

# Voice your values, a tailored advance care planning intervention in persons living with mild dementia: A pilot study

## Original Article

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### Abstract

**Background.** In the early stage of dementia, persons living with dementia (PLwD) can identify their values and wishes for future care with a high degree of accuracy and reliability. However, there is a paucity of research to guide best practices on how best to incorporate advance care planning (ACP) in older adults diagnosed with mild dementia and therefore only a minority of these individuals participate in any ACP discussions. We developed an intervention called Voice Your Values (VYV) that healthcare professionals can implement to identify and document the values of PLwD and their trusted individuals such as friends or family.

**Purpose.** This single-group pre-test and post-test design aimed to determine the feasibility, acceptability, and preliminary efficacy of the VYV intervention.

**Methods.** A convenience sample of 21 dyads of PLwD and their trusted individuals were recruited from five outpatient geriatric clinics. The tailored VYV intervention was delivered to the dyads over two sessions using videoconferencing.

**Results.** In terms of feasibility, the recruitment rate was lower (52%) than the expected 60%; the retention rate was high at 94%, and the intervention fidelity was high based on the audit of 20% of the sessions. In terms of preliminary efficacy, PLwD demonstrated improvement in ACP engagement ( $p < 0.01$ ); trusted individuals showed improvements in decision-making confidence ( $p = 0.01$ ) and psychological distress ( $p = 0.02$ ); whereas a minimal change was noted in their dementia knowledge ( $p = 0.22$ ).

**Conclusion.** Most of the feasibility parameters were met. A larger sample along with a control group, as well as a longitudinal study, are requisite to rigorously evaluate the efficacy of the promising VYV intervention. There is emerging evidence that people living with mild dementia can effectively participate in identifying and expressing their values and wishes for future care.

## Introduction

There is an increasing acceptance of the terminal nature of dementia among clinicians. However, the integration of a palliative approach in dementia care is not a standard of practice. Older adults living with advanced dementia often experience acute care admissions including to critical care in the last month of their life and receive poor end-of-life care (Houttekier et al., 2014; Martinsson et al., 2020). These life-sustaining treatments do not appear to have a positive impact on the person's quality of life and reversal of mortality (Kelly et al., 2019).

In the advanced stage of dementia, people are generally unable to engage in their own care decisions, such as choosing whether to use life-sustaining treatments, as part of their treatment. Their care partners who are expected to make these decisions express feeling confused and burdened with the task of proxy decision-making (Samsi and Manthorpe, 2013). The awareness of an individual's wishes and their prognosis can guide care partners' decision-making during medical crises and may reduce their psychological distress (Hall et al., 2011; Vandervoort et al., 2012). Advance care planning (ACP) is a process that allows individuals to exercise their autonomy in preparing others to make future care decisions for them (Committee on Approaching Death, 2015).

In the early stage of dementia, individuals are able to participate meaningfully in identifying their wishes, values, and goals of care (Gregory et al., 2007; Dening et al., 2011) with a high degree of accuracy and reliability (Feinberg and Whitlatch, 2001). However, the percentage of individuals living with advanced dementia who have engaged in any ACP discussions varies widely from 1.4% to 39% (Mitchell et al., 2004; Garand et al., 2011; Vandervoort et al.,

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2012). In our recent scoping review, we found that primary care practitioners believe they should hold ACP discussions with persons living with dementia (PLwD) and their trusted individuals. But many are not sure when and how to carry out these discussions (Vellani *et al.*, 2021). There is a lack of evidence-informed guidelines to implement ACP discussions for PLwD, particularly for those in the early stages of the disease. To address this gap, we have designed an intervention called Voice Your Values (VYV) that healthcare professionals can implement to identify and document the values and wishes of individuals living with mild dementia as a means of engaging them and their trusted individuals, such as friends or family, in the ACP process. The purpose of this pilot study is to assess the feasibility, acceptability, and preliminary efficacy of the VYV intervention in community-dwelling older adults living with mild dementia and their trusted individuals. The findings related to the acceptability of the VYV delivered through a virtual method are presented elsewhere. In this paper, we report on the following specific objectives:

1. Examine the feasibility of implementing the VYV intervention in community-dwelling older adults with early-stage dementia as measured by recruitment and retention rates and intervention fidelity.
2. Identify the influence of the VYV intervention on trusted individuals' level of decision-making confidence, dementia knowledge, and psychological distress when compared to their baseline levels.
3. Determine the effect of the VYV on PLwD's level of engagement in the ACP process and psychological distress when compared to their baseline levels.

## Methods

### Design

This is a single-group pre-test and post-test design. A randomized controlled feasibility design was initially planned for this study. However, due to the COVID-19 pandemic, it appeared unethical to continue with the control group and deny the opportunity to participate in ACP discussions to interested older adults, given they had a higher number of COVID-19 virus cases, adverse outcomes, and deaths. The study received ethics approval from the University Health Network Research Ethics Board, University of Toronto, as well as the five recruitment sites. The CONSERVE guideline of reporting completed trials modified due to the COVID-19 pandemic was used (Supplementary Appendix A) (Orkin *et al.*, 2021). The template for intervention description and replication (TIDieR) checklist (Hoffmann *et al.*, 2014) was used to describe details of the VYV intervention for future replication (Supplementary Appendix B).

### Participants

Participants were English-speaking community-dwelling individuals 65 years and older who had a diagnosis of mild dementia of any type and confirmed by the referring physician or a nurse practitioner. There was no restriction on the time since the diagnosis as long as the individuals were in the mild stage at the time of their participation in the study. Participants had access to a device with an internet connection for videoconferencing and a trusted individual with at least weekly contact who could enroll in the study. PLwD were not eligible if they had an acute psychotic

disorder, and/or clinical depression, due to concerns that these conditions could limit their ability to participate meaningfully in ACP discussions; blindness or deafness; or if they already had a written advance care plan in place. A written advance care plan was any document that identifies a person's values, wishes, and/or future goals of care. Living wills, power of attorney, and financial planning documents were not considered ACP documents. English-speaking trusted individuals 18 years and older were included, who did not have dementia, blindness, or deafness, and had access to a device for videoconferencing.

### Consent

Participants were recruited from five outpatient geriatric clinics from geographically diverse locations in Ontario, Canada. Recruitment and data collection began in July 2020 and was completed in February 2021. Eligible participants were identified by a physician or a nurse practitioner at the clinics and their names were shared with the PI (SV). Enhanced consenting techniques were used (Mittal *et al.*, 2007) for obtaining verbal consent over the Health Information Protection Act, 2016 (Ontario, 2016) compliant, Microsoft (MS) Teams videoconferencing platform. Participants' comprehension was assessed using the teach-back method (Cornett, 2009).

### The VYV intervention

The VYV intervention was developed based on empirical data and the theoretical underpinnings of the Representational Approach to Patient Education (Leventhal *et al.*, 1984; Leventhal & Diefenback 1991; Donovan *et al.*, 2007) and the Transtheoretical Model of Stages of Change (Prochaska, 1997), while the process of delivering it was guided by the recommendations of Piers *et al.* (2018). The Representational Approach asserts that effective education can only happen if patients are given the opportunity to share their knowledge and beliefs about the matter on hand, *i.e.*, dementia and ACP before they are provided with new information. The Transtheoretical Model suggests that people move through six stages of changes to acquire a new behavior (Prochaska, 1997). Increasingly, ACP is considered to be a complex process that involves multiple behaviors such as expressing one's values and wishes and sharing them. And a change in behaviors is dependent on several processes of change such as consciousness-raising (knowledge), environmental re-evaluation (effects of behavior on others, *i.e.*, impact of sharing wishes on trusted individuals), helping relationships (social support), as well as self-efficacy (Prochaska, 1997; Fried *et al.*, 2021). These processes of change can be positively influenced by the presence of an interventionist (PI) with knowledge and experience in the care of older adults who can help individuals to move forward in the ACP process.

Piers *et al.* developed 32 recommendations under eight domains for healthcare professionals to implement ACP for PLwD, of which five were relevant to this study: (i) timing to initiate ACP, (ii) capacity evaluation, (iii) carrying out ACP discussions, (iv) role of those close to the PLwD, and (v) documentation of wishes (Piers *et al.*, 2018). In terms of carrying out the ACP discussion, which is the core of the VYV intervention, its essential elements included: (1) education to increase dementia knowledge, (2) promoting an understanding of the ACP process, and (3) personalized coaching to identify future care values and wishes of PLwD. The VYV intervention was a tailored ACP intervention

delivered over two sessions and involved one-on-one interactions between the dyads and the interventionist (PI) using videoconferencing. Due to a lack of standard guidelines and robust experimental studies for conducting an ACP intervention in persons with early-stage dementia, the choice of two sessions in the delivery of the VYV intervention was informed by the work of Levoy et al. that involved oncology patients, (2019) while the timing of the sessions was identified based on a study by Song et al. involving older adults, not including those with cognitive impairment (2015). In both studies, no negative consequences were found concerning the length of the sessions or the number of sessions.

As part of the VYV intervention, in addition to discussing the general trajectory of dementia, a tailored education session was provided to each dyad on a variety of topics according to their learning needs and requests. As well, the PLwD were coached to identify their values and wishes related to future medical care with being in terminal or vegetative states which could occur with disease progression. Values and wishes shared by the PLwD were compiled in a document by the PI and its hard copy was sent to the PLwD. This document served as a tangible product for the PLwD to use as a resource for further ACP discussions with family and clinicians and may serve as a decision-making aid for their proxy decision-makers in the future. A letter was also sent to the MRP informing them about their patient's participation in the study and requesting them to follow up with their patient about the discussions held during the VYV sessions (see Table 1 for the description of the VYV intervention sessions).

### Measures

Sociodemographic data were acquired from all participants. The Charlson Comorbidity Index (Charlson et al., 1987) and the most recent cognitive test scores were obtained from the referring clinic. Although the referring nurse practitioner or a physician used their clinical judgment of "mild dementia" to refer PLwD into the study, the Quick Dementia Rating Scale (QDRS) was used to confirm they exhibited mild impairment with scores between 6 and 12 (Galvin, 2015). The QDRS score was acquired from the trusted individuals to prevent distress that may be caused by cognitive testing in PLwD. The QDRS has been compared with the Clinical Dementia Rating (CDR) scale, which is the gold standard for cognitive evaluation in a variety of clinical and research projects (Morris, 1993). The QDRS has demonstrated excellent

equivalence to the CDR scores, with an interclass correlation coefficient of 0.90 (Morris, 1993).

### Assessment of feasibility

Feasibility was determined based on the (1) recruitment rate, percentage of enrolled dyads out of the total number of eligible participants invited; (2) retention rate, percentage of consenting dyads who completed all VYV study procedures; and (3) intervention fidelity based on a checklist completed by the interventionist after each session. The fidelity checklist was created using the intervention manual that served to ensure that the ACP intervention elements identified earlier were implemented, while also documenting any unplanned activities to help design a larger future trial. Another research staff audited 20% of both sessions by crosschecking the session videorecordings against the fidelity checklist (Supplementary Appendix C).

### Preliminary efficacy

Five outcomes were measured to determine the preliminary efficacy of the VYV intervention in PLwD and their trusted individuals at baseline (T1) and 7–14 days post-intervention (T2) by a research assistant (RA), a nurse with experience in caring for older adults. RA was trained in all outcome measures and how to best collect data using videoconference. Based on previous studies, this timeframe was chosen to minimize the risk of bias that may occur due to any acute changes in condition of the PLwD that may hamper their ability to participate in post-intervention data collection (Sudore et al., 2013). The measures included a 5-item Decision-Making Confidence (DMC) scale (Song et al., 2019) in trusted individuals, that demonstrated excellent internal consistency in the current study (Cronbach alpha 0.88), and the 15-item ACP engagement survey that had two subscales of the ACP processes including self-efficacy and readiness in older adults (Sudore et al., 2013; Sudore et al., 2017). The Cronbach alpha was 0.76, indicating acceptable internal consistency of this measure. The responses on the readiness items were used to categorize participants in various stages of behavior change (Sudore et al., 2013). Other outcomes included dementia knowledge in trusted individuals as measured by the 21-item Dementia Knowledge Assessment Tool (Toye et al., 2014), demonstrating high internal consistency with a Cronbach alpha coefficient of 0.979. Psychological distress in all participants was measured using the 10-item Kessler Psychological Distress Scale (K-10) (Brooks et al., 2006; Bougie et al., 2016). K-10 showed

**Table 1.** Description of the VYV intervention

VYV sessions	Time	Session overview/goal/s	Conceptual framework and other resources
Session 1	20–45 min <sup>a</sup>	<ul style="list-style-type: none"> <li>Gather information about PLwD's understanding of dementia, desire to learn about these dementia and ACP, life goals, fears/worries related to dementia diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>The Representational Approach to Patient Education</li> <li>The Transtheoretical Model (Stages of Change)</li> <li>6-step conversation guide, SPIKES (Back et al., 2007).</li> </ul>
Session 2	45–60 min <sup>a</sup>	<ul style="list-style-type: none"> <li>Summary from the first session</li> <li>Tailored education about dementia and ACP</li> <li>Address in-the-moment questions by dyads</li> <li>Coach PLwD to identify values and wishes for future healthcare in relation to terminal and vegetative states</li> <li>Document values and wishes, making this a tangible product of the VYV intervention for the dyad to use in future discussions with clinicians and others</li> </ul>	<ul style="list-style-type: none"> <li>The Transtheoretical Model (Stages of Change)</li> <li>6-step conversation guide, SPIKES (Back et al., 2007)</li> <li>Educational resources from the Alzheimer Society of Canada, Advance Care Planning in Canada, and Canadian Hospice Palliative Care Association</li> </ul>

<sup>a</sup>Opportunity to take breaks and reschedule if required.

high internal consistency in this study with a Cronbach alpha coefficient of 0.88 for PLwD and 0.86 for trusted individuals.

### Statistical analysis and sample size estimation

Statistical analyses were conducted using the SPSS IBM Statistical Software version 27.0 with an  $\alpha$  value of  $<0.05$ . Results are expressed as percentages, mean, and standard deviation (SD). A paired-sample  $t$ -test was conducted to compare the mean score on all measures before and after the VYV intervention and the change in outcome measures (difference, 95% confidence interval). Preliminary effect sizes of changes were calculated. The McNemar test was used to identify the percentage of participants in the pre-contemplative phase of behavior change at baseline and the percentage of those who moved forward in the behavior change using the readiness subscale of the ACP Engagement Survey. As this was a feasibility study, no sample size was statistically calculated. However, a 60% recruitment rate was targeted, given the virtual mode of delivery requiring no travel for the participants. According to the pre-pandemic data provided by the recruitment sites, at least 20 dyads were expected to be recruited per month from all sites combined. This number decreased due to the COVID-19 pandemic, as clinics were functioning at a reduced capacity due to leadership changes, staff redeployment to other areas, and additional mandatory measures to prevent the spread of the virus, resulting in lower-than-expected referral rates. The recruitment rate was also low, in the end, 21 dyads were recruited over an 8-month period, at which point it was decided to close the study.

## Results

### Characteristics of participants

The sociodemographic and clinical characteristics of the participants are summarized in Table 2. There were an equal number of male and female PLwD who were mostly white ( $n = 11$ , 55%) followed by South Asians ( $n = 5$ , 25%). The mean age of the PLwD was  $80 \pm 6.6$  years. On average, they were diagnosed with dementia  $1.8 \pm 1.2$  years before enrollment. The average cognitive score using QDRS was 8.3, also suggestive of mild dementia. In terms of trusted individuals, most were females ( $n = 13$ , 65%) and children of the PLwD ( $n = 11$ , 55%), whereas 45% were spouses ( $n = 9$ ). And the majority had contact with the PLwD at least once daily ( $n = 14$ , 70%). Of these 14, nine were spouses, and five were children who lived in the same household as the PLwD.

### Feasibility

#### Recruitment and retention rates

Altogether, the five recruitment sites referred 47 potential participants with a recruitment rate of 52%. Seven individuals were ineligible, and 21 individuals (1 PLwD and 19 trusted individuals) declined to participate. Twenty-one dyads were recruited over 8 months leading to a recruitment rate of 52%. The most common reason for refusal was related to trusted individuals being unavailable for various reasons. Other reasons expressed by the trusted individuals included fear of being alienated by their PLwD or causing them psychological distress due to the topic of the study, as well as the perception that the PLwD could not engage in ACP discussions due to their diagnosis (see Figure 1 for the

**Table 2.** Characteristics of participants

	PLwD ( $n = 20$ )	Trusted individuals ( $n = 20$ )
	Mean (SD), range	Mean (SD)
Quick dementia rating scale	8.3 (3.3), 2.5–15	
Days since diagnosis	660 (439), 92–1,450	
Charlson comorbidity index <sup>a</sup>	6.7 (2.5), 3–15	
Age	80 (7), 67–91	62 (11.5) 44–81
Sex, $n$ (%)		
Females	10 (50)	13 (65)
Males	10 (50)	7 (35)
Years in Canada	56 (23)	
Relationship of TI, $n$ (%)		
Spouse		9 (45)
Daughter		7 (35)
Son		4 (20)
Residence, $n$ (%)		
Own home	19 (95)	
Retirement facility	1 (5)	
Living situation, $n$ (%)		
Alone	3 (15)	
Spouse	11 (55)	
Children	6 (30)	
Relationship status, $n$ (%)		
Married	11 (55)	14 (70)
Widow/widower	5 (25)	0
Separated/divorced	3 (15)	3 (15)
Single	1 (5)	3 (15)
Level of education, $n$ (%)		
Elementary school	2 (10)	0
High school	9 (45)	1 (5)
Non-university training	2 (10)	1 (5)
Diploma/certificate	3 (15)	6 (30)
Bachelor's degree	3 (15)	10 (50)
Master's degree	0	2 (10)
Professional degree, e.g., doctor	1 (5)	0
Race/ethnicity, $n$ (%)		
Black	2 (10)	2 (10)
White	11 (55)	11 (55)
Asian-Chinese	1 (5)	1 (5)
South Asian	5 (25)	5 (25)
West Indian	1 (5)	1 (5)
Had POA, $n$ (%)	13 (65)	

(Continued)

Table 2. (Continued.)

	PLwD (n = 20) Mean (SD), range	Trusted individuals (n = 20) Mean (SD)
Hospital visits in last 3 months, n (%)	3 (15)	
Hospital admission in last 3 months, n (%)	3 (15)	
Receiving homecare, n (%)	7 (35)	
Employment status, n (%)		
Employed full time		10 (50)
Unemployed		1 (5)
Retired		9 (45)

QDRS Scale: 0–1 normal cognition; 2–5 mild cognitive impairment; 6–12 mild dementia; 13–20 moderate dementia; 21–30 severe dementia.

\*Missing for one PLwD.

study flow diagram listing the reasons for refusal). The retention rate was high at 94%, with 18 dyads completing all study procedures, and 100% attending both the intervention sessions. Twenty trusted individuals completed all study procedures. One PLwD declined to participate on the day of the baseline data collection, resulting in the trusted individual leaving the study as the intervention required both to participate as a dyad. One PLwD missed the post-intervention data collection appointment, and another declined to complete one of the measures at post-test due to feeling overwhelmed.

**Intervention fidelity**

The comparison of the intervention fidelity checklist scores showed full agreement between the PI and the other research staff. On average, VYV session 1 ranged between 33–63 min, which is consistent with what was planned, and 45–60 min. Of the two sessions that went longer than 60 min, the PLwD were fatigued. The VYV session 2 ranged between 47–100 min rather than the planned 60–90 min, where 4 of 20 dyads had sessions approximately 10 min over the allotted time. Three dyads completed the second session over two appointments because of fatigue experienced by the PLwD. The duration of the sessions did not differ based on the last cognitive test scores or the time since dementia was diagnosed. Other reasons for the longer sessions included participants’ desire to share their past experiences with friends and family at their end of life, engaging in discussions with each other to seek/provide clarifications on expressed wishes, questions raised about diverse topics such as the risk of responsive behaviors in advanced stage and medical assistance in dying. And in one case, expressive aphasia of the PLwD required a longer time to share their wishes and values.

**Preliminary efficacy outcomes**

The VYV intervention demonstrated a significant improvement in the decision-making confidence scores from baseline to post-intervention for the trusted individual. There was also a significant difference in the mean scores of PLwD on the ACP engagement survey. 55% (n = 11) of the PLwD were in the pre-contemplative stage of behavior change at T1, which decreased to 40% (n = 8) post-intervention, showing upward

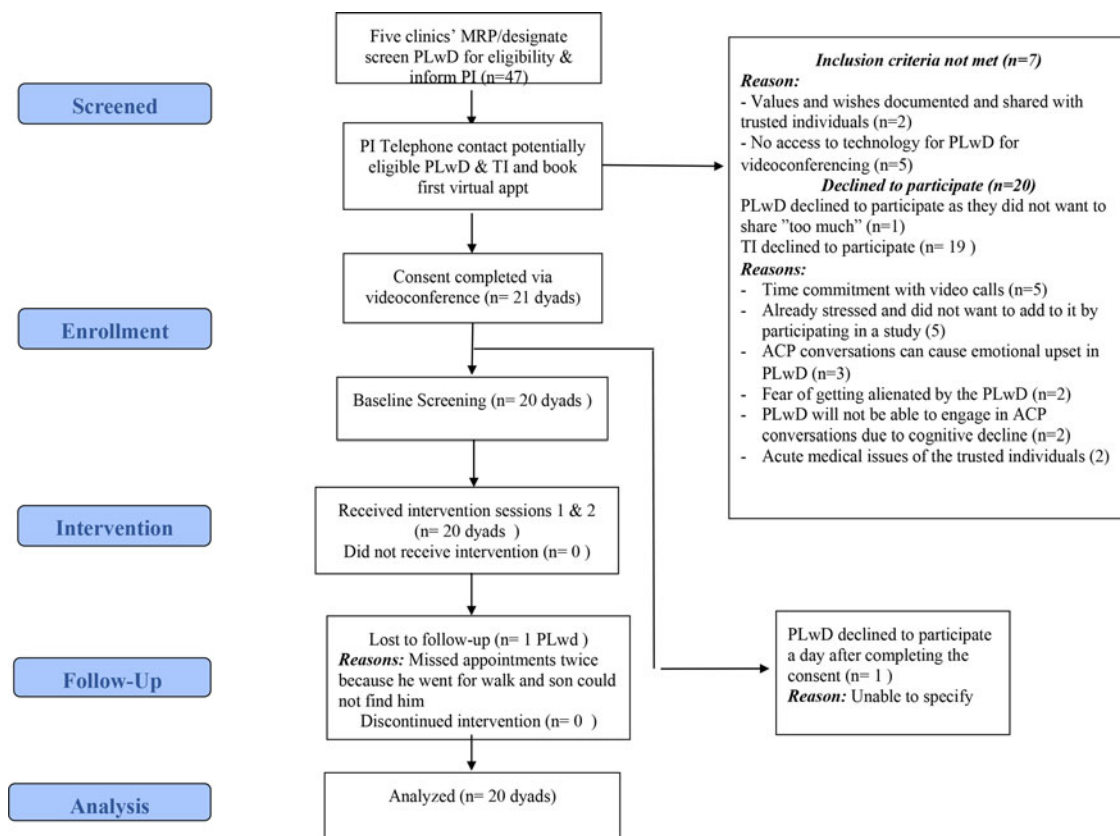


Fig. 1. Flow diagram for the voice your values study.

movement in the behavior change stage, though it was not statistically significant ( $p = 0.32$ ). Six of the 20 PLwD did not remember the partial or full content of the VYV sessions at the time of the outcome data collection. In terms of the impact on psychological distress using K-10, PLwD had a non-statistically significant decrease in the mean scores from baseline, whereas the trusted individuals showed a significant improvement in their scores. The scores related to dementia knowledge in trusted individuals stayed about the same post-intervention (see Table 3 for change in outcomes post VYV).

**Discussion**

The VYV-tailored ACP intervention demonstrated the evidence of feasibility in community-dwelling older adults living with mild dementia and their trusted individuals as evidenced by a high retention rate and a high degree of concurrence between the interventionist and the RA on the intervention fidelity audit. However, some of the intervention sessions took longer than expected to deliver and the recruitment rate was 8% less than expected. In terms of the preliminary efficacy, our findings demonstrated that the VYV intervention led to significant improvement in decision-making confidence and psychological distress in trusted individuals. Minimal improvement was seen in their dementia knowledge which is likely due to the dyads receiving tailored education based on their specific needs and not necessarily assessed in the standard dementia knowledge questions found in the DKAT. To our knowledge, this is the first study that used the ACP engagement survey (Sudore et al., 2013) in community-dwelling older adults living with mild dementia for an ACP intervention.

One of the indicators of the feasibility of the VYV intervention was intervention fidelity, which involved conforming to the elements of the VYV sessions laid out in the intervention manual. The interventionist was able to follow the intervention components as planned. However, the time taken to complete the sessions was wide-ranging, with some sessions taking longer than expected. Also, three dyads completed the intervention in three to four sittings rather than the planned two. Longer sessions may raise concerns about the feasibility of the VYV intervention in clinical practice and/or future trials. However, similar observations have been made in another ACP intervention study where it took an average of 100 min for a single-session intervention delivered to PLwD instead of 82 min when delivered to other older individuals (Song et al., 2019). The authors suspected that the lengthier sessions were due to PLwD taking longer to understand questions and retrieve information from their memory to respond. The authors did not recommend breaking the sessions into more than one due to limited memory in PLwD (Song et al., 2019). Given that there are no standard guidelines on how best to engage PLwD and their trusted individuals in ACP, there are opportunities to test various options related to the number of sessions and the time required for their delivery. It is important to bear in mind that ACP is a process involving multiple behaviors that cannot be completed in one session regardless of the diagnosis of the person (Levoy et al., 2019). Furthermore, ACP conversations can be emotionally charged for many, requiring sufficient time to prepare for the interventionists and the participants (Frechman et al., 2020).

What appears critical is taking a person-centered approach to ACP, given the unique characteristics and circumstances of PLwD. Cognitive and behavioral strategies that help reduce the

**Table 3.** Change in outcome measures after VYV intervention

	PLwD (n = 19)			Trusted individuals (n = 20)			Significance	Effect sizes
	T1 Mean (SD), %	T2 Mean (SD), %	Change (95% CI)	T1 Mean (SD)	T2 Mean (SD)	Change (95% CI)		
ACP engagement survey (Readiness and Self-efficacy subscales)	3.2 (0.6)	3.7 (0.8)	0.5 (0.3-0.7)				$p = 0.00014$	1.1
Pre-contemplative stage of behavior change	55% (n = 11)	40% (n = 8)	15% moved to higher stages of behavior change				$p = 0.32$	
K-10	15 (2.9)	14.95 (3.2)	-0.05 (-1.60 to 1.50)	17.6 (5.9)	15.6 (5.1)	-2.0 (-3.7 to -0.25)	PLwD: $p = 0.94$ TI: $p = 0.027$	PLwD: 0.02 TI: 0.53
DKAT				15.2 (2.9)	16.0 (2.1)	0.80 (-0.52 to 2.1)	$p = 0.220$	0.28
SDMC				4.35 (0.69)	4.63 (0.52)	0.29 (0.06-0.51)	$p = 0.016$	0.59

PLwD, person living with dementia; TI, trusted individual; CI, confidence interval; K-10, Kessler Psychological Distress; DKAT, Dementia Knowledge Assessment Tool; SDMC, Substitute Decision-Making Confidence.

cognitive burden in PLwD are promising. These include repetition, use of concrete examples, structured format to guide the conversations, frequently checking comprehension of the content, and involving a trusted individual (Kasl-Godley and Gatz, 2000). Previous studies have also shown enhanced communication strategies, such as candid discussion, shared decision-making, and assessed readiness for change and empathy, to be critical to the higher uptake of ACP in older adults (Frechman et al., 2020). The feasibility of conducting ACP sessions in busy clinicians' offices or virtually requires more research going forward. Teaching interdisciplinary team members to build the knowledge, skills, and competence in the care of older adults and engaging PLwD in the ACP process are also important going forward.

In terms of the feasibility of recruitment for the VYV intervention, 48% of all referred declined to participate. Although trusted individuals may be trying to be protective of their PLwD to prevent distress by refusing to participate in the VYV study, these attitudes raise concerns about unknowingly engaging in benevolent ageism (Vale et al., 2020) while depriving their PLwD of the opportunity to exercise their autonomy. The findings of this study did not demonstrate any increase in PLwD's level of psychological distress post VYV intervention, so in many cases, this is likely to be an unfounded concern. The PLwD were keen to talk about their values and wishes related to care during the terminal and vegetative states. They appreciated the opportunity to share what they value. Trusted individuals generally report a lack of confidence in decision-making for future care, and a lack of knowledge of the PLwD's wishes can aggravate the caregiving burden, as well as lessen the prospect of true person-centered care in the future (Maslow, 2013). One of our critical findings was a statistically significant improvement in decision-making confidence in trusted individuals. Knowing the wishes of the PLwD may help trusted individuals plan for changing care needs as dementia progresses. As such, future studies may also focus on strategies to educate trusted individuals on the importance of participating in ACP. Furthermore, the inability to meet recruitment targets is one of the most commonly identified reasons for trial inefficiencies and premature stopping (Bertram et al., 2019). Recruitment for an ACP trial is an intricate matter as is, and the COVID-19 pandemic increased the complexity even further. Nonetheless, practical suggestions to optimize recruitment by Bertram and colleagues may be helpful in the future larger VYV trial (Bertram et al., 2019). These include a site feasibility assessment to optimize recruitment, identifying champions at the sites, as well as training and compensation.

Compared to other studies, the VYV intervention had some similar features such as structured discussion and strong theoretical underpinnings (Hilgeman et al., 2014; Song et al., 2019). The VYV study also had some unique features. Firstly, it was conducted by a knowledgeable interventionist who not only prepared tailored education based on each dyad's needs and gaps in knowledge but was also able to address questions that arose in the moment given her expertise in the care of older adults. The intervention was delivered to dyads over at least two sessions. To maintain the PLwD's interest during the intervention, ad hoc activities were incorporated such as singing, stretching, and encouraging the PLwD to share interesting anecdotes. These appeared to have a positive impact on rapport building and overall engagement of the PLwD in the ACP process to move them forward on the behavior change trajectory.

Our findings are in line with previous ACP studies involving people with mild dementia, which also showed a high retention

rate where PLwD meaningfully participated in ACP discussions (Hilgeman et al., 2014; Song et al., 2019). However, what was unique in the current study was a wide variation seen in the time since participants were diagnosed with dementia, making it difficult to suggest how soon after the diagnosis ACP discussions should be initiated. Previous research has demonstrated a lack of agreement among PLwD and their families on the right time to initiate ACP discussion (Dickinson et al., 2013). While around the time of diagnosis, PLwD may have many emotions to process, and ACP conversations may add to the emotional toll (van der Steen et al., 2014). Nonetheless, each participant had mild dementia at the time of the intervention and no differences were observed in their level of engagement. Several PLwD displayed signs of anosognosia, and some had difficulty recalling the full contents of the previous sessions. As such, each one of them appreciated a summary of the previous session and all were able to articulate their values and wishes for future care with a high degree of clarity. Therefore, it is important not to construe a person's inability to recall information or unawareness of dementia as a failure of the ACP intervention. In addition, future studies should include larger sample sizes to pool the results in order to compare the level of engagement among individuals with different ranges of time since the diagnosis of dementia.

In terms of the efficacy of ACP, there is no consensus on what the outcomes for ACP studies in PLwD should be (Wendrich-van Dael et al., 2020). While the outcomes related to PLwD and trusted individuals were selected for this study based on other ACP trials, future longitudinal studies are necessary to examine additional meaningful outcomes for individuals with mild dementia. There is a need to identify outcomes that do not solely rely on PLwD's memory, and hence, there is merit in examining outcomes targeting trusted individuals such as an increased incongruence between the dyads, impact on caregiving stress associated with proxy decision-making, planning for contingencies, and sense of empowerment in performing as an advocate for PLwD. There is also a lack of evidence on the impact of ACP when conducted in the mild stage on receiving wish concordant care or the receipt of burdensome interventions at the end of life (Kelly et al., 2019) such as comfort oral feeding versus enteral nutrition. Hence, future studies should also examine if ACP conversations can transition into goals of care discussions with worsening cognition and frailty, and acute changes in the PLwD's condition. It is also critical to examine the impact on the health system related to early engagement in the ACP such as the rate of hospitalizations, admission to intensive care, nursing home, and hospice care in the advanced stage; and preferred place of death. There is an important role for clinicians to make concerted efforts to engage PLwD and their trusted individuals in ACP conversations to help normalize these discussions as a necessary part of the patient's dementia care plan. Measures should be taken to increase the capacity of primary care clinicians through education, resource allocation, and monitoring indicators of ACP.

### Limitations

Though the VYV study provides great insights for future ACP research and clinical initiatives, there are limitations to be considered. There was a small sample size and an absence of a control group. However, it was our intention to focus on a feasibility study and to make considerations for outcome measures to help researchers plan for a larger study to test and refine the elements of ACP in persons living with mild dementia. Though the

recruitment rate was lower than expected; there was minimal attrition and missing data and most of the indicators that were set out to measure feasibility success were met. Most measures used in the study had not been tested for use virtually; however, the reliability of the measures was acceptable. Given the pre- and post-test design, improvement in the outcomes may be related to repeated testing rather than the effect of the VYV intervention. A larger sample size along with a control group, as well as a longitudinal study, are requisite to rigorously evaluate the effectiveness of the VYV intervention and the outcomes highlighted above.

## Conclusion

The current pilot study demonstrated promising results. While recruitment was challenging, we achieved an acceptable sample size, along with a high retention rate and intervention fidelity scores. Most of the preliminary efficacy outcomes showed a small-to-medium effect size in favor of the VYV intervention. Although research is nascent, there is promising evidence that people living with mild dementia can effectively participate in ACP to identify their values and wishes for future care.

**Supplementary material.** The supplementary material for this article can be found at <https://doi.org/10.1017/S1478951522000475>.

**Conflict of interest.** There are no conflicts of interest.

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