Engaging Persons with Dementia in Advance Care Planning:

Challenges and Opportunities

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Abstract

This paper reports findings from a series of focus groups with persons with dementia and family caregivers intended to explore (1) perceptions of and experiences with advance care planning (ACP); (2) concerns related to future care including, but not limited to, end of life care; and (3) practices that may support positive engagement with ACP. A total of 18 participants including ten persons with dementia and eight family caregivers participated in five focus groups held in two urban cities in Canada. All focus group deliberations were audio-recorded, transcribed verbatim and analyzed in five stages using a semantic thematic approach. All participants expressed some form of engagement in ACP, but understandings were limited and divergence was expressed regarding the timing of more expansive conversations about future care. Although some persons with dementia were ready to engage in future care discussions, most preferred focusing on the present and suggested their families did not require direction. This placed families in the complex dilemma of protecting their loved ones whilst compromising their own needs for dialogue. Although individually focused models of ACP engagement hold promise for those persons with dementia ready to engage in future planning, our findings suggest that early engagement of families in the reflective process may go a long way in supporting ACP activation. Our findings further suggest that persons with dementia who do not have close family/friends may require extensive ACP encouragement and support from service providers.

Keywords: Dementia, advance care planning, family caregiver, decision-making, end of life care

Engaging Persons with Dementia in Advance Care Planning: Challenges and Opportunities

Advance care planning (ACP) is an iterative process whereby persons with serious chronic conditions reflect on, communicate, and sometimes document values, wishes, and preferences for future care, including end of life care (Howard et al., 2015). ACP aims to help guide family, friends, legally appointed decision-makers and health providers to make in-the-moment care decisions on behalf of individuals who are not capable of expressing their own preferences (Sudore & Fried, 2010). For persons with dementia, ACP is ideally activated early in the illness trajectory when capacity for reflection, communication, and decision-making is more consistently present (Piers et al., 2018).

Evidence of positive outcomes associated with ACP for persons with dementia is growing (Dixon et al., 2018; Givens et al., 2018; Lum et al., 2015; Phenwan et al., 2020; Wendrich-van Dael et al., 2020). Positive outcomes include fewer invasive end of life care interventions (Litzelman et al., 2017; Nicholas et al., 2014; Robinson et al., 2012), improved quality of life (Vandervoort et al., 2014), and better congruence between expressed wishes and care delivered at end of life (Jeznach et al., 2015).

Yet, uncertainties about both the timing and the focus of such conversations have been reported as a major barrier to ACP activation for persons with dementia and their families (Brazil et al., 2015; Sinclair et al., 2016; Tilburgs et al., 2018; van der Steen et al., 2014). For example, for persons with dementia future care encompasses much more than end of life planning. Nevertheless, ACP research to date has largely focused on the benefits and timing of discussing medical directives such as use of feeding tubes, resuscitation or hospitalization (Givens et al., 2018; Phenwan et al., 2020; Wendrich-van Dael et al., 2020). Hence descriptions of more expansive conversations about values, preferences and concerns for future care have been scant (Murray et al., 2005; Rait et al., 2010). Further, while persons with dementia are most consistently capable of engaging in ACP conversations early in the care trajectory, some suggest ACP discussions cannot take place until a person with dementia acknowledges and accepts their diagnosis, which may not occur until years into the diagnosis when judgement is already impaired (Dickinson et al., 2013). Finally, much of the existing research on ACP engagement has been conducted with healthcare providers or family caregivers not persons with dementia themselves (Read et al., 2020). Yet, persons with dementia are best positioned to inform the focus and timing of ACP discussions (Jones et al., 2019; van den Block, 2019).

Redressing these gaps in knowledge, this paper reports findings from a series of focus groups with persons with dementia and family caregivers intended to explore (1) perceptions of and experiences with ACP; (2) concerns related to future care including, but not limited to, end of life care; and (3) practices that may support positive engagement with ACP.

Methods

This focus group study was informed by a semantic thematic analysis, a qualitative approach that guides the researcher through a process of inductively identifying, analyzing and reporting on key themes on underresearched topics, such as the thoughts and experiences of ACP from the perspective of persons with early stage dementia and their families (Braun & Clarke, 2006). Focus groups can be useful forms of data collection when addressing sensitive topics, because participants can help one another open up, elaborate, and reflect (Kitzinger, 1995; Krueger & Casey, 2014). They also allow researchers to minimize the distance between themselves and participants, and therefore prove useful when aiming to include participants whose voices have been overlooked in research (Rodriguez et al., 2011).

This research study was conducted in accordance with the standards of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans and was approved by the Research Ethics Board Office at McGill University [file number 186-0917].

Site Selection & Recruitment

Participants were recruited from two Alzheimer Society chapters in Canada (one in Ontario and one in Quebec). A key contact person in each organization purposefully identified and contacted eligible participants to inform them of the study, and the date and time of the planned focus groups. To be eligible participants had to be (a) someone with dementia capable of expressing their thoughts and wishes in a 60 minute focus group; (b) a family member supporting a person with dementia capable of participation; (c) capable of communicating in French or English. All participants were informed that participation was voluntary and would have no impact on their service provision. All individuals expressing an interest in participation were contacted by the research coordinator who further reviewed the study's purpose and the voluntary nature of participation. Signed written consent was attained on the day of focus group participation. Although focus groups were initially scheduled for persons with dementia and caregivers separately, some mixed groups were added to accommodate participant preferences.

Data Collection

The focus groups were held for approximately 60-90 minutes at each study site and were facilitated by one or two members of the research team. In focus groups, the skills of the researcher are noteworthy in terms of their ability to facilitate and moderate the group discussion (Nyumba et al., 2018). All members of the team who facilitated the focus groups were graduate students in the fields of social work and nursing who had training and experience with dementia care, as well as strong active listening, relationship-building, and communication skills. The facilitators monitored the discussions to ensure that all participants had equal opportunities to contribute their experience/opinions, and that no single person dominated the conversation.

The facilitators used a semi-structured interview guide aimed at exploring participants' views on and experiences with ACP. The interview guide included open-ended questions that inquired about perceptions and experiences (e.g. what do you think about the idea of ACP? How, if at all, have you engaged in ACP?); factors that support or hinder ACP engagement (e.g. what helps people with dementia think about future care?) and suggestions for improving ACP uptake for persons with dementia and their families.

All participants were provided with a holistic definition of ACP at the beginning of each focus group discussion to ensure a common understanding of the topic under study. More specifically, participants were informed that ACP is a process that involves reflecting on, discussing, and sometimes documenting concerns and values related to *future care*, which includes but is not limited to end of life care. Participants were further provided with examples of different aspects of care they might consider reflecting on and/or discussing, including preferences for family/friend involvement in decision-making, or spiritual or religious rituals/beliefs that are important to consider during the dying process.

Written consent was obtained for all participants prior to conducting each focus group. Willingness and capacity to participate was also monitored during the discussions (Thorogood et al., 2018).

Participants

A total of 18 participants including 10 persons with dementia and 8 family members participated in five focus groups. One focus group was conducted with persons with dementia only, one focus group was conducted with family caregivers only, and three focus groups were mixed (combining people with dementia and family caregivers together). While the original design aimed to separate persons with dementia and family caregivers in order to create a safe space for each group's voices to be heard (Wiersma et al., 2016), some persons with dementia expressed an interest in participating with their family members. The mixed groups were offered to accommodate this preference. The mean group size was four participants (range 2-6 participants).

Data Analysis

All focus groups were audio-recorded, transcribed verbatim, and thematically analyzed in five stages (Braun & Clark, 2006; Marshall & Rossman, 2016). To ensure accuracy, all transcribed data were cross-checked with their associated audio-recordings by one of the focus group facilitators. All transcripts were analyzed in their original language.

In the first stage of analysis a research assistant read each transcript twice, noting observations and meanings in memo form. This process of familiarization informed the second stage of analysis wherein the team inductively developed a list of codes thought to broadly capture the challenges and opportunities expressed by participants as they recounted their reactions to and experiences with ACP (Braun & Clark, 2006). *Post-mortem planning*, *more than end of life*, *confronting deterioration*, and *levels of readiness* were examples of codes developed at this stage because they were thought to represent words or phrases that closely resembled participants' accounts. At this second stage, one research assistant coded large chunks of data to ensure that the contexts surrounding participants' accounts could be captured and considered alongside initial codes. Following this process, all members of the research team engaged in a discussion of possible meanings and patterns within, between, and across codes in an effort to group them under potential themes (Marshall & Rossman, 2006). Possible differences between sentiments emerging from persons with dementia and those emerging from families were also considered. For example, through discussion, reading, and reflection, the team noted that data coded under *post-mortem planning* and *more than end of life* appeared to represent examples of a larger theme indicating that initial understandings of ACP are limited. The team also identified that there were divergent responses to ACP timing, with some participants noting immediate readiness and others noting the importance of waiting for the right unspecified time in the future. Finally, the team noted that both persons with dementia and families found it threatening to engage in thoughts of deterioration, and that negative experiences with the healthcare system further deterred persons with dementia from ACP engagement. These discussions informed the third stage of the analytic process wherein a draft report of the data was produced framed around five broad themes developed collectively through team discussions: Initial understandings of ACP are limited, the time is [not] now, thinking about deterioration is more challenging than thinking about death, negative healthcare experiences create challenges for ACP engagement, and ACP has specified benefits for caregivers.

In the fourth stage of analysis, all members of the team reviewed the written report for accuracy, comprehensiveness, and redundancy (Braun & Clark, 2006). The themes and coded extracts were also re-examined alongside the literature on ACP, which identifies reflection as a core element of ACP engagement (Sudore et al., 2008). Four themes were retained at this stage and the fifth, ACP has specified benefits for caregivers, was refined to more accurately and comprehensively capture the challenges and opportunities surrounding ACP reflections from the perspective of both persons with dementia and families. Hence, the fourth stage of analysis produced the following six themes (1) Initial understandings of ACP are limited; (2) timing conversations: the time is [not] now; (3) thinking about deterioration appears more challenging than thinking about death; (4) negative healthcare experiences create challenges for ACP engagement; (5) Family support serves as a protection from reflecting on future deterioration; and (6) ACP as a mechanism for persons with dementia to support their families.

The fifth stage of analysis involved comparing and contrasting the emergent themes developed in stage four with the original un-coded transcripts. Particular attention was paid to the extent to which each theme represented the core ideas expressed within each type of focus group (i.e. persons with dementia, mixed groups, caregivers). No new codes or themes emerged from this re-examination, suggesting a level of thematic saturation and representation across group types (Saunders et al., 2018). At this final stage of analysis all selected extracts from interviews conducted in French were translated by XX and verified for accuracy by XX and XX (initials blinded for review). The team's capacity to work with French transcripts helped to preserve the contextual meanings of extracted text throughout the analytic process (Roth, 2013). All participants have been ascribed pseudonyms.

Findings

Initial understandings of ACP are limited

Despite our initial orientation to ACP, when speaking about thoughts and experiences with ACP all participants across groups spoke specifically about post-mortem decision-making and planning such as burial/cremation, funeral arrangements, and financial planning. For example, when asked if participants had engaged in ACP, typical responses were as follows:

> *Yes, our family has discussed it. And we looked into what had to be done. And so, in our case, that whoever dies in our family, that we'd be cremated. […] Everything is in place so there is no feeling of "Oh, they have to pay money" and all of that. It's all been done.* (Mark, person with dementia, persons with dementia focus group)

> *We got prepaid funeral […] and it's all written down what we want.*
>
> (Kim, family caregiver, mixed focus group 2)
>
> *So having it planned in advance, having the funeral in advance. All of that stuff to me, is, is a necessity. It has to happen.*
>
> (Marie, family caregiver, mixed focus group 2)

Hence, while many saw value in making plans in advance, such plans appeared to be reserved for easing any complications with post-death arrangements rather than reflecting on and discussing preferences and concerns during moments of deterioration and dying. Exceptionally, a small number of participants did mention having engaged in some discussions about particular medical directives, such as communicating their preference for non-resuscitation. However, these rare conversations did not include accompanying discussions of underlying values by the person that may inform under what circumstances to activate such decisions (e.g. what constitutes quality of life for a given person).

Overall participants' initial reflections on ACP suggested a narrow understanding. Most participants understood ACP to involve post-mortem planning and many had engaged in such discussions. As will be seen in the next section, when asked to expand notions of ACP to include discussions of future care needs, many found this to be more threatening and none had yet engaged in such discussions.

Timing conversations: The time is [not] now

While all participants acknowledged the importance of planning for death, they expressed varying thoughts and feelings about engaging in conversations focused on their future care needs as their illness progresses. Reactions ranged from "the earlier the better" to "it hasn't happened yet [so I] haven't needed to address it". Those vocalizing their readiness wanted to learn everything about their condition so that they could be prepared. This approach is expressed by the following participant:

> *Well me, I would like to know more about the, the deterioration of the Alzheimer's process. [...] It's not too early to talk about it because the more you move forward in time, the less you are aware. While now, uh, now I am a little more aware, so it's time to talk about it.* (Jean, person with dementia, persons with dementia focus group)

Others preferred to remain focused on day to day challenges. When asked about future care preferences and concerns, these participants focused on here-and-now issues emphasizing what they have done to adapt to their current realities.

> *For me, no. It hasn't happened. I haven't needed to address this.*
> (André, person with dementia, persons with dementia focus group)
>
> *I think people, from what we're doing, it's [dealing with things] as it happens. Which probably may, may not be a good thing to do but that's what happens. We have a rough idea, yeah.* (Sandra, family caregiver, mixed focus group 3)

Caregivers also described their family member's reluctant approach to thinking about the diagnosis and the meaning it holds for future functioning, as noted in the following comment:

> *I think his doctor could be one who could raise [the ACP conversation]. Have you thought about… But I know my husband. "But I'm so healthy, why would I want to look at end of life care?"* (Iris, family caregiver, caregiver focus group)
>
> *You know, a lot of people are in denial they don- they don't want to talk about it. "Who? Me? Have Alzheimer's? Or dementia?"*
>
> (Ruth, family member, caregiver focus group)

In sum, as participants reflected on the meaning and importance of discussing concerns and preferences for future care beyond planning for death, varying reactions ensued. Some felt such conversations were essential to ensure their involvement in planning and decision-making. Others either directly stated or indirectly inferred that remaining focused on the day to day was most useful to them for the time being.

Thinking about deterioration appears more challenging that thinking about death

Whether one was open to learning everything about their condition to inform future decision-making, or one felt that the time to engage in such reflections was in the unspecified future, all participants suggested that their fears of deterioration and decline make these thoughts somewhat overwhelming. As one participant expressed:

> *So, for me, death doesn't bother me at all. It's the fact that I will decline, and I will be a burden for my family.* (François, person with dementia, persons with dementia focus group)

Such expressions illuminated the psychological and emotional differences between talking about death and talking about dying, with the latter necessitating reflection on the process of decline. For persons with dementia in particular, being asked about future care elicited intense emotions about the current losses they are managing. For example, one participant spoke of the dread elicited when he thinks about a time where he may no longer be able to bowl in a competitive bowling league:

> *In the group that I belong, there-, because I still do, uh, I'm in leagues, uh, bowling leagues, and they know me. Well, I told them, uh, that, uh it won't change, because they notice- would notice, you know, because I don't act normal, because, let's admit, I've been bowling for 20 years, 25 years, and then they wonder how come I no longer have the- I – I can play but at, you know...So I came to a- I realize that at some point, I would*

> *have to give up this sport because it's competitive leagues.*
>
> (Michael, person with dementia, persons with dementia focus group)

A second participant described how horrible it has been for him to adjust to losing his driver's license:

> *Me, I lost my driver's license about, about four months ago. And, that's it, taking public transportation, it's horrible... It's a life-changing thing.*
>
> (François, person with dementia, persons with dementia focus group)

A third responds to a question about possible future deterioration by focusing on how she problem-solves *current* deficits, as follows:

> *I: Do you guys talk ever about what you would want to do, like, if you couldn't walk, you know, that being in a wheelchair would be OK or starting to use a walker or not being able to do the stairs. Do you ever talk about things like that that could happen in the future?*
>
> *Bonnie: When there are stairs, I'm holding on to the railing now so it's OK.*
>
> (Bonnie, person with dementia, mixed focus group 1)

These participants' used their emotional energy to manage and adapt to their *daily* losses and how to deal with them. Planning for further deterioration seemed almost contraindicative to the strategies they were using to manage their condition.

Negative healthcare experiences create challenges for ACP engagement

Persons with dementia were also highly aware that the enactment of their care preferences was heavily reliant on the care and concern from others. This meant that current interactions that elicited feelings of disrespect activated fears for the type of care they would receive in the future, when they were no longer positioned to advocate for themselves. One participant described this experience when she attended a lecture by a physician to learn more about what she may face with her condition, as follows:

> *[The doctor] would say sometimes that, "You probably have to go like, um, Yes [said very slowly]". Like [she was] talking to a baby. And I thought, "Wait a minute." You are saying that? So what, what am I? I am a baby now and you're talking to me like, "Yeah, yeah, yeah. One. Two. Three. Four. Five."…You're talking down to me and I am able, I have the [capacity] to see that's what you're doing and I will resent it.*
>
> (Bonnie, person with dementia, mixed focus group 1)

This circumstance led the participant to steer clear of informational sessions that could otherwise help her to think about and anticipate future care needs and preferences.

Caregivers likewise spoke of the stories they had had heard about long-term care homes, which included limited resources. In these cases, talking about and thinking about the future became fraught with fears about relocating to such settings that seemed ill-equipped to provide care based on needs and preferences. As one caregiver stated, *"I think even, even some of those homes, I hate to say it but I don't think you get the proper care. You hear all weird things about it, right?"*(Robert, family caregiver, mixed focus group 3).With questions about the care system's capacities to truly provide optimal care based on their personal preferences, some participants found it easier to avoid thinking about the future and focus their limited energy on managing the here and now.

For one person with dementia, worries about quality care were a motivating factor in her interest in relying on her family for this type of support when the time comes. What is important in this statement is that while she concludes by suggesting she has a preference for family support, she also provides information that could help guide her family should they need to pursue outside help (i.e. the importance of credentials):

> *And I will have to be very particular about the person who is going to come and do my future care. I want to know what is your training? What are you doing exactly and all the rest of it.[...] Of course I wouldn't want just any Tom, Dick or Harry coming in. Yet, I mean, you have, I know you have people who say that they're caregivers and all the rest of it. And I don't mean your family caregiver that come in. Well, have you had training to do this sort of thing? You know? Just because you want a job and you can do this job. I don't want that. Somebody coming into my home to, to do that. So I would not be dependent on them. I would be dependent more on my daughter-in-laws, my daughter, and or course, my husband.* (Bonnie, person with dementia, mixed focus group 1)

While fears of decline and deterioration served as deterrents for reflection on future care, so too did fears that personal preferences and values could not be respected in the current care environment. Negative interactions with health providers, coupled with stories reflecting examples of poor care quality exacerbated these fears. Validating participants' fears regarding the quality of care that could be expected from formal care providers, however, seemed to offer some opportunities for ACP, as such conversations about what one does *not* want also revealed important information about participants' personal values and preferences regarding future care decisions.

Family support served as a protection from reflecting on future deterioration

Given the emotional challenges associated with managing the daily losses of dementia, many family members felt it was their role to protect their relatives from facing their losses by focusing on strengths and managing the day-to-day. Asking about future deterioration in these instances felt potentially harmful. The presence of supportive family members appeared to offer important emotional protections for persons with dementia. One caregiver, for example, started driving herself despite hating it to ensure her husband did not have to "*go through that indignity [of losing his license].*" (Iris, family caregiver, caregiver focus group) This caregiver also normalized her husband's impaired mobility by offering him the use of walking poles typically used by hikers, rather than a cane or a walker associated with age and decline:

> *I'm sharing this because he was a very caring person and he feels I should keep him at home. What-, no matter what. Even if he can't manage the stairs in and out of the house, etc. […] I got my husband the walking poles. One for each arm. That I use when I'm hiking. I say, "Look. I use them." 'Cause it helps my knees, my hips. Everybody should be using hiking poles. Truly, hiking poles show a lot of, you know. It's like having four legs. […] There's no stigma, and not only that, you're better balanced with two than with one.* (Iris, family caregiver, caregiver focus group)

Seeing their role in part as protecting their relatives from the impact of day-to-day decline, many caregivers worried about the deleterious effects of encouraging their loved ones to face their future decline.

In addition, people with dementia who had supportive families questioned the need to engage in direct conversations about future care. Rather these individuals felt their families *"will know"*. One person with dementia noted for example that being surrounded by caring and engaged family members meant much could go unsaid. She stated: "*it depends on who you have around you. In my family I have so many people around me who are interested in what is happening. [...] So they know everything, they have an idea already, what is needed, you know*?" (Bonnie, person with dementia, mixed focus group 1). Another person with dementia who has not discussed the particulars of her future care preferences stated, "*I have complete faith in him and he does with me. We'll do the right thing"* (Geneviève, person with dementia, mixed focus group 3). In this example, the person with dementia is so confident that her husband's decisions will represent her wishes that she speaks in the plural about doing the right thing when the time comes. The longstanding relationship and strong support offered by the family caregiver appeared to protect the person with dementia from the potential fears and discomforts that can be associated with ACP reflection and conversation around future deterioration.

ACP as a mechanism for persons with dementia to support their families

While caregivers were uncertain as to how ACP conversations could impact persons with dementia, they were more clear on the benefits such conversations could hold for them. One caregiver, whose relative felt comfortable leaving things unsaid, suggested that a more direct conversation could help her make more informed in the moment decisions. She stated,

> *…[know] their wishes as opposed to [asking yourself] "did she ever say anything? I don't know. Did she ever say anything?" You know, I, I, I think that has to all be in place. And, and you do that earlier than later so that you've still got their input.*
>
> (Marie, family caregiver, mixed focus group 2)

Caregivers thought such conversations may provide them with the support they may need to resolve disagreements between family members, as suggested in the following statement:

> *I'd say absolutely [this is useful] because we've got a situation where there's arguing, there's fighting. Nodoby wants to do certain things or anything. So we made a plan, a situation – [ACP conversations] will help.*
>
> (Mark, person with dementia, persons with dementia focus group)

In an effort to resolve the dilemma of protecting themselves from future distress, and protecting their relatives from facing their future deterioration, some caregivers found ways of framing ACP as an act of care that their relatives with dementia could do for them. Such an approach is depicted in the following excerpt:

> *I: If you know the person with dementia is just not wanting to [engage in ACP], what's the alternative?*
>
> *Iris: But that's how I'm handling what I'm doing here because he gets so upset that I say "I need your support."* (Iris, family caregiver, caregiver focus group)

By framing ACP as supportive of *her*, this caregiver has placed the person with dementia in the role of care *giver* thereby preserving his sense of capacity while also ensuring her need for information and direction.

Discussion

Our findings suggested that persons with dementia and their families typically see advance care planning in a limited way. Despite being provided with a holistic definition of advance care planning prior to the focus group deliberations, persons with dementia and caregivers alike viewed advance care planning as restricted to funerals, organizing wills and specific medical decisions such as resuscitation. This finding has been noted elsewhere (Phenwan et al., 2020; Wendrich-van Dael et al., 2020) and should come as no surprise given much research in the area of ACP and dementia endorses such limited understandings by confounding ACP with the more narrow idea of advance directives (Givens et al., 2018). Unfortunately such limited understandings and discussions are unlikely to improve family members' knowledge of their relatives care preferences (Perkins, 2007; Teno et al., 1997).

As focus group discussions evolved and a more holistic definition of ACP was understood, persons with dementia and families alike differed in their perceptions of the ideal timing of such conversations. Exceptionally, some persons with dementia felt ready to engage in such discussions about future care immediately. These individuals suggested that opportunities to sensitively learn about the elements of their condition and the decisions they or their families may face could encourage such exchanges. Unfortunately, such sensitivity was not always experienced, serving as a deterrent to pursue ACP further (Ryan & McKeown, 2020; Sellars et al., 2019).

Many more persons with dementia and their families saw future care planning as threatening. For these individuals, planning for the future meant focusing on deterioration, an emotionally charged process that threatened their tendencies to manage deterioration by living in the moment and focusing on their capacities rather than their limitations (Dickinson et al., 2013; Ryan & McKeown, 2020; Sellars et al., 2019). Families likewise saw it as their roles to protect their relatives from the devastation of their losses, and devoted much time and energy to preserving a sense of capacity. For both, engaging in discussions about future deterioration seemed daunting and counter-intuitive. Debates about the ideal timing of ACP conversations for persons with dementia have been noted in the literature as a major barrier to introducing ACP by health providers (Jones et al., 2019). Our findings suggest that for those who are heavily reliant on maintaining a focus on in the moment functioning and capacities, no one time will ever be ideal. Hence, strategies that recognize and address these tensions are sorely needed.

Persons with dementia who had strong family support found comfort in the thought that their relatives would simply know what they would want when the time comes, without having to reflect on and discuss future preferences (de Vries & Drury-Ruddlesden, 2019). While families saw this protection as part of their role, many expressed the pressure this placed on them to make in the moment decisions without any advance direction or input (Ashton et al., 2016; Givens et al., 2018; Sellars et al., 2019).

Some families were able to resolve this dilemma by framing ACP as a way that their relatives with dementia could help *them*. This is an interesting approach as it allows families to position persons with dementia as partners in the caring relationship rather than passive recipients of care. It suggests that a caring relationship may play a critical role in ACP engagement by expressing the way in which the process may help them (Moorman et al., 2014).

A number of models or frameworks for ACP engagement currently exist in the literature (Canadian Hospice Palliative Care Association, 2019; Sudore et al., 2017; Sudore, 2008). Typically the steps identified suggest that individuals must first reflect on their preferences for future care alone or in partnership with a health provider, so that they are positioned to identify their preferences for future care and subsequently communicate them to designated decision-makers and health providers. Framed around processes of change, such models suggest that ACP reflection is largely an individual process. Our findings suggest that such approaches may be ill-suited for some persons with dementia whose avoidance of such reflections serves as a protective measure to cope with their condition. In these instances, dialogue between persons with dementia and families focused on the importance of ACP for family members rather than persons with dementia may go a long way in supporting ACP activation.

Implications and Recommendations

Our findings provide some direction to improve ACP engagement for persons with dementia. First, our findings suggest that some persons with dementia may openly engage in reflection once they are made aware of the importance and possible benefits of ACP reflection.

These individuals may find it empowering to learn more about their condition so they can reflect on their preferences and values and ensure they are communicated to others. In a sense, these individuals are those for whom many ACP strategies are built. Receiving a workbook, attending an information session or engaging in a discussion with a health provider may be enough to activate their reflections, provided information is relayed with sensitivity and respect.

Second, our findings affirm that many individuals with dementia may require more support to reflect on their future care. When supportive families are available these individuals, persons with dementia could be quick to suggest they do not require ACP as their families will know what to do. These individuals may be most likely to engage in reflections on future care with the support and encouragement of their families at an early stage. Hence, ACP engagement may require working with both persons with dementia *and* their families, so that families are supported in expressing their need for information, and persons with dementia are provided with the opportunity to support their families by facing difficult questions (Geshell et al., 2019). When applicable, significant individuals in the larger family unit could be invited and encouraged to participate in dialogue about future care preferences to ensure that conversations extend beyond the designated healthcare proxy/surrogate decision-maker (van den Block, 2019).

Third, special focus should be placed on persons with dementia who are *not* ready to engage in ACP and *do not* have the support of family/caregivers. This group is the most at risk for end of life care that is not aligned with their values/wishes if they do not express their wishes in advance, because they do not have family members or caregivers who will advocate for them at end of life. Without the support of others, it is unlikely that these people with dementia will move from precontemplation to reflection and discussion without extensive encouragement and support (Piers et al., 2018; Wendrich-van Dael et al., 2020). Approximately 13 per cent of persons with dementia in North America reside alone, many of whom have limited access to familial support (Gould et al., 2015). In these circumstances, sustained efforts to foster connections with health providers or community agencies (e.g. Alzheimer Society) are necessary to ensure oversight and support service utilization as the disease progresses. Within the context of such ongoing outreach and engagement, encouraging reflections, communication and eventual documentation of future care preferences is recommended so that preferences and concerns can be carried forward. Training programs targeting community groups, volunteers and providers charged with ongoing outreach and oversight of persons with dementia may go a long way in improving organizational comfort in engaging in such conversations and improving access to ACP for this otherwise invisible population of persons with dementia (BC Centre for Palliative Care, 2017).

Finally, although this study was conducted prior to the onset of the COVID-19 pandemic, ACP directives and responses during the pandemic affirm the importance and applicability of our study findings. For example, the pandemic has resulted in the development of workbooks and materials to support conversations about end of life issues specific to COVID-19. While creating such materials are useful in the current context, much of the focus remains on medical decision-making such as the pros and cons of ventilators and ICU intervention (Block et al., 2020; Curtis et al., 2020). This reinforces a limited conceptualization of ACP (Hopkins et al., 2020).

It is our hope that COVID- 19 serves as a reminder that all humans are mortal, health status can change rapidly, and we would all benefit from discussing how we might find social, emotional and physical comfort should our health take a turn for the worse.

Study Limitations

This study should be viewed in light of three important limitations. First, the study relied on a small sample of self-selected persons with dementia and caregivers who were connected to community supports. These circumstances limit transferability of findings to other persons with dementia and caregivers without such connections. Transferability of findings for persons with dementia with little or no familial support is also limited. Since this group may be most at risk for poor end of life care, future research should explore ACP engagement and recommendations for persons with dementia without familial support. Second, while some researchers have documented divergent engagement with and uptake of ACP based on race and ethnicity (McAfee et al., 2019; Pettigrew et al., 2019) our small sample size precluded us from exploring such differences. Third, focus groups at each of the study sites were co-facilitated by two different members of the research team, resulting in a total of four moderators. Given the variability in interviewing style and facilitation experience among the moderators, the reliability (equivalence) of the data may have been affected (Kidd & Parshall, 2000; Nyumba et al., 2018). In order to address this threat to internal consistency, XX and XX (blinded for review) oversaw the analysis of all transcribed data and field notes.

Declaration of Conflicting Interests

The authors declare that there are no potential conflicts of interest for the research, authorship, and/or publication of this article.

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References

Ashton, S. E., Roe, B., Jack, B., & McClelland, B. (2016). End of life care: The experiences of advance care planning amongst family caregivers of people with advanced dementia - A qualitative study. *Dementia*, *15*(5), 958–75. https://doi.org/10.1177/1471301214548521

BC Centre for Palliative Care. (2017). *Peer-facilitated advance care planning public sessions: Program overview*. https://www.bc-cpc.ca/cpc/wp-content/uploads/2017/10/Program-Overview-August-2017-FINAL.pdf

Block, B. L., Smith, A. K., & Sudore, R. L. (2020). During COVID-19, Outpatient Advance Care Planning is Imperative: We need All Hands on Deck [Letter to the editor]. *Journal of the American Geriatrics Society*. 1-3. https://doi.org/10.1111/jgs.16532

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

Brazil, K., Carter, G., Galway, K., Watson, M., & van der Steen, J. T. (2015). General practitioners perceptions on advance care planning for patients living with dementia. *BMC Palliative Care*, *14*(1), 1-6. https://doi.org/10.1186/s12904-015-0019-x

Canadian Hospice Palliative Care Association. (2019). *Advance care planning in Canada: A pan Canadian framework*. https://www.advancecareplanning.ca/wp-content/uploads/2019/11/ACP-Framework-ENMODIFIED.pdf

Canadian Hospice Palliative Care Association. (2019). *Advance care planning in Canada: A pan Canadian framework*. https://www.advancecareplanning.ca/wp-content/uploads/2019/11/ACP-Framework-ENMODIFIED.pdf

Curtis, J. R., Kross, E. K., & Stapleton, R. D. (2020). The importance of addressing advance care planning and decisions about do-not-resuscitate orders during novel coronavirus 2019 (COVID-19). *Jama*, *323*(18), 1771-1772. https://doi.org/10.1001/jama.2020.4894

de Vries, K., & Drury-Ruddlesden, J. (2019). Advance care planning for people with dementia: Ordinary everyday conversations. *Dementia*, *18*(7-8), 3023-3035. https://doi.org/10.1177/1471301218764169

Dickinson, C., Bamford, C., Exley, C., Emmett, C., Hughes, J., & Robinson, L. (2013). Planning for tomorrow whilst living for today: The views of people with dementia and their families on advance care planning. *International Psychogeriatrics, 25*(12), 2011–2021. https://doi.org/10.1017/S1041610213001531

Dixon, J., Karagiannidou, M., & Knapp, M. (2018). The effectiveness of advance care planning in improving end-of-life outcomes for people with dementia and their carers: A systematic review and critical discussion. *Journal of Pain and Symptom Management*, *55*(1), 132–150. https://doi.org/10.1016/j.jpainsymman.2017.04.009

Geshell, L., Kwak, J., & Radhakrishnan, K. (2019). Perspectives and experiences of persons with dementia with advance care planning: An integrative literature review. *Journal of Geriatric Psychiatry and Neurology*, *32*(5), 231-245. https://doi.org/10.1177/0891988719853040

Givens, J. L., Sudore, R. L., Marshall, G. A., Dufour, A. B., Kopits, I., & Mitchell, S. L. (2018). Advance care planning in community-dwelling patients with dementia. *Journal of Pain and Symptom Management*, *55*(4), 1105-1112. https://doi.org/10.1016/j.jpainsymman.2017.12.473

Gould, E., Maslow, K., Lepore, M., Bercaw, L., Leopold, J., Lyda-McDonal, B., Ignaczak, M., Yuen, P., & Wiener, J. M. (2015). *Identifying and meeting the needs of individuals with dementia who live alone*. https://nadrc.acl.gov/sites/default/files/uploads/docs/PWD_Living_Alone%202015.pdf

Hopkins, S., Lovick, R., Polak, L., Bowers, B., Morgan, T., Kelly, M., & Barclay, S. (2020). Reassessing advance care planning in the light of covid-19: Focus on creating a shared narrative not recording choices [Editorial]. *BMJ, 369,* 1927. https://doi.org/10.1136/bmj.m1927

Howard, M., Bernard, C., Tan, A., Slaven, M., Klein, D., & Heyland, D. K. (2015). Advance care planning: Let's start sooner. *Canadian Family Physician*, *61*(8), 663-665.

Jeznach, A., Tuokko, H. A., Garcia-Barrera, M. A., & Stajduhar, K. (2015). Findings on advance care plans among cognitively impaired older adults. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, *34*(2), 165-175. https://doi.org/10.1017/S0714980815000021

Jones, K., Birchley, G., Huxtable, R., Clare, L., Walter, T., & Dixon, J. (2019). End of life care: A scoping review of experiences of advance care planning for people with dementia. *Dementia*, *18*(3), 825-845. https://doi.org/10.1177/1471301216676121

Kidd, P. S., & Parshall, M. B. (2000). Getting the focus and the group: Enhancing analytical rigor in focus group research. *Qualitative Health Research, 10*(3), 293-308. https://doi.org/10.1177/104973200129118453

Kitzinger, J. (1995). Qualitative research: Introducing focus groups. *BMJ, 311*(7000), 299-302. https://doi.org/10.1136/bmj.311.7000.299

Krueger, R.A., & Casey, M.A. (2014). Focus groups: A practical guide for applied research. Sage Publications Inc, Thousand Oaks.

Litzelman, D. K., Inui, T. S., Griffin, W. J., Perkins, A., Cottingham, A. H., Wendholt, K. M., & Ivy, S. S. (2017). Impact of community health workers on elderly patients' advance care planning and health care utilization: Moving the dial. *Medical Care*, *55*(4), 319. https://doi.org/10.1097/MLR.0000000000000675

Lum, H. D., Sudore, R. L., & Bekelman, D. B. (2015). Advance care planning in the elderly. *Medical Clinics of North America*, *99*(2), 391–403. https://doi.org/10.1016/j.mcna.2014.11.010

Marshall, C., & Rossman, G. B. (2016). *Designing qualitative research* (6th ed). Thousand Oaks, CA: Sage.

McAfee, C. A., Jordan, T. R., Sheu, J. J., Dake, J. A., & Kopp Miller, B. A. (2019). Predicting racial and ethnic disparities in advance care planning using the integrated behavioral model. *OMEGA-Journal of Death and Dying, 78*(4), 369–389. https://doi.org/10.1177/0030222817691286

Moorman, S. M., Carr, D., & Boerner, K. (2014). The role of relationship biography in advance care planning. *Journal of Aging and Health*, *26*(6), 969-992. https://doi.org/10.1177/0898264314534895

Murray, S. A., Kendall, M., Boyd, K., & Sheikh, A. (2005). Illness trajectories and palliative care. *BMJ, 330*(7498), 1007-1011. https://doi.org/10.1136/bmj.330.7498.1007

Nicholas, L. H., Bynum, J. P., Iwashyna, T. J., Weir, D. R., & Langa, K. M. (2014). Advance directives and nursing home stays associated with less aggressive end-of-life care for patients with severe dementia. *Health Affairs*, *33*(4), 667-674. https://doi.org/10.1377/hlthaff.2013.1258

Nyumba, T.O., Wilson, K., Derrick, C. J., & Mukherjee, N. (2018). The use of focus group discussion methodology: Insights from two decades of application in conservation. *Methods in Ecology and Evolution*, *9*(1), 20-32. https://doi.org/10.1111/2041-210X.12860

Perkins, H. S. (2007). Controlling death: The false promise of advance directives. *Annals of Internal Medicine*, *147*(1), 51–7. https://doi.org/10.7326/0003-4819-147-1-200707030-00008

Pettigrew, C., Brichko, R., Black, B., O'Connor, M. K., Austrom, M. G., Robinson, M. T., Lindauer, A., Shah, R. C., Peavy, G. M., Meyer, K., Schmitt, F. A., Lingler, J. H., Domoto-Reilly, K., Farrar-Edwards, D., & Albert, M. (2019). Attitudes toward advance care planning among persons with dementia and their caregivers. *International Psychogeriatrics*, *32*(5), 585-599. https://doi.org/10.1017/S1041610219000784

Phenwan, T., Sixsmith, J., McSwiggan, L., & Buchanan, D. (2020). A narrative review of facilitating and inhibiting factors in advance care planning initiation in people with dementia. *European Geriatric Medicine*, 1-16.

Piers, R., Albers, G., Gilissen, J., De Lepeleire, J., Steyaert, J., Van Mechelen, W., Steeman, E., Dillen, L., Vanden Berghe, P., & Van den Block, L. (2018). Advance care planning in dementia: Recommendations for healthcare professionals. *BMC Palliative Care*, *17*(1), 88. https://doi.org/10.1186/s12904-018-0332-2

Rait, G., Walters, K., Bottomley, C., Petersen, I., Iliffe, S., & Nazareth, I. (2010). Survival of people with clinical diagnosis of dementia in primary care: Cohort study. *BMJ*, *341*(7768), 337-337. https://doi.org/10.1136/bmj.c3584

Read, S. T., Toye, C., & Wynaden, D. (2020). The participation of people with dementia in the planning of their care and support: An integrative literature review. *Dementia*, *19*(3), 691–707. https://doi.org/10.1177/1471301218784806

Robinson, L., Dickinson, C., Rousseau, N., Beyer, F., Clark, A., Hughes, J., Howel, D., & Exley, C. (2012). A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age and Ageing*, *41*(2), 263-269. https://doi.org/10.1093/ageing/afr148

Rodriguez, K. L., Schwartz, J. L., Lahman, M. K., & Geist, M. R. (2011). Culturally responsive focus groups: Reframing the research experience to focus on participants. *International Journal of Qualitative Methods*, *10*(4), 400-417. https://doi.org/10.1177/160940691101000407

Roth, W. M. (2013). Translation in qualitative research: The possible impossible. *Forum: Qualitative Social Research, 14*(2), art. 13.

Ryan, T., & McKeown, J. (2020). Couples affected by dementia and their experiences of advance care planning: A grounded theory study. *Ageing & Society*, *40*(2), 439-460. https://doi.org/10.1017/S0144686X1800106X

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality & Quantity*, *52*(4), 1893-1907. https://doi.org/10.1007/s11135-017-0574-8

Sellars, M., Chung, O., Nolte, L., Tong, A., Pond, D., Fetherstonhaugh, D., McInerney, F., Sinclair, C., & Detering, K. M. (2019). Perspectives of people with dementia and carers on advance care planning and end-of-life care: A systematic review and thematic synthesis of qualitative studies. *Palliative Medicine*, *33*(3), 274-290. https://doi.org/10.1177/0269216318809571

Sinclair, J. B., Oyebode, J. R., & Owens, R. G. (2016). Consensus views on advance care planning for dementia: a Delphi study. *Health & Social Care in the Community*, *24*(2), 165-174. https://doi.org/10.1111/hsc.12191

Sudore, R. L., & Fried, T. R. (2010). Redefining the "planning" in advance care planning: Preparing for end-of-life decision making. *Annals of Internal Medicine, 153*(4), 256-261. https://doi.org/10.7326/0003-4819-153-4-201008170-00008

Sudore, R. L., Lum, H. D., You, J. J., Hanson, L. C., Meier, D. E., Pantilat, S. Z.,Matlock, D. D., Rietjens, J.A.C., Korfage, I. J., Ritchie, C. S., Kutner, J. S., Teno, J. M., Thomas, J., McMahan, R. D., & Heyland, D. K. (2017). Defining advance care planning for adults: A consensus definition from a multidisciplinary Delphi panel. *Journal of Pain and Symptom Management*, *53*(5), 821-832. https://doi.org/10.1016/j.jpainsymman.2016.12.331

Sudore, R. L., Schickedanz, A. D., Landefeld, C. S., Williams, B. A., Lindquist, K., Pantilat, S. Z., & Schillinger, D. (2008). Engagement in multiple steps of the advance care planning process: A descriptive study of diverse older adults. *Journal of the American Geriatrics Society*, *56*(6), 1006-1013. https://doi.org/10.1111/j.1532-5415.2008.01701.x

Teno, J. M., Licks, S., Lynn, J., Wenger, N., Connors, A. F. J., Phillips, R. S., O'Connor, M. A., Murphy, D. P., Fulkerson, W. J., Desbiens, N., & Knaus, W. A. (1997). Do advance directives provide instructions that direct care? *Journal of the American Geriatrics Society*, *45*(4), 508–12. https://doi.org/10.1111/j.1532-5415.1997.tb05179.x

Thorogood, A., Mäki-Petäjä-Leinonen, A., Brodaty, H., Dalpé, G., Gastmans, C., Gauthier, S., Gove, D., Harding, R., Knoppers, B. M., Rosser, M., & Bobrow, M. (2018). Consent recommendations for research and international data sharing involving persons with dementia. *Alzheimer's & Dementia*, *14*(10), 1334-1343. https://doi.org/10.1016/j.jalz.2018.05.011

Tilburgs, B., Vernooij-Dassen, M., Koopmans, R., van Gennip, H., Engels, Y., & Perry, M. (2018). Barriers and facilitators for GPs in dementia advance care planning: A systematic integrative review. *PloS one*, *13*(6). https://doi.org/10.1371/journal.pone.0198535

van der Steen, J. T., van Soest-Poortvliet, M. C., Hallie-Heierman, M., Onwuteaka-Philipsen, B. D., Deliens, L., de Boer, M. E., Van den Block, L., van Uden, N., Hertogh, C. M. P. M., & de Vet, H. C. (2014). Factors associated with initiation of advance care planning in dementia: A systematic review. *Journal of Alzheimer's Disease*, *40*(3), 743-757. https://doi.org/10.3233/JAD-131967

van, den Block. L. (2019). Advancing research on advance care planning in dementia. *Palliative Medicine*, *33*(3), 259-261. https://doi.org/10.1177/0269216319826411

Vandervoort, A., Houttekier, D., Vander Stichele, R., Van der Steen, J. T., & Van den Block, L. (2014). Quality of dying in nursing home residents dying with dementia: Does advanced care planning matter? A nationwide post-mortem study. *PloS one*, *9*(3). https://doi.org/10.1371/journal.pone.0091130

Wendrich-van Dael, A., Bunn, F., Lynch, J., Pivodic, L., Van den Block, L., & Goodman, C. (2020). Advance care planning for people living with dementia: An umbrella review of effectiveness and experiences. *International Journal of Nursing Studies, 107*(103576). https://doi.org/10.1016/j.ijnurstu.2020.103576

Wiersma, E. C., O'Connor, D. L., Loiselle, L., Hickman, K., Heibein, B., Hounam, B., & Mann, J. (2016). Creating space for citizenship: The impact of group structure on validating the voices of people with dementia. *Dementia*, *15*(3), 414-433. https://doi.org/10.1177/1471301216642339