

Implementing Advance Care Planning Tools in Practice: A Modified World Café to Elicit Barriers and Recommendations from Potential Adopters

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Abstract

This paper reports findings from a modified World Café conducted at a palliative care professional conference in 2019, where input on tools to support advance care planning (ACP) was solicited from healthcare practitioners, managers and family members of patients. Barriers to ACP tool use included insufficient structures and resources in healthcare, death-avoidance culture and inadequate patient and family member engagement. Recommendations for tool use included clarification of roles and processes, training, mandates and monitoring, leadership support, greater reflection of diversity in tools and methods for public engagement. This paper illuminates factors to consider when implementing ACP tools in healthcare.

Background

Advance care planning (ACP) is a process that supports adults at any age or health status with understanding and sharing their personal values, life goals and preferences regarding future medical care. The goal of ACP is to ensure that people suffering from serious and chronic illnesses receive medical care that is consistent with their values, goals and preferences (Sudore et al. 2017). Prospective and randomized trials have found that engaging in ACP increases the likelihood that clinicians and families understand and align care to patients' wishes (Detering et al. 2010; Hammes and Rooney 1998; Metzger

et al. 2016; Silveira et al. 2010); reduces hospitalization and intensification of treatments toward end of life (according to patients' wishes); and increases use of hospice services (Houben et al. 2014; Teno et al. 2002).

Despite the known benefits of ACP, uptake across healthcare sectors is sub-optimal (Committee on Approaching Death; Addressing Key End of Life Issues, Institute of Medicine 2015; Gauvin and Lavis 2013). There are deficiencies in the quantity and quality of ACP discussions between patients, their future substitute decision makers and healthcare practitioners (Heyland et al. 2006, 2013; Howard et al. 2018b; Teixeira et al. 2015). Key barriers to these discussions across different areas of the healthcare system include patients and families being unprepared to engage in these conversations, suboptimal communication skills and lack of time (Howard et al. 2018a; Kryworuchko et al. 2016; Siu et al. 2020; You et al. 2015).

Interest in the role of tools to educate and support the public and healthcare practitioners with ACP is increasing. Two systematic reviews including 149 studies of ACP communication tools and conversation guides reported that use of tools generally increases the consistency of engagement in ACP activities, documentation of wishes and concordance between preferences and written medical orders; however, there is substantial heterogeneity in the effects of the tools (Fahner

et al. 2019; Oczkowski et al. 2016). When optimally tailored and implemented, the use of tools alongside supporting ACP policies and practices can lead to an increase in ACP uptake across populations (Hammes et al. 2010; Simon et al. 2019; Wilson et al. 2014). It is essential that ACP tools are adapted to the target population, tailored to reduce barriers in the local context and evaluated to ensure that anticipated benefits are realized (Lund et al. 2015; Stacey et al. 2019).

Our team is engaged in a federally funded research program to adapt and evaluate ACP tools for the hospital, primary care and long-term care (LTC) sectors of the healthcare system in Canada and to investigate how ACP tools might be adapted to be more inclusive of marginalized groups, including older adults who identify as lesbian, gay, bisexual, or transgender (LGBT) and older adults from ethnic minority populations. Study settings include four hospitals, three multi-physician primary care practices, five LTC homes and one assisted living facility. In addition, members of two LGBT community groups and seniors representing ethnic minorities from two community centres have provided input on implementation issues from the LGBT and ethnic minorities' perspectives.

We were interested in learning about the perceptions of these tools and anticipated implementation issues from members of the healthcare community who represent the future audience of our knowledge translation efforts as adopters of ACP tools. Individuals for whom we considered ACP to be relevant are those who interact with patients or LTC residents regarding ongoing medical or psychosocial care (e.g., nurses, physicians, social workers, personal support workers), in this paper referred to as "healthcare practitioners." We leveraged a conference workshop in which we presented various ACP tools to elicit from the participants their perceptions of barriers to and recommendations for implementing ACP tools, including issues of access for specific marginalized groups.

Method

Modified World Café

We held a modified World Café workshop at a palliative care professional conference in 2019. The World Café is a method for hosting conversations around "questions that matter" (The World Café Community Foundation 2021). It uses a style that is meant to be similar to a comfortable "café" environment, with small groups discussing questions of interest (Biondo et al. 2019).

We first presented an overview of our research program and the ACP tools under study in consecutive 10-minute presentations by researchers from each of three subprojects representing a sector of the Canadian healthcare system

(hospital, primary care, LTC) as well as from a marginalized and ethnic minority populations subproject. Participants were then invited to join one of the four subproject tables – where physical copies of the tools being evaluated were displayed – to discuss their uptake within their organization or client population. Participants changed tables every 30 minutes. There were three rotations, so each participant could visit three of the four tables.

Each table had two research team members: a facilitator to ask discussion questions and a notetaker.

Tools presented

Tools presented included a clinician tool and four tools for patients and family members. Tools were selected based on their suitability for each particular sector and the unique characteristics of the population within each sector. The clinician tool was an evidence-based conversation guide, the *Serious Illness Conversation Guide* (SICG) (Bernacki and Block 2014; Bernacki et al. 2015; Lakin et al. 2016, 2020). The tools for patients included (1) The Conversation Starter Toolkit for Persons with Dementia (Institute for Healthcare Improvement 2021), a tool specifically designed to help families engage persons with dementia to reflect on and discuss fears and preferences regarding future care; (2) the main version of The Conversation Starter Toolkit for people with chronic progressive conditions to reflect on and discuss their preferences and concerns regarding future care (both Conversation Starter Toolkits were created in the US for the public); (3) the *My Wishes My Care* booklet, an ACP resource developed in British Columbia (BC Centre for Palliative Care 2020); and (4) The Best Worst Values Clarification tool, an online interactive values clarification tool (unpublished) that asks users to choose and prioritize among end-of-life care values (e.g., remaining independent, living as long as possible) (Scheunemann et al. 2012). Among the tools discussed at the various tables, the hospital table was the only one to discuss only the clinician tool. Table 1 summarizes the tools by the healthcare sector in which they were implemented in our ACP study and the context in which they were discussed at the World Café tables.

Data collection and analysis approach

We used the Ottawa Model for Research Use (OMRU) to guide data collection and analysis (Graham and Logan 2004; Logan and Graham 1998). The OMRU is a theoretical framework for understanding how to increase the transfer and use of research findings into practice (Graham and Logan 2004; Logan and Graham 1998). The model recommends assessing barriers and supports for adoption of the intervention at multiple levels (the innovation, the potential adopters and the practice environment). We selected this model for its simplicity compared with other models, as well as its focus on multiple

TABLE 1.
Tools presented at the four World Café discussion tables according to each area of focus for implementation

| Hospital | Primary care | Long-term care | Marginalized and ethnic minority populations |
|--|---|---|---|
| Serious illness Conversation Guide* (Bernacki et al. 2015) | Serious illness Conversation Guide* | The Conversation Starter Kit for Residents with Dementia† (Institute for Healthcare Improvement 2021) | The Conversation Starter Kit† (Institute for Healthcare Improvement 2021) |
| | Best-Worst Values Clarification Tool† (unpublished) | | My Wishes My Care† (BC Centre for Palliative Care 2020) |

* Tool designed for healthcare practitioners.

† Tool designed for patients/public.

levels of the system. Guided by the model, the discussion questions regarding the tools were as follows: (1) How can you see this tool being used in your practice setting? (2) Can you describe any barriers that you anticipate in implementing this tool in your practice or setting? and (3) What recommendations do you have for implementing this tool in your practice or setting? Facilitators were instructed to probe the multiple levels for questions 2 and 3.

The notetakers used a template to document comments relating to each question. As the discussions progressed, group facilitators verbally summarized the comments and reflected these back to the group. As a method of member checking

(Creswell 2013), the notetaker and facilitator at each table reviewed the notes after the workshop to ensure that they were complete and reflected the discussions. These documented comments became the data.

A directed content analysis approach was used for data analysis (Hsieh and Shannon 2005) given that our intent was to use the OMRU framework to guide both data collection and analysis. The analysis team included Dawn Elston (DE), Michelle Howard (MH), Sharon Kaassalainen (SK), Gloria Gutman (GG), Brian De Vries (BDV), Rachel Z. Carter (RZC) and Marilyn Swinton (MS). The analytic process is summarized in Table 2.

TABLE 2.
Summary of the analytic process

| Analytic steps | Analytic activities (authors involved) |
|----------------|---|
| 1. | A template was created, informed by the OMRU framework, to analyze content according to the following broad domains (MH, SK): <ul style="list-style-type: none"> • The practice environment: patient factors, social and cultural factors, economic factors, uncontrolled events • Potential adopters: awareness, attitudes, knowledge/skills, concerns, current practice • The innovation: development process, innovation attributes |
| 2. | Analysts, including one representative from each table in the World Café, met to review the framework and develop a set of working definitions for each of the domains to ensure the context wherein discussions took place was not lost (MH, MS, GG, BDV, SK). |
| 3. | Analysts (MH, MS, GG, BDV, SK) coded all the comments from their table according to the template themes. Another author (DE), who was not present at the workshop, independently coded all comments from all four workshop tables. |
| 4. | Coding from all the analysts (MH, MS, GG, BDV, SK, DE) was reviewed for consistency, and discrepancies were noted. Analysts met and discussed how to apply the OMRU framework consistently and reviewed the OMRU framework. |
| 5. | All of the analysts (MH, MS, GG, BDV, SK, DE) met again and came to consensus on the following coding decisions: <ol style="list-style-type: none"> (i) Comments pertaining to more objective descriptions of groups, i.e., when patients are described by the participant as a group would be coded to the practice environment domain. (ii) Comments that were more subjective – for example, the perspective of a patient – would be coded to the potential adopters domain. |
| 6. | Two of the analysts (MH, DE) further refined the working definitions for the domains and revised the coding to be consistent with the coding decisions made in step 5. Some of the OMRU publication domains were reworded to be specific to our topic in the presentation of results, and some were not used because they were not represented in our data. |
| 7. | All analysts (MH, MS, GG, BDV, SK, DE) reviewed the revised coding and discussed discrepancies until consensus was reached on the final grouping of comments within domains. |

FIGURE 1.
Domains adapted from the OMRU framework

| Characteristics of the practice environment | Characteristics of potential adopters | Evidence-based innovation |
|--|---|---|
| <ul style="list-style-type: none"> • Patient factors • Cultural factors – death avoidance • Structural and material factors | <ul style="list-style-type: none"> • Attitudes, knowledge and skills | <ul style="list-style-type: none"> • Characteristics of the tools and ideas for implementation |

Ethics

Prior to the event, the Hamilton Integrated Research Ethics Board (the institutional board of MH) waived the need for research ethics board review because the intent was to inform future knowledge translation. Attendees of the workshop were informed about the intent to record and analyze discussion points that may be included in a publication, that no identifiable information would be presented and that we had obtained a waiver from a research ethics board.

Results

A total of 32 participants attended: 11 identified as nurses, five as physicians, five as administrators, three as educators, one as a researcher, one as a volunteer three as family member representatives of organizations and three did not specify. The data comprised 155 comments documented by the facilitators.

Findings are presented by three domains we adapted from the OMRU framework: characteristics of the practice environment, characteristics of potential adopters and characteristics of the tools and ideas for implementation (Figure 1) (Logan and Graham 1998). The practice environment refers to the set of factors that encourage or discourage the use of research: structural, social, patient and other situational factors. Potential adopters are those who will use the research, such as clinicians whose behaviour is influenced by factors other than the evidence, such as through attitudes and knowledge. Characteristics of the innovation (i.e., tools) include the innovation itself, the process to encourage its use and how potential adopters perceive these.

Characteristics of the practice environment

This domain includes three sub-domains of patient (or LTC resident) and family member factors, healthcare culture and structural and material factors.

Patient factors

Barriers to ACP that were attributed to patients and family members included family dynamics, lack of understanding of the illness and cultural and language factors. Family dynamics, including lack of or late involvement of family members, were mentioned:

Family emotions or wishes may not be conducive to resident's wishes ... [Family] may not live close by,

meaning that they may not understand the resident's condition or circumstances. (LTC table)

One participant noted that they had “seen patients give different answers to questions like this [values clarification tool] when family is in the room versus when not” (primary care table).

Perceived differing family structures were considerations, for example, “challenges with LGBT people re[garding] SDM [substitute decision maker] and family (biological vs. choice)” (marginalized and ethnic minority table). In LTC, cognitive impairment in residents was a challenge as “many residents are not able [to] have a conversation.” A generational effect was also suggested:

Coming out of the war [referring to the older generation's views], “[they] just don't want to suffer”; baby boomers [referring to the younger generation's views] want everything done but then [they are] non-compliant with treatments that may prolong life.

Participants also discussed considerations related to religious and cultural norms, for example:

[The] South Asian community has concerns about burial location[s].

In [the] Chinese community, [the] relationship between food/feeding [and] nasogastric tubes [is] causing complications but [the] family needs to keep them alive.

Indigenous people face unique challenges – people [at the end of life] are kept inside, away from the land and become agitated. (Marginalized and ethnic minority table)

It was noted that staff in LTC homes may experience challenges with different languages and cultural sensitivities of residents.

Recommendations centred on greater engagement of patients and the public, specifically “integration of the family,” in ACP in LTC. Examples included “hold education sessions on ACP as an ‘event’ in the home, normalize these discussions” and “[use it as] a facilitator to help residents/families

through the process.” Recommendations at the marginalized and ethnic minorities table centred on greater involvement of the public in creating ACP tools and methods so that they are more inclusive. It was suggested that ACP approaches would need to leverage structures outside formal healthcare, for example, through influential members of marginalized and ethnic minority communities:

[There is] high uptake in some diverse communities (Hindu) because religious leaders promote ... (Marginalized and ethnic minority table)

Healthcare culture

Cultural views of both the public and the healthcare sector regarding death and dying were raised. The general “death-denying” culture in the healthcare system was noted. For example, the healthcare culture was perceived as not supporting talking about dying or sharing a poor prognosis, as these are associated with a sense of failure. As a participant noted at the LTC table, “sometimes it’s very hard to get physicians to provide prognosis,” and at the primary care table, a participant stated, “We do a poor job of informing patients re: realistic expectations.” The avoidance of honest discussion was believed to lead to avoidance of palliative care:

Fear/stigma/culture (in [the] hospital and elsewhere) in attitudes towards palliative care – [there is a] conflict between [a] culture of cure in medicine and acknowledgement of death, [a] sense of failure amongst physicians (e.g., oncologists) ... (Hospital table)

There was a sense that the situation would not change within the current environment:

[We] need a culture change of younger physicians “changing the system.” (Hospital table)

The need for a change in healthcare culture among physicians through systems and leadership was noted:

[We] need a system/culture change in the system. [We] need process measures and outcome measures to induce/foster this change. [We are] trying to get all healthcare workers and their families to do this for themselves [and for organizational leadership to support a role for a] “physician champion from within your own group as opposed to an ‘outsider’ expert.” (Hospital table)

Structural and material factors

Participants recognized that successfully engaging in ACP in the healthcare sector required dedicated time, clarity on whether ACP is within the professional scope of some healthcare practitioners – such as personal support workers – resources and processes to ensure correct timing, documentation and communication of discussions:

How physician booking works (15-minute appointments, double booking, electronic medical record documentation requirements) does not enable time/space for these conversations.” (Hospital table)

One commentator noted:

Informational continuity across [the] system is a real challenge; documenting the conversation can be challenging. (LTC table)

In LTC, an issue with staff scope of practice was identified as a challenge:

Personal support workers are not able to document [conversations with residents], yet families/residents often want the personal support worker or care aide to help them.

Participants recommended various structural improvements in existing systems to trigger the initiation of ACP. They suggested using flags and forms in electronic medical records, a welcome kit for LTC admissions and triggers for the public to identify their substitute decision maker when renewing their health card. Embedding triggers for ACP within care pathways when a resident’s health is deteriorating in LTC could ensure that the resident’s wishes “travel with them” and are honoured “seamlessly” across healthcare sectors. Accountability approaches such as systematic supports for ACP at specific times were suggested for LTC, which, for example, “could be a series of trigger points to have a check-in, whether these are negative or positive (e.g., hospitalization, sudden decline in health, birth of grandchild, etc.)” A multi-disciplinary approach was recommended in LTC, for example, having a nurse start a conversation using a tool with patients before a discussion with a physician. A facilitator role was suggested for LTC, but physician involvement was also seen as necessary, as “people listen to their doctors – sometimes nobody else” (LTC table).

Characteristics of potential adopters

Characteristics of potential adopters comprised discussions on the attitudes, knowledge and skills of healthcare practitioners regarding ACP discussions.

Attitudes, knowledge and skills

Participants discussed their perceptions of healthcare practitioners as adopters of ACP tools with respect to attitudes, knowledge and skills.

Healthcare practitioners' lack of knowledge and skills in conducting ACP discussions was identified at the hospital table. The attitude that ACP was perceived by healthcare practitioners as a "palliative discussion" and, therefore, "taboo" was also noted. Attitudes could influence uptake of training on the SICG, such as "[It is] difficult getting physicians to attend training," "We already do these conversations; why do I need the training?" and that "The prognosis piece is the largest barrier in having these conversations." Another need for training in the hospital was to understand "legal things like capacity and goals of care, etc." Training needs in LTC were also noted, where "staff do not have training in [a] palliative approach to care."

Participants perceived that there was a need to practise the skill of conducting serious illness conversations in order to sound natural:

People who are not good communicators sound robotic using the guide. (Hospital table)

In addition to formal training, other supports were suggested at the hospital table, such as "Having a community of practice for clinicians to share success stories allows for peer mentoring" and "A lot more of role modelling and role play ... Most clinicians have not done this work for themselves." At the hospital table, participants realized that the SICG training can teach healthcare practitioners to identify and overcome conversational inadequacies as well as "identify patients earlier and have conversations earlier."

Participants at the marginalized and ethnic minorities table recommended attitudinal changes for healthcare such that it can become more person centred:

[We need] individualized care – ask, follow, don't assume, regardless of culture.

They also highlighted the need for clear, specific communication, such as:

Have you talked to your family?

Characteristics of the tools and ideas for implementation

This domain encompassed discussion about perceptions of how the tools would be received, especially by diverse groups, suggestions for improving tools and implementation issues to consider.

There were structural barriers relating to the inconsistencies in the ACP language used and the meaning of terms in

different provinces. The cost of obtaining paper-based tools was a barrier noted in LTC.

Issues regarding how adopters might perceive and use tools were noted. When discussing the values clarification tool at the primary care table, there was a perception that it was "hard to get your head around at first" and that it is "a bit too focused on end of life," but it was also perceived as useful because it helped people consider their values explicitly. Participants at the primary care table suggested that the patient ACP values clarification tool could help prepare patients for conversations by "priming the pump," being a "conversation starter" and "emphasizing the importance of ACP in a non-threatening way." The SICG for clinicians was perceived to help healthcare practitioners know their patients better, "not as a tool to make decisions regarding end of life" but rather "as a listening tool" (Hospital table).

In the context of marginalized and ethnic minority populations, it was noted that people needed to "see themselves represented in the tools," for example, by incorporating photos of diverse groups and more "common language[s]" in tools. Commonly used language that equates substitute decision makers with a person's "relatives" was perceived as problematic for LGBT people if they are estranged from their biological families. For greater representation, a consultation about the tool development process with vanguard organizations and jurisdictions, including progressive countries and global groups, was suggested. There were recommendations to normalize conversations outside of healthcare, through schools, faith communities, social media and targeting of youth.

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Discussion

In this modified World Café involving potential adopters of ACP tools, numerous factors were suggested that may influence whether or not ACP tools are adopted in healthcare and by the public. Participants had concerns about patient and family reticence to engage in ACP; the appropriateness of tools; the context of healthcare systems and the culture in which ACP is undertaken; and attitudes among healthcare practitioners. Participants also seemed to hold some stereotypes about certain groups of patients.

Our results suggest that system changes within healthcare are needed for ACP tools to be optimally used. It was interesting that although the presentation at the event and the discussions centred around specific ACP tools for patients and healthcare practitioners, much of the discussion focused on system-level and material challenges to undertaking ACP in

healthcare. Similar challenges have been reported previously in Canada and elsewhere (De Vleminck et al. 2013; Howard et al. 2018a; Lund et al. 2015; You et al. 2015). It was interesting that barriers were different between the hospital care and LTC tables. In LTC, where physicians are not the majority of healthcare practitioners, much of the discussion was around the appropriateness of various levels of staff being involved in ACP. In the context of LTC, 70–90% of the hands-on care is provided by non-clinical staff, such as nursing aides and dietary aides. It has been noted that these staff members could play a role in ACP discussions in LTC as they have frequent interactions with and know the residents very well. However, these staff members do not feel empowered or supported in doing so (Kaasalainen et al. 2017). In contrast, the hospital table focused on physician training, mentorship and leadership, perhaps recognizing the autonomy and control of physicians in initiating ACP. Suggestions at the LTC table focused on concrete procedures within existing structures and oversight mechanisms.

The engagement of diverse groups in ACP was recognized by participants, particularly when considering the LTC sector and marginalized and ethnic minority groups. This is especially important given the perception among participants that the culture of death avoidance in healthcare results in delays in discussions about mortality. Introducing ACP outside of healthcare and targeting youth were strategies that were suggested to normalize the topic among the general population in an environment not constrained by medical norms. Examples of successful strategies to empower communities, such as peer-led education sessions, are emerging (BC Centre for Palliative Care 2020; Fink et al. 2020; Somes et al. 2018), yet more research is needed on such strategies. Ideally, ACP approaches in the community and in healthcare will not evolve in isolation of each other. Understanding how to best prepare patients and families in the community for future decision making should be a consideration in the adoption and implementation of ACP tools (Fahner et al. 2019; Hall et al. 2019; Heyland 2020).

Participants spoke about the intersection between the identity of potential adopters (patients, families or residents in LTC) and assumptions and stereotypes held by healthcare practitioners. This finding suggests that barriers to tool use are quite distinct from any insufficiencies of the tools themselves and reinforces the importance of including community representatives, patient advisors and family members in the development of ACP tools and resources. Comments regarding the influence of leaders in ethnic minority communities reinforces the need to think beyond our typical professionals and look to community leaders to ensure that ACP tools are relevant to and used by the potential adopters. Approaches to ensure broad inclusion may also reduce stereotyping of patients.

Discussions at the marginalized and ethnic minorities

table raised the issues of a lack of inclusivity of diverse people in images of people in ACP tools, in the language used to describe relationships, which generally is heteronormative, and in approaches. Efforts are under way in Canada to remedy this, with language adaptations of patient ACP tools and the SICG (BC Centre for Palliative Care 2020), and it will be important to ensure that the best practices are used for further language and cultural adaptations.

This study has limitations. First, participants self-selected to attend the workshop, and their views may not represent all healthcare practitioners. Second, for feasibility purposes, our data source consisted of summarized comments rather than fully transcribed discussions. Third, because time was limited in the workshop, we were unable to probe deeply into the issues raised by participants. Nevertheless, with the use of a guiding framework and content analysis approach that involved several analysts who were present at the discussions, we believe our results provide useful insights into issues that may impact the adoption of ACP tools across healthcare sectors.

In order for ACP tools to be adopted, attention is needed to improve structures and resources in healthcare, attitudes toward acknowledging mortality and strategies for successful patient and family member engagement, including those from marginalized groups and ethnic minorities. Recommendations from potential adopters included clarification of healthcare practitioner roles and processes, training, oversight, leadership support and a greater reflection of diversity in the tools and methods for public engagement. **HQ**

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