JOHNS HOPKINS
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Roger and Flo Lipitz Center
to Advance Policy
in Aging and Disability

2025 ISSUE BRIEF

ADVANCE CARE PLANNING

The Roger and Flo Lipitz Center to Advance Policy in Aging and Disability

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INTRODUCTION

Advance care planning (ACP) is a communication process that helps individuals to understand and share their personal values, life goals, and preferences for future medical care. Primary care is an important setting for advance care planning, especially for older adults, due to longstanding and trusted relationships with clinicians, the frequent periodicity of visits, and because older adults prefer their primary care clinicians to initiate such conversations.

Early initiation of advance care planning is particularly important for persons with Alzheimer's Disease and Related Dementias given the long course of illness and impacts on memory and judgement. However, advance care planning in the context of memory loss can be difficult: individuals with dementia are less likely and able to participate in advance care planning conversations, appoint decision-makers, or complete a living will. The lack of attention to advance care planning in this population leads to persons with dementia being at higher risk for unnecessary suffering and costly, burdensome end-of-life care.

A recent 33-country Delphi panel identified special considerations when engaging advance care planning for persons with dementia, including attention to: 1) capacity for medical decision-making, 2) family involvement, and 3) engagement and communication. A May 2024 workshop convened by the National Institute on Aging identified notable evidence gaps due to most practice and policy initiatives being devoted to increasing advance care planning in general primary care populations, while excluding persons with dementia. This issue brief summarizes recent work at the Roger and Flo Lipitz Center to Advance Research in Policy and Practice that has sought to address this evidence gap.

WHAT DID WE **DO**

A multidisciplinary team based at the Roger and Flo Lipitz Center to Advance Research in Policy and Practice have recently completed two complementary studies that have tested primary care-based advance care planning strategies to better reach and support advance care planning among all older adults, including those who are living with cognitive impairment or dementia. Both studies were supported by the National Institute on Aging. Both studies involved extensive preliminary pilot work in close partnership with two health systems in the MidAtlantic Region, Johns Hopkins Community Physicians, and MedStar Health System. Both studies tested the effects of the following therapeutic elements:

1. A letter from the clinic introducing an initiative to improve communication with the goal of normalizing advance care planning in routine care;
2. Patient-family agenda-setting checklist to align perspectives about the role of family and stimulate discussion about advance care planning;
3. Facilitated registration to the patient portal (patient and family) as desired by the patient, to legitimize the role of family in communication with the primary care practice;
4. Access to a facilitator trained to lead advance care planning; and
5. Education and resources about dementia to support capacity of clinic staff to identify cognitive impairment and make appropriate referrals to supportive services or follow-up.

Patient- and family-facing materials were branded for each clinic and/or care delivery organization

A foundational therapeutic element in both studies was access to a facilitator trained in Respecting Choices, an evidenced-based program with a manualized advance care planning curriculum and structured conversation guide. This curriculum has been found to benefit a range of communication processes and outcomes that are valued by patients, families, and health systems. Importantly, Respecting Choices can be delivered by non-clinician lay facilitators, with benefit for scalability. Our two studies are the first to evaluate the implementation of Respecting Choices among persons with cognitive impairment, ranging from mild through severe.

IMPLEMENTATION

Interventional research is too often not translated into real-world benefit due to implementation challenges. Successful evidence translation requires that the delivery not only yield clinically meaningful benefit, but align with priorities, workflows, and data systems of care delivery organizations and care settings. The two studies focused on advance care planning in primary care with the same organizational partners and therapeutic modalities (see Table) but were designed to answer very different research questions.

	SHARE (R01AG058671)	**SHARING CHOICES (R33AG061882)**
Research question	Does the intervention work?	Does the intervention work in routine practice?
Study design	Efficacy	Pragmatic
Unit of randomization	Patient	Primary care clinic
Participating primary care clinics	8	51
Informed consent	Yes	No
Eligibility of primary care patients	English speaking, age 80+, cognitive impairment, involved care partner	65+
Number of participants	273 dyads (patients and care partners)	64,915 patients
Primary outcome	Care partner reported quality of communication	Doccumented end of life wishes (e.g., advance directive); potentially burdensome care at end-of-life
Secondary outcomes	Advance care planning; experiences at end-of-life	Implementation experiences (barriers, facilitators, sustainability)
Data sources	Patient and care partner surveys	Electronic health record & regional health information exchange

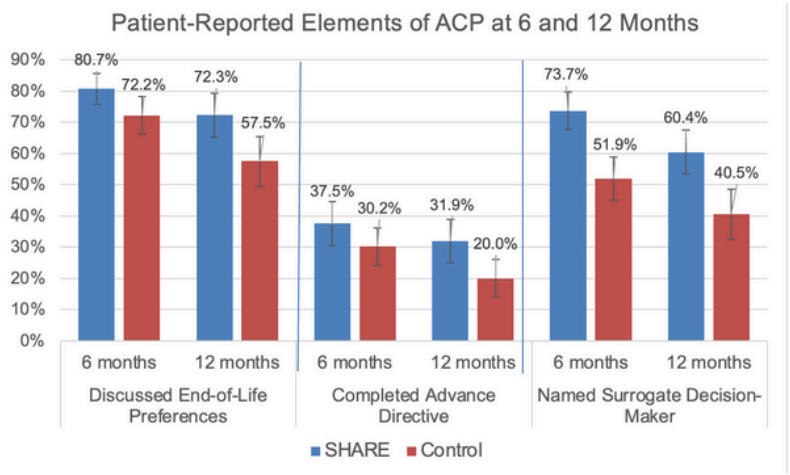
As an efficacy study, "SHARE" (NCT04593472), sought to answer "does the intervention work"? The SHARE trial protocol involved recruiting a selected population of patients aged 80 and older with cognitive impairment. The SHARE study recruited 273 patient-family dyads. Eligible patients were 80 years and older, screened positive for cognitive impairment (mild-severe) in a 6-item telephone interview, provided informed consent, and had a care partner who also agreed to participate. Enrolled patients were 88 years of age on average, nearly 1/3 were Black, and nearly 3 in 4 were characterized as having moderate to severe cognitive impairment. After completing baseline surveys, dyads were randomized to the intervention or to a control protocol of minimally enhanced usual care. In the intervention group, nearly 2 in 3 dyads engaged in at least one advance care planning conversation, and the study team provided oversight of facilitators to ensure fidelity to the protocol. Patients and care partners completed interviews at 6, 12, and 24 months, with bereavement sureveys fielded to care partners.

As an embedded pragmatic trial, "SHARING Choices" (NCT04819191), sought to answer "does the intervention work in routine practice"? The SHARING Choices protocol was undertaken as a part of routine care delivery with few eligibility criteria – a total of 64,915 older adults from 51 primary care clinics were included. SHARING Choices was conducted as a part of routine care and did not recruit or consent participants. Patients thus reflect the demographics of primary care practices: they were 74.0 years old on average, about 1/3 were Black, and 7.7% had a documented diagnosis of dementia in the electronic health record. The implementation of SHARING Choices built on pilot work and workflows that were co-designed with the partner organizations to address primary care practice staffing, workflows, and priorities with the input of primary care practice champions.

A total of 19 clinics were randomized to the intervention protocol, and 32 clinics to a protocol of usual care. The trial prioritized real-world implementation in close partnership with health system leaders and allowed flexibility to accommodate system-specific workflows and priorities. These adaptations were essential in overcoming the resource constraints faced by primary care practices and responding to the clinical context of each location.

WHAT DID WE **FIND**

Our primary outcome in SHARE was the Quality of Communication (QOC) Questionnaire, which has been validated and widely used but had not previously been fielded in our target population or setting. A number of adaptations were needed to overcome challenges that surfaced in our pilot work to simplify the cognitive demand of skip patterns for patients and uncertainty among care partners in reporting on behaviors they may not have observed. Our hypothesis was that intervention care partners would report better quality of communication about end-of-life care and ACP processes. Although we did not observe a treatment effect on care partner-reported QOC at 6 months, intervention patients reported better quality of communication about end-of-life care at 12 months. Intervention care partners and patients reported greater readiness to engage in ACP at 6 and 12 months, respectively, and were more likely to report having completed selected key aspects of ACP. Care partners were more likely to report having discussed patient preferences about end-of-life care, while patients were more likely to report having named a surrogate decision maker (Figures).



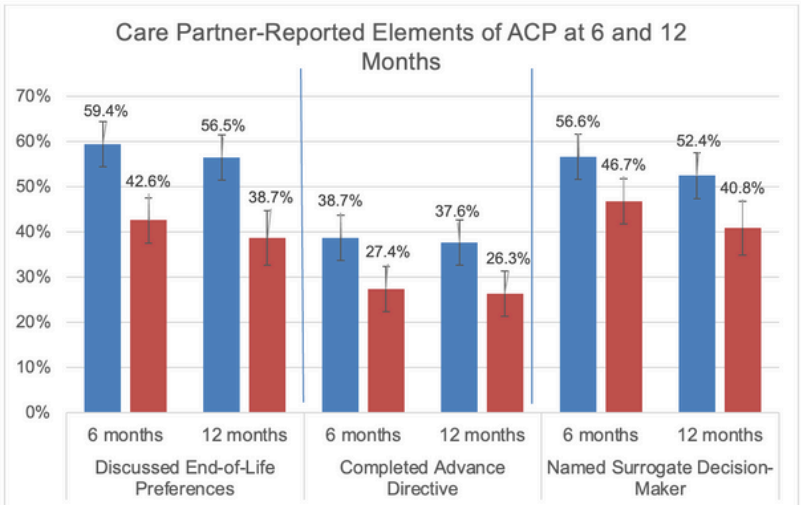


Figure 1. Proportion of Care Partners (Upper Panel) and Patients (Bottom Panel) Reporting Completion of Key Aspects of Advance Care Planning at 6- and 12-Months by Treatment Group. Wolff et al. Alzheimers & Dementia. 2024.

The collection of audio-recorded advance care planning conversations contributed depth to the interpretation of SHARE findings. Longer discussions, greater facilitator experience, and more engaged care partners were associated with higher fidelity to the advance care planning conversation guide. Cognitive impairment was also a factor: care partners were more actively engaged in advance care planning conversations involving older adults with severe impairment.

SHARING Choices hypothesized that the intervention protocol would increase electronic health record (EHR) documentation of end-of-life preferences (e.g., advance directives involving naming a surrogate decision-maker or completing a living will) and reduce potentially burdensome care at end of life for patients who died with serious illness. The intervention increased new documentation of end-of-life preferences among older primary care patients more than two-fold (aOR 2.15, 95% CI: 2.02-2.30). These effects were consistent and statistically significant, yet attenuated, in vulnerable subpopulations by older age, Black race, and dementia diagnosis (Figure).

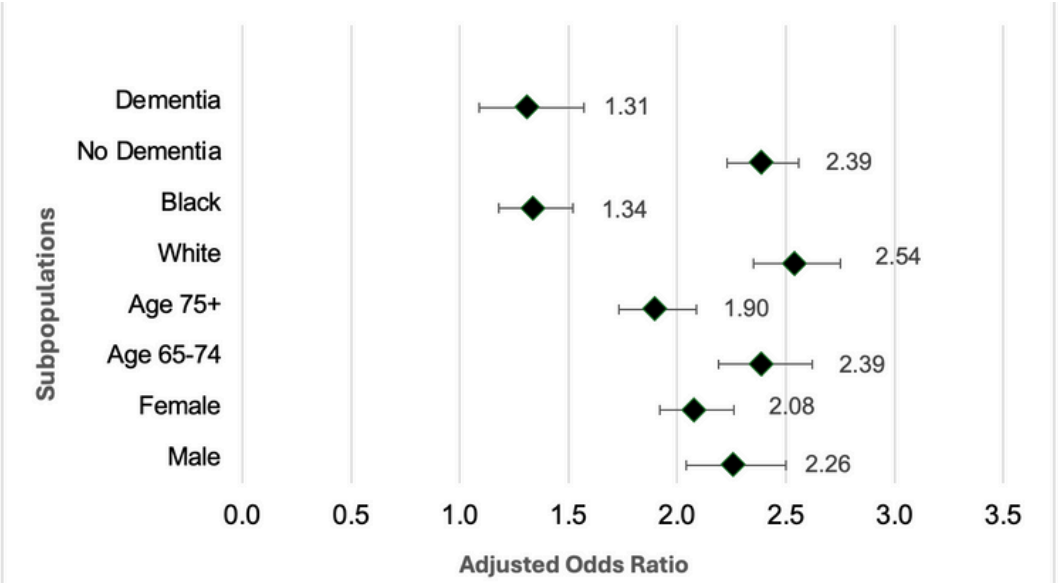


Figure 2. New EHR Documentation of End-of-Life Preferences. Adjusted Odds Ratios of the SHARING Choices Intervention vs. Usual Care. Wolff et al. JAMA IM. 2024

Less than 5% of intervention group patients engaged in facilitator-led ACP. A qualitative evaluation of the implementation of SHARING Choices found that clinicians' perceptions of the intervention were mostly positive. The dementia-related and family engagement components of the intervention were challenging to implement but reinforced the need for additional attention to meeting the specific needs of persons with dementia and the lack of engrained systems to support families in advance care planning. Another challenge was that patients with dementia comprise a small proportion of patients who engaged in ACP, and the COVID-19 outbreak necessitated transitioning to remote modalities, which inhibited accessibility in this target population.

FUTURE DIRECTIONS

Planning for future medical decision-making is multifaceted, highly personal, and affected by individual, family, and setting specific factors. Findings from SHARE and SHARING Choices underscore the complexity of implementing and evaluating the effects of advance care planning among persons with heightened vulnerability in the primary care context.

Both SHARE and SHARNG Choices were proposed in an era that preceded the COVID-19 pandemic outbreak and proposed relying on facilitators who were embedded in primary care practices to accommodate in-person interactions to overcome technical challenges for those with sensory impairment or limited experience with electronic technologies. Notable adaptations were made to accommodate virtual modalities, which were more challenging to implement in the target populations. Health systems in the SHARE and SHARING Choices trials prioritized ACP by integrating it with Medicare Annual Wellness Visits to reduce additional copays for patients and anchor this activity in a care encounter focused on health maintenance and prevention.

SHARE findings reinforce the importance of family relational dynamics in advance care planning and in facilitating understanding of patients values and wishes. In examining audio-recorded visits, care partners were found to often assume a translator-like role, providing useful context, reorienting the older adult to prior conversations, and integrating supportive communication techniques such as repetition and mirroring to elicit participation and engagement. We found especially strong treatment effects for relational and communication aspects of ACP that pertain to eliciting values and creating a shared framework for future decisions, which are especially important in dementia care. This work suggests possibilities for better preparing family members for their role in shared decision making, particularly as it relates to end-of-life decision making. Creating such opportunities in clinical workflows that are already overwhelmed with requirements may require investigating nurse- and community health worker-led advance care planning conversations, but how best to created shared understanding among multiple clinicians remains a concern.

Findings from SHARING Choices reinforce opportunities to build on new Medicare benefits to support primary care-based preventive services, but that tailoring is necessary to accommodate the needs of individuals with more extensive social and health needs. Primary care is a vital setting in dementia care but patients with dementia comprise a relatively small proportion of the typical primary care panel. Clinicians report a lack of confidence and training in the diagnosis and management of this condition – and advance care planning is just one of many important needs to be addressed in this population. Care partners are commonly present in primary care visits, but strategies to support their involvement in primary care conversations are not well developed or widely deployed – and their effort to support, protect, and respect a patient living with dementia can mask clinician understanding of cognitive functional, and behavioral challenges – including initiation of advance care planning. Complex scheduling and sustainability considerations further amplify the difficulties of delivering advance care planning in practice.

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