TITLE: Goals of care conversations and subsequent advance care planning outcomes for people with dementia

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ABSTRACT (250 words):

Background

Advance care planning has been shown to improve end of life decision-making for people with dementia. However, the impact of goals of care conversations between people with dementia and their caregivers has not been characterized.

Objective

In this study, we evaluate the association between goals of care conversations and advance care planning outcomes.

Methods

Retrospective advance care planning measures were collected via a questionnaire administered to 166 caregivers after the death of the person with dementia for whom they provided care.

Results

At time of death, the majority of decedents with dementia had advance directives, health care agents, and previous goals of care conversations with their caregiver. Goals of care conversations were significantly associated with the perceived usefulness of advance directives, the perceived adherence to advance directives, and decedent dying at their desired place of death, but not with disagreements around end of life care.

Conclusion

Our findings suggest that goals of care conversations are an important component of advance care planning. These findings support the development of interventions that facilitate such conversations between people with dementia and their caregivers.

KEY WORDS (4-10): advance care planning, dementia, Alzheimer’s disease, terminal care, patient preference

INTRODUCTION

Despite significant research efforts, dementia remains a terminal illness that requires complex physical and psychosocial support that often intensifies near the end of life[1]. End of life medical care for people with dementia is more aggressive[2-5] and expensive[6–8] than for those without dementia, and caregivers are often dissatisfied with this care[9–11]. Progressive cognitive decline and associated changes in behavior and decision-making are especially pronounced features of dementia as compared to other terminal illnesses. Therefore, advance care planning early in the disease course is increasingly viewed as a critical palliative care intervention for people with dementia[12,13]. However, the components of effective advance care planning are not well characterized for people with dementia, caregivers, and clinicians.

Advance care planning is defined as a process that supports adults in understanding and sharing their values, goals, and preferences regarding future medical care[14] . Studies have linked advance care planning with improved end of life outcomes for people with dementia[15,16] including less aggressive care at the end of life[17–19], fewer hospitalizations[20–23], and increased patient and caregiver satisfaction[24,25]. In the United States, advance care planning has often been narrowly conceived in terms of completing legal documents in the form of advance directives such as living wills and durable powers of attorney to designate health care agents. However, this conception has shifted in more recent literature to encompass a broader, ongoing process of communicating and planning for future care[26].

One important component of advance care planning that requires fuller characterization is the goals of care conversation between a person with dementia and their caregiver. Unfortunately, caregivers often serve as surrogate decision-makers without ever having discussed wishes and preferences for end of life medical care with the person with dementia[27,28]. People with dementia and caregivers may avoid such conversations because of discomfort with the subject, denial, or lack of understanding of the disease course[29–32]. Those with dementia may discuss wishes with lawyers in the course of drafting directives, but such conversations and documents are not always revealed to caregivers, sometimes due to attorney-client confidentiality[33]. As a result, surrogate decision-makers often poorly predict the preferences of people with dementia[34–36] and lack concordance with advance directives [37,38]. Goals of care conversations between people with dementia and their caregivers may help better prepare caregivers for their roles as surrogate decision-makers and improve end of life outcomes. Interventions that aim to support people with dementia across the disease spectrum might emphasize goals of care conversations as a key aspect of advance care planning. In this study, we evaluate the association between goals of care conversations and advance care planning outcomes.

METHODS

Study design

We used data from the Care Ecosystem randomized controlled trial, a telephone and web-based support intervention which provides people with dementia and their caregivers with trained care team navigators and clinicians with dementia expertise[39,40]. A total of 804 dyads of people with dementia and their caregivers were enrolled from March 2015 to May 2019. As of October 2020, 270 participants with dementia were deceased and 166 caregivers completed a planned post-mortem survey. This study was approved by the University of California, San Francisco (UCSF) and the University of Nebraska Medical Center (UPMC) Institutional Review Boards. Dyads provided written informed consent. A legally authorized representative provided written informed consent for participants with dementia who lacked capacity.

Study participants

Inclusion criteria for participants with dementia included dementia diagnosis, age ≥45, Medicare- or Medicaid-enrolled or pending, the presence of an unpaid family caregiver, residence in California, Nebraska, or Iowa, and death at the time of the study. Additional inclusion criteria for caregiver participants included having primary responsibility for the enrolled person with dementia, being a legal adult, and survey completion. People with dementia were excluded from initial Care Ecosystem trial enrollment if they had a life expectancy of less than 3 months or were living in a nursing home.

Measures

During the postmortem survey, we asked caregivers retrospectively whether the person with dementia possessed an advance directive, designated a health care agent, and had a prior conversation with them about goals of care at the end of life. Caregivers were also asked whether they found the advance directive useful, whether the wishes in the advance directive were followed, whether the decedents died where they wanted to die, and whether there were disagreements among the family or medical team about end of life care decisions. Decedent and caregiver demographic characteristics, dementia severity using the Quick Dementia Rating System (QDRS)[41], and decedent comorbidities were collected upon study enrollment.

Analysis

We used nested univariable and multivariable logistic regression to evaluate the associations between goals of care conversations and the four outcomes of interest: perceived usefulness of advance directives, perceived adherence to advance directives, death at desired location, and disagreements around end of life decisions.

Decedent and caregiver predictors were selected based on literature on advance care planning in dementia. Decedent race and ethnicity variables were combined and dichotomized (‘non-white and/or Hispanic’ and ‘white and non-Hispanic’) to avoid model estimation errors due to small cell counts. Caregiver race and ethnicity were not included given collinearity with decedent race and ethnicity. Caregiver relationship to decedent was also dichotomized (‘spouse and/or partner’ and ‘not spouse or partner’). Predictor variables for age, education, and dementia severity were mean centered for analysis.

We developed three nested logistic models for each of the four outcomes of interest. The first model applied univariable logistic regression to assess isolated associations of prior goals of care conversations between decedents and their caregivers with the model outcomes. The second model applied multivariable logistic regression to assess associations with prior goals of care conversations alongside decedent characteristics. Finally, the third model applied multivariable logistic regression to assess associations with prior goals of care conversations alongside both decedent and caregiver characteristics. Decedent characteristics included age at death, gender, race/ethnicity, education, dementia severity at enrollment, and number of comorbidities. Caregiver characteristics included caregiver age at decedent death, gender, education, and relationship to decedent. Both multivariable models also controlled for randomization to the study intervention arm after no association was detected.

Odds ratios and confidence intervals were calculated from the logistic regression coefficients. Model selection was performed using ANOVA sequentially to test whether each more complex model significantly explained more deviance than the next simplest model. All statistical analyses were conducted using R Studio; a two-tailed p value of <0.05 was considered statistically significant.

RESULTS

Study population characteristics

166 of 270 eligible caregivers completed the postmortem survey after the death of the person with dementia by the time of this analysis. Characteristics of the decedents and their caregivers are summarized in Table 1.

Advance care planning at time of decedent death as reported by caregivers is also summarized in Table 1. The great majority of decedents participated in advance care planning prior to death. Among the 166 caregiver respondents, 130 caregivers (78.3%) reported having at least one goals of care conversation with the decedent and 155 (93.4%) reported that the decedent had an advance directive. Out of the 155 decedents reported to have advance directives, 149 decedents (96.1%) designated a health care agent as part of the advance directive. 143 of the 149 designated health care agents (96.0%) were the caregiver participants enrolled in this study.

Table 1. Characteristics of the 166 PWD-caregiver dyads

Variable by participant category	
Decedents with dementia	**n = 166**
Age at death, mean (SD)	80.9 (10.0)
Female (%)	89 (53.6)
Care Ecosystem intervention (%)	114 (68.7)
State of residence (%)	
California	104 (62.7)
Nebraska	58 (34.9)
Iowa	4 (2.4)
Race (%)	
White	138 (83.1)
Asian	15 (9.0)
Black	6 (3.6)
Other or mixed	7 (4.2)

Hispanic ethnicity (%)	11 (6.6)
Education (%)	
<High school	10 (6.0)
High school graduate	36 (21.7)
Some college	30 (18.1)
College degree or higher	90 (54.2)
Dementia severity at enrollment (%)	
Mild (QDRS score <12)	55 (33.1)
Moderate (QDRS score 13-20)	67 (40.4)
Advanced (QDRS score 20-30)	44 (26.5)
# of comorbidities, mean (SD)	2.4 (1.8)
Caregivers	**n = 166**
Age at decedent death, mean (SD)	66.8 (10.8)
Female (%)	126 (75.9)
Race (%)	
White	140 (84.3)
Asian	12 (7.2)
Black	8 (4.8)
Other or mixed	6 (3.6)
Hispanic ethnicity (%)	10 (6.1)
Education (%)	
<High school	2 (1.2)
High school graduate	11 (6.6)
Some college	33 (19.9)
College degree or higher	120 (72.3)
Relationship to decedent (%)	
Spouse or partner	96 (57.8)
Daughter	55 (33.1)
Son	10 (6.0)
Other family	3 (1.8)
Other	2 (1.2)

Advance care planning	**n = 166**
Caregiver had a goals of care conversation with decedent (%)	130 (78.3)
Decedent had an advance directive (%)	155 (93.4)
Decedent's advance directive designated a health care agent (%)*	149 (96.1)
Enrolled caregiver was the decedent's designated health care agent (%)**	143 (96.0)

*Responses out of the 155 decedents who had an advance directive.

**Responses out of the 149 decedents who had designated a health care agent.

Associations of goals of care conversations with advance care planning outcomes

Table 2 displays the logistic regression models which analyze the associations of goals of care conversations with the advance care planning outcomes of interest. For the association of goals of care conversations with the perceived usefulness of the advance directives, the preferred model included decedent but not caregiver characteristics as predictors. In this model, goals of care conversations were strongly associated with the perceived usefulness of advance directives. Decedent age (OR 1.17, 95% CI 1.09 – 1.29) and decedent educational attainment (OR 2.23, 95% CI 1.27 - 4.30) were also positively associated with the perceived usefulness of advance directives. For the association of goals of care conversations with the perceived adherence to advance directives, the preferred model also included decedent but not caregiver characteristics as predictors. In this model, goals of care conversations were strongly associated with the perceived adherence to advance directives. Non-white and/or Hispanic race/ethnicity (OR -1.88, 95% CI 0.66 – (-2.83)) was negatively associated with perceived adherence to the advance directive while decedent educational attainment (OR 0.68, 95% CI 0.33 - 2.03) was positively associated. The univariable model was the preferred model for the association of goals of care conversations with decedent dying at their desired location. Finally, goals of care conversations were not significantly associated with disagreements around end of life care in the univariable or multivariable models. Of note, the Care Ecosystem intervention had no association in any of the models with the four outcomes of interest.

Table 2. Odds ratios and 95% confidence intervals of nested logistic regressions with goals of care conversations as a predictor of advance care planning outcomes

Variable	Proportion	Univariable		With decedent predictors		With decedent and caregiver predictors	
		OR (95% CI)	p	OR (95% CI)	p	OR (95% CI)	p
Perceived usefulness of advance directives	125/154 (81.2%)	8.8 (3.5 – 22.9)	<.001	**19.1 (5.9 – 75.2)**	<.001	17.7 (5.2 – 75.2)	<.001
Perceived adherence to advance directives	140/155 (90.3%)	3.4 (1.1 - 10.5)	.033	**3.7 (1.0 - 14.2)**	.049	3.3 (0.8 - 13.4)	.101
Decedent dying at their desired location	88/165 (53.3%)	**2.7 (1.3 - 6.2)**	.012	2.7 (1.2 - 6.1)	.016	2.9 (1.3 - 7.0)	.012
Disagreements around end of life care	32/165 (19.4%)	**1.2 (0.5 - 3.4)**	.768	1.2 (0.44 - 3.7)	.733	1.1 (0.4 - 3.9)	.828

Parameters for the preferred models from ANOVA comparison are presented in bold text.

DISCUSSION

In this sample of community-dwelling decedents with dementia and their caregivers in the United States, we found that goals of care conversations between people with dementia and their caregivers independently predict the perceived usefulness of advance directives, the perceived adherence to advance directives, and decedent dying at their desired location. This association was observed in univariable models and multivariable models that adjusted for decedent and caregiver demographic factors. Goals of care conversations were not found to predict disagreements over end-of-life care. Overall, these findings suggest that goals of care conversations provide important guidance on the preferences of people with dementia and augment existing advance care planning documents that may not be sufficient in isolation to guide treatment decisions. These findings also support the development of advance care planning interventions for people with dementia that promote effective goals of care conversations.

Recently, there have been increasing criticisms on the focus of advance directives in the United States. One major criticism of advance directives is that people cannot accurately predict what medical decisions they would want in the future; also, a previous study found that advance directives typically address issues that arise near the end of life such as life-sustaining treatments, but often do not account for the complex and individual care decisions that can arise in a gradually progressive dementia[42]. Our study found that 81.2% of surrogate decision makers reported the advance directive to be useful. These findings indicate that advance directives can be an important component of advance care planning.

Our study found high rates of advance care planning. 93.4% of were reported by their caregivers to have an advance directive and 96.1% of decedents with advance directives were reported to have assigned a health care agent. Our high rates of advance directive possession and health care agent designation are concordant with recent studies in community-dwelling populations of people with dementia in the United States[27,37,38]. To our knowledge, there have been two previous studies assessing goals of care conversations between people with dementia and their caregivers[27,28]. Both studies report similar rates of such conversations and also found that caregivers want more information about the disease course of dementia and end of life health care options. Our study further identifies a significant gap in that some decedents with dementia never had goals of care conversations with their designated health care agent, which was associated with poorer end of life outcomes.

This study adds to our understanding of advance care planning in people with dementia by evaluating associations between goals of care conversations and key planning outcomes. Focusing on community-dwelling people with dementia also allows our study to better examine the unique and challenging roles assumed by caregivers. Our findings contribute towards literature around what constitutes effective advance care planning and provides further support for newer conceptions of advance care planning as a continual process of communication that goes beyond the completion of medical-legal documents. Advance care planning is especially critical for people with mild to moderate dementia who can meaningfully engage in their care for a limited time. Additional research is needed to evaluate how long people with dementia can meaningfully engage in advance care planning and what opportunities there are to engage people with dementia who have more advanced disease.

Limitations

This study has several limitations. Our sample draws participants from the Care Ecosystem randomized control trial and is subject to selection bias. Caregivers recruited from clinics often report greater caregiver burden than in the general population so recruited dyads may have had more unmet needs than otherwise expected[43]. Another limitation is that the advance care planning data was collected from caregivers who may not have been privy to all of the advance care planning activities of the decedent. Finally, while our study sample was drawn from a larger study of 804 dyads, the sample of decedents included is relatively small, and generalizability is limited given underrepresentation of racial and ethnic minorities and overrepresentation of people with higher educational attainment. Evaluation of the impact of the Care Ecosystem intervention may also have been limited by small cell counts.

Conclusion

In this study, we identified a significant association of goals of care conversations between people with dementia and their caregivers with increased advance directive perceived usefulness, advance directive perceived adherence, and decedent death at desired location. These findings highlight the value of goals of care conversations between people with dementia and their caregivers in advance care planning. We also found lower rates of goals of care conversations compared to other advance care planning activities such as advance directive completion and health care agent designation within the advance directive. These findings support the development of interventions that facilitate goals of care discussions between people with dementia and their caregivers early in the disease process.

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CONFLICT OF INTEREST

The authors have no conflict of interest to report.

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