & Dunne, 2019).

Advance care planning (ACP) is an important component of a comprehensive palliative approach program because it empowers individuals with non-reversible health conditions to reflect on, communicate, and sometimes document their values, beliefs, and preferences for future end-of-life care (Cornally et al., 2015; Rietjens et al., 2017). As such, ACP provides a mechanism to ensure that persons with life-limiting conditions remain at the centre of their own care by providing avenues for communicating care preferences to family/close friends, legally appointed decision-makers and health providers, when capacity for reflection, communication, and decision-making is consistently present (Fleuren, Depla, Janssen, Huisman & Hertogh, 2020; Howard et al., 2018; Sudore & Friend, 2010).

When ACP is introduced in LTC, it is associated with reductions in hospital admissions, increased concordance between preferred and received care, and decreases in stress, depression, and anxiety for residents and their families (Brinkman-Stoppelenburg, Rietjens., & van der Heide, 2014; Cornally et al., 2015; Robinson et al., 2012; Shanley et al., 2011).

Despite the known benefits, ACP is rarely a component of usual practice in LTC (Ampe, Sevenants, Smets, Declercq, & Van Audenhove, 2017; Jeong, Higgins, & McMillan, 2011). Key barriers to ACP engagement include lack of resident and family preparedness (Jimenez et al., 2018; Lund, Richardson, & May, 2015), limited staff time, and discomfort and uncertainties from all parties regarding what to discuss beyond single medical decisions and funeral planning (McGlade et al., 2017; Reinhardt, Downes, Cimarolli, & Bomba, 2017; Sussman et al., 2017a; van Soest-Poortvliet et al., 2015). ACP programs that include multiple-steps have shown some successful outcomes in increasing ACP engagement in LTC (Ampe et al., 2017). However such programs have proven difficult to sustain into daily practice in LTC where access to clinical staff is exceptionally limited (Ampe et al., 2017). Hence within these settings ACP materials designed for self-use could be of particular benefit (Fryer, Bellamy, Morgan, Gott, 2016; Kontos, Miller & Mitchell, 2009).

Interactive tools like workbooks and card games that require limited professional support have recently been developed to encourage holistic conversations about EOL issues with one's family and healthcare staff throughout the general population (Butler, Ratner, McCreedy, Shippee, & Kane, 2016; Van Scoy, Reading, Scott, Green and Levi, 2016). Some such tools could specifically support ACP uptake in LTC, by (a) increasing resident and family awareness of the importance of ACP conversations and (b) providing guidance about topics to reflect on and discuss (Bridges et al., 2018). Yet, the extent to which these available materials hold promise in improving ACP uptake in LTC has not been explored.

Redressing this gap in the literature this study combined focus groups discussions with LTC staff and a content analysis of available ACP tools to explore (1) what, if anything, would make tool-supported ACP an acceptable and feasible method of improving ACP in LTC, and (2) does the content and format of available ACP tools align with the needs and preferences of clinical and support staff in LTC?

Methods

This paper reports findings from two initiatives: (1) a series of focus groups held with LTC home staff to explore the acceptability of tool-supported ACP in LTC, including content and format that would support feasible implementation, and (2) a content analysis of publicly available ACP tools, including material identified by focus group participants as relevant for a LTC home context.

The research was conducted in accordance with the standards of the Tri-Council Policy Statement for Ethical Conduct for Research Involving Humans 1998 (with 2000, 2002, and 2005 amendments). Procedures were approved by the Office of Research Ethics Board at X (*Blinded for Review*) University and Y (*Blinded for review*) University.

Step One: Focus Groups:

Focus Group Recruitment and Data Collection:

In order to first explore the acceptability and feasibility of tool-supported ACP in a LTC environment, staff in four LTC homes in southern Ontario were invited to participate in focus group deliberations. Staff were known by the research team to be palliative leaders in their respective LTC homes, as this was a component of a larger study in all four LTC homes aimed at strengthening a palliative approach in LTC (*Blinded for review*).

Recruitment took place one month prior to each focus group and was limited to staff who had been active members of palliative care champion teams (n = 55). All potential participants were contacted directly by the research team via email or verbal invitation. 32 of 55 eligible staff participated in four focus groups, including 13 nurses, seven allied health professionals, four support staff, three clinical leaders, and five trainees/volunteers.

Focus groups lasted 60 minutes and were facilitated by two members of the research team. Participants were first provided with a range of ACP tools including one card game, two workbooks (one of which culminated in the development of advance directives and another which did not) and one worksheet with an accompanying video. Participants were then invited to share any reactions to the tools and discuss their thoughts on implementing them in a LTC environment. Written informed consent was attained on the day of focus group deliberations.

Data Analysis Focus Groups:

All focus group deliberations were audio-recorded and transcribed, and field notes were taken throughout. Transcripts and field notes were analyzed by two members of the research team in two steps guided by the principles of content analysis (Neuendorf, 2019). In step one, researchers independently and then together coded comments about each tool as either strengths or limitations. In step two, commonalities and discrepancies between tools and across groups were examined to identify if particular tools were consistently viewed either positively or negatively and to illuminate overall themes related to the strengths and limitations of all tools to support ACP discussions in LTC. The following four themes emerged as a result of this two-step process as together they were thought to capture a comprehensive narrative of staffs' reactions to the materials (: (1) *Tools with sufficient information and direction are key*; (2) *Psychosocially-focused tools seen as preferable*; (3) *Workbooks are a preferred medium for ACP tools*; and (4) *No one tool will fit all*.

Step Two: Content Analysis Search Strategy:

Informed by findings from our focus group deliberations, we aimed to identify and analyze publicly available paper-based ACP workbooks with psychosocial content that could be easily accessed and utilized by residents, families, and staff in LTC. We sought to identify workbooks through a grey literature search using Google as our search engine. The key words “Advance Care Planning Tools” were used to locate paper-based materials. We also solicited Key Informants for additional tool identification.

Guided by the themes emerging from our focus group deliberations, tools were excluded from review if they (1) focused exclusively on recording medically-oriented advance directives or decisions including do-not-resuscitate orders or the cessation of particular treatments such as kidney dialysis for advanced renal failure; (2) were not available in printable workbook form; and (3) did not provide sufficient information and direction for use by non-clinically trained staff. The research team also decided to exclude tools that were (4) developed for substitute decision-makers only because we were interested in materials that would support the inclusion of residents in their own future care planning (Sussman et al., 2017b; 2019).

Two researchers were involved in determining tool retention/exclusion. The first researcher conducted an initial review of identified tools once exclusion criteria were established. The second was consulted with a random selection of tools slated for exclusion and purposefully when uncertainties arose.

A total of 611 tools were identified through our key word Google search, of which 489 (80% of identified tools) were excluded because of their sole medical focus. An additional 49 tools (8%) were excluded because they were not paper-based and/or required internet access to be utilized and 32 tools (5%) could not be accessed because the website housing them had expired or the tool was otherwise unavailable. A further 12 tools (2%) were excluded because they were designed solely for clinicians or decision-makers.

Hence, we retained 29 ACP workbooks for further review. To ensure we had located all viable paper-based ACP materials, we emailed the list of 29 tools to our broad network of national and international collaborators and researchers engaged in the areas of palliative care, long-term care, and aging (N = 75). This process yielded an additional 3 tools. A total of 32 ACP workbooks were retained for full content review.

Content Analysis Acp Tools:

The content of the workbooks was analyzed in three stages by the two researchers responsible for tool selection (Hsieh & Shannon, 2005). In the first stage we used conventional content analysis to categorize psychosocially-oriented excerpts from each guide into the broad ACP areas of reflection (components designed to encourage thinking about personal values, goals, and preferences), communication (components designed to encourage conversations between patients, decision-makers, and others, including steps to take to begin the conversation), and documentation (components left for patients to record any wishes or preferences that could be referred to by others). These aspects are commonly denoted in the literature as critical and unique steps in the ACP process (Sudore et al., 2013; Sudore & Fried, 2010; You et al., 2014).

In the second stage, through discussion and a collective review of coded excerpts, the team further refined the categories for reflection, communication, and documentation into what we considered vague psychosocial content (e.g. reflecting on what one considered quality of life) and specific psychosocial content (e.g. reflecting on music preferences at end-of-life). We also specified whether psychosocial reflections, communication, and documentation were geared towards future EOL care or on designating a decision-maker, as both are considered unique aspects of ACP (Sudore et al., 2013; Sudore & Fried, 2010; You et al., 2014). Noting the extent to which substitute decision-makers were encouraged to participate in reflections, communication, and documentation seemed important both because these distinctions were emerging from the content and because recent models of ACP recognize that decision-maker involvement in all stages of the ACP process can encourage ACP activation for older adults living with frailty (Piers, et al., 2018; Wendrich-van Dael., Bunn, Lynch, Pivodic, Van den Block, & Goodman, 2020).

In the third and final stage, the frequency with which each tool had psychosocial content falling within each category was recorded to illustrate the most and least common applications of psychosocial content. At this stage two researchers independently coded content. Any identified discrepancies were discussed with a third researcher who helped make a final determination based on consensus. We also created formatting-related categories noted in the literature to support readability for older persons, including tool length, use of pictures/images, and inclusion of scenarios applicable to older persons (National Institute on Aging, 2007).

Results

Focus Group Results:

Deliberations in all focus groups suggested that staff consider tool-supported ACP to be a promising approach to trigger more consistent ACP discussions between residents, families, and LTC staff. While staff felt such tools could not direct *when* discussions should happen, many expressed that with the proper content and format, ACP tools could provide important direction for open, honest, and comprehensive discussions with residents and families. The following sections highlight the content and format considered most acceptable and feasible for a LTC environment.

Tools with sufficient information and direction are key:

ACP tools with sufficient information and direction were seen as particularly helpful to guide ACP discussions between staff, residents, and families. As one participant stated, *"this [tool] can be used as a great guide to staff when talking with families"* (Focus Group 1). Others re-iterated that tools that offered *"good ways to start a conversation"* (Focus Group 2) and *"good direction about what to ask"* (Focus Group 4) were useful as they would provide staff with the support they need to activate such conversations.

Psychosocially-focused tools seen as preferable:

Focus group deliberations further suggested that staff were apprehensive about tools with a strong medical focus. This theme was particularly evident when discussing one selected tool which had an associated advance medical directive. This tool was consistently viewed as “*too medical*” (Focus Group 2), “*too harsh*” (Focus Group 4), and “*not the best fit for a LTC setting*”(Focus Group 3). Overall, participants within and between groups suggested that “*having psychosocial aspects covered in a tool is good*” (Focus Group 4) and would enhance uptake in LTC. Psychosocial topics considered of high relevance in a LTC environment included views on family involvement, beliefs about quality of life/death, environmental conditions thought to enhance care, and religious/spiritual preferences.

Workbooks are a preferred medium for ACP tools:

While all tools reviewed had strengths and weaknesses, participants across groups expressed preferences for paper-based workbooks over videos, card games, and web-based materials. This medium was favoured because it could include education/information alongside interactive elements, and did not depend on computer accessibility.

No one tool will fit all:

Because ACP is about exploring individual wishes, beliefs, and preferences, most attendees suggested that no one tool would ever be appropriate for all LTC residents. Rather, participants expressed the desire for a list of potential tools they could refer to. As one participant stated about the tools, “*We need different ways of delivering [ACP] as not every resident will like any one option.*” (Focus Group 2).

Content Analysis Results:

Table 1 provides a brief overview of all 32 tools retained for analysis including where they can be located and whether they have been evaluated in the scholarly literature. It is noteworthy that of the 32 tools located only three appear to have been formally evaluated as evidenced by a search in the published literature and email-outreach to all organizations wherein tools were housed. Table 2 reports results of our content review. These findings are also reported below.

Domain		Frequency	Example
Psychosocial reflections	General	30 (94%)	“Think about what’s important to you and how your values help you make healthcare decisions”. (Michael Garron Hospital: My Health, My Wishes ACP Workbook)
	Specific	22 (69%)	“What cultural or traditional practices are important to you? Do you wish the plans to observe certain religious or non-religious beliefs?” (College of Family Physicians: ACP Resource for Patients)
Communication about psychosocial issues	General	32 (100%)	“To do:... discuss your thoughts with those close to you; your family, your GP and other involved health care providers.” (Respecting Patients’ Choices Planning Guide)
	Specific	5 (17%)	“{T}ell your SDM(s), family and friends: What is important to you at the end of your life; Religious readings or ceremonies you want to have; Music you want to listen to; Books you want to read or have read to you; Where you might want to spend the last days of your life.” (Acclaim Health)
Documentation of psychosocial directives	-	7 (22%)	“Goals for end-of-life care: What do you hope for most when you are near the end of your life? (For example: presence of family or other persons; access to places or items of significance; music; any personal, religious or cultural practices to be followed): <i>{lined writing space is provided}</i> ”. (Respecting Patient Choices: Advance Care Plan (Aged Care))

Readability And Formatting:

Retained tools ranged in length from 3-102 pages. Although a small minority were less than 12 pages (6/32, 19%), one third (11/32, 34%) exceeded 25 pages. Most tools in our review (21/32, 67%) included photos or graphics and offered vignettes or case situations to encourage ACP reflection (18/32, 56%). Workbooks often featured photos that appeared to be of people having discussions with loved ones, or graphics or symbols depicting certain healthcare scenarios such as hospitalization. Half of the tools reviewed included vignettes about the care of an older person (16/32, 50%), such as imagining oneself having Alzheimer’s disease and being unable to recognize loved ones or communicate with them, or of someone contracting pneumonia and moving from a nursing home to a hospital.

Psychosocial Content In Tools:

Psychosocial Reflections:

The vast majority of tools included in the review encouraged some form of psychosocial reflection (30/32, 94%). Common psychosocial reflections included asking users to think about or write down what constitutes quality of life, a good death, and/or what gives life purpose or meaning, through questions like *“What are your values and beliefs about death and dying? ... What does suffering mean and what makes life worth living?”* (The College of Family Physicians of Canada: Advance Care Planning Resource for Patients). These general reflections were framed as a way of beginning to uncover underlying beliefs, values, and preferences that could help to inform future decision-making. Some tools went a step further, moving from more global reflections to encouraging specific reflections about EOL preferences. Specific reflection about location of death was most common, as featured in 27/32 (84%) of tools, via prompts such as *“If possible, would I prefer to die at home, in a hospice or in the hospital? What might change my mind about my choice?”* (Speak Up). Slightly fewer (22/32, 69%) included additional specific reflections, including what they think may bring them comfort in their final days, and whom, if anyone, they would elect to have by their side should their health deteriorate. Tools often provided reflective questions like *“If you could plan it today, what would the last day of your life be like? ... What would you be doing? Who would be with you? What would you eat, if you were able to eat?...”* (Dying With Dignity Ontario), or enabled users to select from listed items such as *“When I am nearing the end of my life I want: my family nearby; someone holding my hand; my religious leader to visit me...”* (My Voice Advance Care Planning Guide).

Communication about Psychosocial Issues:

All tools (32/32, 100%) mentioned the importance of communicating and sharing reflections with families, friends, healthcare professionals, and substitute decision-makers, and many (27/32, 84%) encouraged users to think about who they may select as a substitute decision-maker in light of their reflections and preferences. Yet far fewer tools (14/32, 44%) provided users with tips on how to initiate conversations with families, friends, and decision-makers, how to speak with their decision-makers about their comfort acting in the role in light of their wishes (13/32, 41%), or provided guidance directly to substitute decision-makers regarding what they may ask or think about (7/32, 22%).

When communication tips were provided they tended to be general in nature, such as encouraging people to find the right time to have a conversation or providing them with an opening prompt such as *“I need to think about the future. Will you help me?”* (Conversation Starter Kit). Only a handful of workbooks (5/32, 17%) specifically encouraged the user to speak about their psychosocial preferences for end-of-life care with those close to them, via prompts including *“...ACP Conversations are a process so you do not have to think about this until you are ready. But if you have thought about it, tell your SDM(s), family and friends: what is important to you at the end of your life... music you want to listen to, books you want to read or have read to you...”* (Acclaim Health) or *“What is important [in the following exercise] is that you understand what each person involved in your conversation wants for himself or herself... Would you like someone to be with you when you die? Who?”* (Critical Conditions Planning Guide).

Documentation of Psychosocial Directives:

While documentation is a common element of medically-oriented ACP workbooks, only a fifth (7/32, 22%) of the workbooks we reviewed included a formal opportunity to document psychosocial preferences for EOL. Those that included a documentation component encouraged users to turn their reflections into a formalized plan that identified specific psychosocial directives such as “*I wish to have religious readings and well-loved poems read aloud when I am near death*” (Five Wishes); “*I want X at my bedside [at end of life]*” : ... [I] want someone to hold [my] hand” (Begin the Conversation). While not necessarily legally binding, this process ensures the translation of reflections and discussions into actionable conditions that users hoped would be applied in their final moments of life.

Discussion

This study used the combination of focus group deliberations and content analysis of existing ACP tools to explore the extent to which existing ACP materials hold promise for improving ACP uptake in LTC. Our focus group deliberations suggested that tool-supported ACP seems acceptable in LTC, especially in its potential for directing conversations about end-of-life topics. More specifically, LTC staff considered paper-based workbooks to offer viable direction for ACP uptake if such material included information about the importance of ACP and interactive exercises and prompting questions stimulating reflection and communication. Focus group deliberations further uncovered that tools that were too medically-focused were considered ill-suited for LTC. Yet our content review identified that a striking 80% (489/611) of existing ACP tools focused solely on supporting discussions and documentation of preferred *medical care* at EOL including non-resuscitation and non-intubation orders (i.e. advance directives). Current ACP research in LTC affirms the high prevalence of medically-focused ACP materials, as most studies exploring ACP impacts in LTC actually look more specifically at the implementation of advance medical directives (Capps, Gillen, Haley & Mason, 2018). While outcomes from this work have certainly shown some promise, our findings suggest such interventions are unlikely to be successfully adopted into usual practice in LTC if psychosocial issues are excluded, such as preferences for family involvement/non-involvement in EOL care, views about dying alone, spiritual beliefs that may provide comfort at EOL, and values related to quality of life/quality of care (Brinkman-Stoppelenburg et al., 2014; Sussman et al., 2017b).

Quite possibly the recurrent distribution and testing of medically-oriented ACP materials also perpetuates the limited understanding of ACP amongst residents and families in LTC reported in the literature (Mignani, Ingravallo, Mariani & Chattat, 2017). Until such time as ACP is understood more broadly to include reflections on values, beliefs, and preferences that can be used to inform in-the-moment decisions rather than solely on the identification of pre-specified medical decisions that may not be easily implemented within unforeseen contexts, it will not be consistently implemented in LTC or elsewhere (Howard et al., 2018; You et al., 2014).

Our initial screening of available ACP workbooks resulted in the retention of 32 tools found to include some psychosocially-oriented content. The vast majority of these tools encouraged reflections about psychosocial issues pertinent for EOL decision-making in LTC such as beliefs about quality of life/death.

Many also went a step further to help users unpack such reflections by orienting them towards smaller, more specified reflections such as preferred location of death, rituals of importance, and specific actions that may provide comfort. Encouraging specific reflections that can be more easily communicated has been found to be a useful approach to ACP activation (Sudore & Fried, 2010).

However, most of the tools we reviewed included less content and direction around how to communicate psychosocial preferences to decision-makers, family/friends, and health providers or how to select decision-makers and speak to them about their roles and responsibilities. Further, and almost none of the tools offered formalized directions on how to transform wishes and preferences into a documented plan that included psychosocial elements. While some have argued that pre-prescribed plans are of limited use because they fail to account for the specific and contextualized decisions that emerge at EOL (Tulsky, 2005), selection of and communication with substitute-decisions makers and health providers about roles, responsibilities, and preferences has been consistently recognized as a critical component of ACP (Bridges et al., 2018; Howard et al., 2018; Sudore & Fried, 2010; Sudore et al., 2008; You at el., 2014). Although workbooks alone may not be sufficient to support the movement from reflection to oral or written communication, more orientation towards this challenging aspect of ACP could hold promise for a LTC home environment by providing residents, families, and staff at all levels with tips and directions that may encourage communication on this emotionally complex and difficult topic.

In terms of applicability to a LTC home environment, two thirds of the tools reviewed were a moderate length (12–25 pages), most included graphics and images supporting readability, and half infused scenarios and examples relatable to circumstances/situations older persons living with frailty may face. Hence, some of the psychosocially-oriented workbooks and materials available may still require adaptations for a LTC environment.

Implications And Recommendations:

Our findings provide some direction to improve ACP engagement and uptake in LTC. First, our review identified a series of tools that include psychosocial components. We encourage LTC home administrators and directors of care to use the list provided as a starting point to select material for possible distribution. We also encourage them to reconsider any tendencies to use materials with a strictly medical focus. Second, prior to implementation within a selected LTC home environment, we suggest preferred material be altered (if required) to include typical LTC home scenarios that may encourage ACP reflections and to ensure a relatively equal balance between prompting questions and exercises that encourage reflections and those that encourage communication and documentation. With the advent of the COVID-19 pandemic, additional adaptations or companion resources may be crucial to ensure the relevance of these tools. A number of the tools we identified have already evidenced this, including the Speak Up tool (<https://www.speakupontario.ca/wp-content/uploads/2020/04/Engaging-in-Advance-Care-Planning-for-COVID-19.pdf>). Third, given the dearth of evidence located on the effectiveness or implementation of the identified tools we strongly encourage more research on ACP in

LTC that evaluates the identified psychosocially-oriented ACP materials. At the time of writing, we were only able to locate published studies that empirically evaluated three of the tools we reviewed (see Table 1). While our review suggests these materials are of high relevance to a LTC environment, studies evaluating the distribution and use of such materials in LTC are warranted to maximize impact and uptake.

Limitations

At the time of writing electronic materials were considered inaccessible for many residents in LTC and hence our review was limited to paper-based resources. In response to the COVID 19 pandemic and the need to ensure connections between residents and families, electronic communication has become more common in some LTC environments. It is possible that more psychosocially-oriented ACP tools are available in these digital formats and it may be timely to revisit the feasibility of electronically-based ACP materials in LTC.

We did not perform a full systematic review of published work that has evaluated our identified tools, and therefore may have omitted some relevant studies. However, our results made clear that the vast majority of the tools on our list have not been evaluated.

Our review failed to distinguish between workbooks that had some content applicable to a frail older population and those that were predominantly focused on issues related to aging and frailty. Hence our estimate of available psychosocially-oriented workbooks applicable to older persons in their current form may be inflated. We consider this a minor limitation as we expect all identified tools to require some adaptations to ensure applicability in local LTC environments.

Conclusions

A handful of ACP tools currently exist that hold promise for improving uptake of ACP reflection in LTC. However, these psychosocially-oriented tools may require infusion of scenarios pertinent to frail older persons, re-formatting, and a better balance between prompts and exercises encouraging reflections and those geared towards supporting communication to ensure applicability for LTC and to support communication between residents, decision-makers, and staff.

Abbreviations

ACP
advance care planning
LTC
long-term care

Declarations

Ethics Approval and Consent to Participate:

This Study was Approved by McGill University Research Ethics Board (REB) Approval #243-1214. All focus group participants provided informed written consent to participate on the day of deliberations.

Consent for Publication:

Not applicable

Availability of Data Materials:

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request. A list and location of all ACP tools included in the content analysis (Phase II) is provided in the paper (see table 1).

Competing Interests:

The authors declare that they have no competing interests.

Funding:

This work was supported by the Canadian Institutes of Health Research [Planning and Dissemination Grant #354656]. The funding body played no role in the design of the study, or in the collection, analysis and interpretation of study findings. There is no conflict of interest related to funding to declare.

Authorship Contributions:

T. Sussman conceptualized the project, oversaw all aspects of data collection and analysis and led the writing of the manuscript. S. Kaasalainen conceptualized the project and reviewed and edited the manuscript. R. Bimman led the content analysis and participated in the writing and editing of the paper. H. Punia participated in focus group data collection and analysis and manuscript editing. N. Edsell & J. Sussman participated in data analysis and manuscript editing.

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Acknowledgements: Not applicable

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Tables

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