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SHARING Choices: A Pilot Study to Engage Family in Advance Care Planning of Older Adults with and without Cognitive Impairment in the Primary Care Context

Jennifer L. Wolff¹, Danny Scerpella¹, Kimberly Cockey², Naaz Hussain³, Tara Funkhouser³, Diane Echavarria¹, Jennifer Aufferl¹, Amy Guo¹, Danetta H. Sloan^{1,4}, Sydney M. Dy¹, Kelly M. Smith², SHARING Choices Investigators⁵

¹Roger C. Lipitz Center for Integrated Health Care, Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health,

²MedStar Health Institute for Quality and Safety, MedStar Health System

³Johns Hopkins Community Physicians

⁴Department of Health, Behavior, and Society, Johns Hopkins Bloomberg School of Public Health

⁵SHARING Choices Investigators: Martha Abshire, Tom Bauer, Cynthia M. Boyd, Kimberly Cockey, Jessica Colburn, Valerie Cotter, Sydney M. Dy, Diane Echavarria, Stephen Fernandez, Erin Giovannetti, Naaz Hussain, Jason Karlawish, Maura McGuire, Karyn Nicholson, Thomas M. Richards, David L. Roth, Charles Sabatino, Danny Scerpella, Meena Seshamani, Danetta H. Sloan, Kelly M. Smith, Laura Torres, Kathryn A. Walker, David S. Weisman, Jennifer L. Wolff

Abstract

Context.—Few advance care planning (ACP) interventions proactively engage family or address the needs of older adults with and without cognitive impairment in the primary care context.

Objectives.—To pilot a multicomponent intervention involving: an introductory letter describing a new clinic initiative and inviting patients to complete a patient-family pre-visit agenda-setting checklist, share their electronic health information with family, and talk about their wishes for future care with a trained ACP facilitator (SHARING Choices).

Methods.—SHARING Choices was delivered to 40 patient-family dyads from 3 primary care clinics. Facilitators completed post-ACP reports. Patient and family participants completed baseline and 6-week surveys.

Results.—Patients were on average 75 years (range 65–90). Family were spouses (85.0%) or adult children (15.0%). At 6 weeks, nearly half of dyads participated in ACP conversations (n=19) or used the agenda-setting checklist (n=17), one-third (n=13) registered family to access the patient's portal account, and most (n=28) provided the primary care team with a new or previously completed advance directive. Of 12 patients who screened positive for cognitive impairment,

Address correspondence to: Jennifer L. Wolff, PhD, Eugene and Mildred Lipitz Professor, Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, 624 N. Broadway, Room 692, Baltimore, MD 21205, jwolff2@jhu.edu, phone 410-502-0458; fax 410-955-0470, twitter: @jwolff_sph.

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9 completed ACP conversations and 10 provided the clinic with an advance directive. ACP engagement, measured on a 4-point scale, was comparatively lower at baseline and 6 weeks among family (3.05 and 3.19) than patients (3.56 and 3.54). Patients remarked that SHARING Choices clarified communication and preferences while family reported a better understanding of their role in ACP and communication.

Conclusion.—SHARING Choices was acceptable among older adults with and without cognitive impairment and may increase advance directive completion.

Keywords

Advance care planning; primary care; older adults; cognitive impairment; family caregiver; intervention

Introduction

Advance care planning (ACP) is a communication process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.¹ Because clinicians typically turn to the substituted judgment of family in the absence of decision-making capacity,² naming and including a health care agent in longitudinal conversations are essential elements of ACP.^{3,4} However, family is not routinely engaged in longitudinal communication^{2,5} and is often poorly prepared for surrogate decision-making.^{6,7}

Primary care is an important setting for ACP among older adults due to the frequency of interactions in longitudinal trusted relationships,^{8,9} and patient expectations and preferences that clinicians initiate such conversations.^{9,10} Early initiation of ACP is an imperative in the context of dementia due to the long course of illness and its progressive and devastating effects on decision-making capacity. Although persons with mild and moderate cognitive impairment can participate in ACP,^{11,12} little attention has been directed at identifying strategies to support ACP for this population and their family in primary care, which is the most common setting of initial diagnosis and ongoing medical management.^{13–15} Compared to persons without dementia, those living with dementia are less likely to complete an advance directive or formally designate a surrogate decision-maker,¹⁶ and are at heightened risk for unnecessary suffering and burdensome and costly end-of-life care.^{10,17}

Sharing access to Health records with family, Agenda setting, and RespectING Choices (SHARING Choices) is a person- and family-centered model that was developed to address barriers to ACP in the primary care context for older adults with and without cognitive impairment. SHARING Choices integrates strategies to normalize and support ACP discussions in mainstream primary care while proactively respecting older adults' preferences for involving family in primary care interactions. This article describes SHARING Choices and results from a pilot test that was conducted to establish acceptability in primary care in advance of a 3-year pragmatic trial to be launched in 55 primary care clinics in the Baltimore-Washington area.

Methods

SHARING Choices

SHARING Choices integrates communication strategies that have been individually found to be effective but thus far been deployed in isolation of one another. Components include: 1) a letter from the primary care clinic introducing a new initiative to improve communication with older adults,¹⁸ 2.) a person-family agenda-setting checklist to align patient and family perspectives regarding the role of the family member in primary care interactions and stimulate interest in ACP,^{19,20} 3.) ongoing access to a facilitator trained to lead ACP conversations to overcome barriers related to time and expertise in primary care,²¹ and 4.) facilitated registration for the patient portal (for patient *and* family) to enable and extend electronic interactions and information access to family caregivers.^{22,23}

Because of the importance of normalizing ACP and addressing it early in the course of memory loss,^{24,25} the under-diagnosis of dementia^{26,27} and the greater implementation potential of a protocol with broad applicability, SHARING Choices was designed as a clinic-level model for all older primary care patients. SHARING Choices builds on the Respecting Choices educational curriculum, (<http://respecting-choices.org>), which is a structured program that trains clinicians and non-clinicians in the competencies of ACP and includes standardization of policies for embedding ACP in routine care delivery. The educational curriculum includes scripted interview tools and communication techniques to facilitate understanding of ACP, exploring personal values, identifying a health care decision-maker, and communicating preferences for end-of-life care. By normalizing ACP as a routine conversation to be periodically revisited in the presence of an individuals' surrogate decision-maker, and by prioritizing longitudinal triadic (patient-family-clinician) partnerships that are motivated by respect for individual autonomy, SHARING Choices is consistent with principles of person-and family-centered care²⁸ as well as principles for introducing and supporting ACP in the context of cognitive impairment.²⁹

Pilot Study

To test the acceptability of SHARING Choices, we conducted a pilot study at 3 primary care clinics operated by two health systems in the Baltimore-Washington area. At Health System A, we partnered with a freestanding primary care clinic in a suburban area that has had a sustained focus on ACP. At Health System B, we partnered with two hospital-based clinics in an urban location with racially and socio-economically diverse patient panels that had not recently prioritized ACP. Advance care planning facilitators included a social worker who was embedded in the clinic at Health System A and a member of the study team who is a certified medical assistant with experience in patient navigation who worked with the two clinics at Health System B. Advance care planning facilitators were trained in the Respecting Choices First Steps program in June 2019. Study staff introduced SHARING Choices to participating clinics during monthly staff meetings and front desk staff were educated about how to execute the registration process for shared access to the patient portal.

Inclusion criteria for patients included age 65 or older, English speaking, attends primary care visits with a family member or unpaid friend (hereafter “family”), and able to

consent themselves or through a legally authorized representative. Established patients of participating clinicians were mailed recruitment letters describing the study one month in advance of a scheduled visit. Patients who did not “opt out” by mail were contacted by the research team to administer a telephone screening interview, including the 6-item cognitive screen³⁰ and to obtain contact information for the family member/friend who accompanies them to primary care visits, who was also administered a telephone screening interview to describe the study and assess interest.

Eligible dyads who orally consented in a telephone screening interview were mailed materials about SHARING Choices, including: 1) a letter from the clinic introducing the initiative that is modeled on our prior work,¹⁸ 2) a blank copy of the Maryland-DC advance directive, 3) a form to afford a family member access to the patient’s electronic health record through “shared” or “proxy” access, and 4) a person-family agenda-setting checklist.^{19,20} Study staff met eligible/interested dyads 30 minutes before a regularly scheduled primary care visit to answer questions about the study, obtain written consent, execute patient wishes for shared access, and provide dyads with contact information for the Sharing Choices ACP facilitator. Participants were told they would be contacted by the ACP facilitator to inquire about their interest in scheduling a voluntary meeting.

ACP facilitators tracked the number and modality of contacts with enrolled participants and the duration, location, and outcomes of ACP discussions. Research staff conducted telephone interviews with patients and family at baseline and at 6 weeks follow-up. The 15-item ACP engagement survey was fielded to patients³¹ and the 17-item ACP engagement survey for surrogate decision-makers³² was fielded to family, respectively, at both time points. Responses to both instruments are measured on a 4-point scale with higher scores indicating greater engagement. Six-week surveys included semi-structured questions about patient and family perspectives and experience with SHARING Choices.

Analysis

The pilot test was conducted between July 2019 and April 2020. Descriptive statistics were used to characterize the sample. To assess acceptability of SHARING Choices, we examined recruitment and retention, uptake of each therapeutic component (agenda-setting, shared access to the patient portal, ACP conversations), and feedback about the model and delivery characteristics. Information about uptake of SHARING Choices therapeutic components was assessed by research staff at the time of the enrollment visit, by ACP facilitators from contacts that were tracked over the 6 week observation period, and by patient and family participants at 6 weeks. Patient and family ACP engagement was measured at baseline and 6 weeks in total. Due to the focus of SHARING Choices on engaging family in ACP, we additionally examined domain-specific measures of family ACP engagement to assess whether SHARING Choices differentially affected domains of serving as a surrogate decision-maker, contemplation, and readiness to engage in ACP. All quantitative analyses are reported for the overall sample as well as stratified by health system. Finally, we identified patient and family perspectives regarding SHARING Choices components by identifying common themes that were raised in open-ended responses at 6 weeks. The

protocol (IRB00202704) was approved by the single institutional review board of the Johns Hopkins School of Medicine.

Role of the Funding Source

The study was conducted with grant support from the National Institute on Aging (R61AG061882). The funding agency did not have a role in the design, conduct, or reporting of the study results.

Results

Recruitment letters were mailed to 319 patients, of whom 44 (13.8%) returned an “opt-out” card indicating they were not eligible (n=24) or not interested (n=20). Screening calls were made to 275 (86.2%) patients, of whom 39 (14.2%) were not reachable, 150 (54.6%) were not eligible, 46 (16.7%) refused participation, and 40 (14.6%) were eligible and agreed to participate (See Appendix for Consort Diagram). Enrolled patients were on average 75 years (range 65–90; Table 1). Most were white (85.0%) and had beyond high school education (65.0%); about 1 in 3 (30.0%) missed one or more items on a 6-item cognitive screen, suggesting cognitive impairment. Family were on average 70 years (range 27–88) and spouses (85.0%) or adult children (15.0%); half were male (52.5%).

Of the 37 dyads who completed 6-week telephone interviews, 23 (62.1%) reported engaging in one or more of the intervention components. Nearly half (n=17; 45.9%) used the patient-family agenda-setting checklist in advance of a primary care visit. One in three (n=13; 35.1%) registered for shared access to the patient portal and 10 (27.0%) reported they intended to register. The 2 ACP facilitators documented conversations with 19 (47.5%) dyads over the course of the 6-week observation period. ACP conversations were generally 45 minutes or longer (n=12; 60.0%) or 30–45 minutes (n=7; 35.0%); just one conversation was less than 30 minutes. In total, 12 (32.4%) dyads completed a new advance directive, and 16 (43.2%) provided the primary care team with a previously completed advance directive.

Uptake of one or more intervention components was similar among dyads at System A (63.1%) and System B (61.1%), although differences were observed by therapeutic component. More ACP conversations occurred at System A, which relied on an embedded facilitator (n=14; 70.0%) than System B (n= 6; 30.0%). Participant dyads at Health System A were more likely than Health System B to use the agenda-setting checklist (52.6% vs. 38.9%) and register for shared access to the patient portal (42.1% versus 27.8%), though receptivity to shared access was comparable. Participants at System B were twice as likely as those at System A to complete a new advance directive (44.4% versus 21.1%).

Among 12 patients who screened positive for cognitive impairment, 9 (75%) completed an ACP conversation. At 6 weeks, 4 (33.3%) reported using the patient-family agenda-setting checklist, 4 (33.3%) registered for shared access to the patient portal, and 3 (25.0%) reported they intended to register for shared access in the future. A total of 3 (25.0%) completed a new advance directive and 7 (58.3%) provided the primary care team with a previously completed advance directive.

Patient ACP engagement was high at baseline and remained high at 6 weeks (3.56 and 3.54, respectively) while family ACP engagement was comparatively lower and trended up (3.05 and 3.19). Family scores on the “contemplation” domain of the ACP engagement survey were and remained low (2.37 at baseline and 2.36 at 6 weeks). Family scores on “serving as a surrogate decision-maker” and “readiness” domains were higher and trended up (from 3.41 to 3.56 (+0.15) and from 3.09 at baseline to 3.29 (+0.20)), respectively.

Patients and family generally reflected positively on SHARING Choices in answering open-ended questions at 6 weeks (Table 4). Participants reported the letter and agenda-setting checklist stimulated reflection and clarification of roles and preferences. An 80-year patient commented: *This whole thing was in the back of my mind and I've been wanting this kind of thing but didn't know what to call it* (1a). In discussing the agenda-setting checklist, a 73-year patient stated: *It [included] things I didn't really think about before...the main one was I didn't want anyone accompanying me to a certain visit* (2b) while an adult son remarked: *It focused our discussion when we went in and we were both on the same page* (2a). Participants noted the convenience and value of having electronic access to patient health information through the patient portal. A spouse reported: *It makes the whole interface with the care team easier* (3c) while a patient stated: *I want my husband and daughter to have access...to have a second set of eyes* (3b). ACP conversations were noted as being comprehensive and stimulating discussions between patients and family. The spouse of a patient with cognitive impairment stated: *the facilitator helped to organize and speed up thinking about who would be involved...The conversation prompted a call to family* (4b).

Discussion

This study provides early evidence that a multi-component communication intervention to engage both older adults and involved family in ACP in the primary care context is acceptable. More than half of participating patients adopted one or more therapeutic components of SHARING Choices: nearly half engaged in at least one ACP conversation and two-thirds provided the primary care clinic with a new or previously completed advance directive for documentation in their electronic health record. Although patient and family ACP engagement changed little over the 6-week observation period, open-ended comments at six weeks indicate that patients and family who engaged in the program found value in intervention components.

Our most important finding was receptivity to SHARING Choices among dyads of older adults who screened positive for cognitive impairment, of whom three-fourths engaged in ACP conversations and the vast majority provided a new or previously completed advance directive to their primary care team. Prior studies indicate that persons living with dementia are less likely to participate in ACP, appoint surrogate decision-makers, or complete living wills.^{16,33} Existing interventions directed at supporting ACP in persons with cognitive impairment and dementia have primarily been undertaken in nursing homes^{34–36} while primary care-based ACP interventional research has largely excluded those living with cognitive impairment.³⁷ SHARING Choices aligns with best practices principles for approaching ACP in the context of cognitive impairment²⁹ by seeking to normalize ACP and establishing structured processes to support individual autonomy and decision-

making preferences, including wishes to involve family in communication. Our findings are reassuring by suggesting the feasibility of including persons with and without cognitive impairment in primary care-based ACP.

We and others have argued that high quality care not only requires respecting individual autonomy and preferences, but supporting the involvement of family, who so often assist with daily activities and in coordinating care, managing treatments, and participating in routine and high stakes decisions when individuals can no longer do so themselves.³⁸ Older adults commonly value, desire, and rely on family to manage their care needs, but interpersonal dynamics are complex and variable – and the perspectives of older adults and their family are not always aligned. Engaging family in primary care interactions is especially important in the context of cognitive impairment given that memory loss often precipitates family involvement, family are well positioned to facilitate productive information-exchange between persons with cognitive impairment and primary care clinicians,^{39,40} and because family are typically on the front lines of surrogate decision-making.²⁵ Few studies have comparatively examined patient and family ACP engagement and the finding that family engagement was relatively low supports the objective of SHARING Choices in preparing family for their role in longitudinal communication and decision-making.

Although a comparable proportion of patient-family dyads adopted one or more SHARING Choices therapeutic components at both health system partners, differences were observed. Patient-family dyads at Health System A had access to an embedded facilitator and ACP conversations were held at the primary care clinic; two-thirds of patients at Health System A reported providing the clinic with a previously completed advance directive. Patient-family dyads at Health System B had access to an offsite ACP facilitator; these conversations primarily occurred in the community, tended to be longer in duration, and were twice as likely to lead to a new advance directive. A comparable proportion of participant dyads expressed interest in shared access to the patient portal, but uptake was higher at Health System A where overall patient portal registration is more common. Observed clinic-level differences speak to the importance of patient, clinic, and system-level factors in implementation science,^{41,42} which will represent an important line of investigation in the pragmatic trial.

Several limitations merit comment. Most notably, this pilot study sought to evaluate acceptability and establish proof of concept for a multicomponent intervention: it did not involve a comparison group and was not designed to examine or detect pre-post differences. Although the study was conducted in the context of routine primary care, this study enrolled older adults who consented to participate and attended primary care appointments with a family member or friend and likely represents a selected population. The office medical director from the Health System A clinic is a geriatrician who has previously led ACP quality improvement initiatives in the clinic, and completion of advance directives was therefore higher than may be expected in routine care. As our study enrolled patient-family dyads, we cannot comment on the acceptability of SHARING Choices for older adults who are socially isolated or do not have involved family: ACP conversations and advance directive completion present unique challenges in this population^{43,44} but such individuals

were excluded from participation. Enrolled participants in this study were not racially or ethnically diverse. Prioritizing the development and dissemination of ACP strategies that resonate with diverse populations of older adults will be important in closing disparities and improving the quality of end-of-life care for all older adults.

In summary, this study provides early evidence that SHARING Choices is acceptable and was well received in a pilot study involving a limited number of older primary care patients from two health systems. Our finding that older adults with and without cognitive impairment were receptive to therapeutic components of SHARING Choices, including ACP, and that advance directive completion was greater at 6 weeks bodes well for the planned three-year pragmatic trial. The focus of SHARING Choices is timely and relevant in light of recently available Medicare billing codes for ACP and dementia care planning,^{45,46} American Medical Association and National Quality Forum recommendations that ACP be included in ADRD quality measurement,^{47,48} the recent attention toward efforts to proactively engage families in care delivery,³⁸ and most tragically, the COVID-19 outbreak which has disproportionately affected older adults.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Appendix A

SHARING Choices Investigators: Martha Abshire, Tom Bauer, Cynthia M. Boyd, Kimberly Cockey, Jessica Colburn, Valerie Cotter, Sydney M. Dy, Diane Echavarria, Stephen Fernandez, Erin Giovannetti, Naaz Hussain, Jason Karlawish, Maura McGuire, Karyn Nicholson, Thomas M. Richards, David L. Roth, Charles Sabatino, Danny Scerpella, Meena Seshamani, Danetta H. Sloan, Kelly M. Smith, Laura Torres, Kathryn A. Walker, David S. Weisman, Jennifer L. Wolff.

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Table 1.

Characteristics of Patient and Family Participants

	System A (n=20)		System B (n=20)		Total (n=40)	
	Patient n (%)	Family n (%)	Patient n (%)	Family n (%)	Patient n (%)	Family n (%)
Mean age in years (SD)	75.3 (6.0)	72.5 (11.2)	74.5 (7.0)	68.4 (14.1)	74.9 (6.4)	70.4 (12.8)
Relationship to patient						
Spouse	--	17 (85.0)	--	17 (85.0)	--	34 (85.0)
Adult child	--	3 (15.0)	--	3 (15.0)	--	6 (15.0)
Other relative or friend	--	0 (0.0)	--	0 (0.0)	--	0 (0.0)
Gender						
Female	13 (65.0)	8 (40.0)	11 (55.0)	11 (55.0)	24 (60.0)	19 (47.5)
Male	7 (35.0)	12 (60.0)	9 (45.0)	9 (45.0)	16 (40.0)	21 (52.5)
Educational attainment						
High school or less	6 (30.0)	5 (25.0)	8 (40.0)	4 (20.0)	14 (35.0)	9 (22.5)
College	11 (55.0)	6 (30.0)	4 (20.0)	6 (30.0)	15 (37.5)	12 (30.0)
Graduate	3 (15.0)	9 (45.0)	8 (40.0)	10 (50.0)	11 (27.5)	19 (47.5)
6-Item Cognitive Screen						
All items correct	11 (55.0)	--	17 (85.0)	--	28 (70.0)	--
One incorrect item	6 (30.0)	--	1 (5.0)	--	7 (17.5)	--
Two+ incorrect items	3 (15.0)	--	2 (10.0)	--	5 (12.5)	--
Race						
White	19 (95.0)	19 (95.0)	15 (75.0)	14 (70.0)	34 (85.0)	33 (82.5)
Black	1 (5.0)	1 (5.0)	5 (25.0)	6 (30.0)	6 (15.0)	7 (17.5)
Other	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Ethnicity						
Hispanic/Latino	0 (0.0)	0 (0.0)	1 (5.0)	0 (0.0)	1 (2.5)	0 (0.0)
Not Hispanic/Latino	20 (100)	20 (100.0)	18 (90.0)	20 (100.0)	38 (95.0)	40 (100.0)
Refused	0 (0.0)	0 (0.0)	1 (5.0)	0 (0.0)	1 (2.5)	0 (0.0)

Table 2.

Uptake of SHARING Choices by Enrolled Participants by System and in Total

	System A	System B	Combined
Prior to Enrollment ^{a,b}	(n=17)	(n=20)	(n=37)
Dyad recalled received mailed introductory materials	14 (82.4)	14 (70.0)	28 (75.7)
Dyad brought introductory materials to visit	11 (64.7)	8 (40.0)	19 (51.4)
Advance Care Planning ^c	(n=20)	(n=20)	(n=40)
Completion of ACP conversations			
1+ conversation completed	13 (65.0)	6 (30.0)	19 (47.5)
Not interested	6 (30.0)	12 (60.0)	18 (45.0)
Dropped/Withdraw	1 (5.0)	2 (10.0)	3 (7.5)
Location of ACP conversations			
Primary care clinic	14 (100.0)	1 (16.7)	15 (75.0)
Community	0 (0.0)	5 (83.3)	5 (25.0)
Duration of ACP conversations			
Less than 30 minutes	1 (7.1)	0 (0.0)	1 (5.0)
30–45 minutes	6 (42.9)	1 (16.7)	7 (18.0)
45 minutes or longer	7 (50.0)	5 (83.3)	12 (30.0)
Health Care Agent Identified	13 (100.0)	6 (100.0)	19 (100.0)
Living Will Completed	7 (53.8)	1 (16.7)	8 (42.1)
Total ACP facilitator contacts (Range per dyad)	60 (1–7)	51 (1–6)	111 (1–7)
Patient/Family Reports at 6 Weeks ^d	(n=19)	(n=18)	(n=37)
Patient-Family Agenda Setting			
Used	10 (52.6)	7 (38.9)	17 (45.9)
Not used	6 (31.6)	10 (55.6)	16 (43.2)
Do not remember	3 (15.8)	1 (5.6)	4 (10.8)
Shared Access to Patient Portal			
Registered	8 (42.1)	5 (27.8)	13 (35.1)
Intend to register	4 (21.1)	6 (33.3)	10 (27.0)
Not interested	7 (36.8)	6 (33.3)	13 (35.1)
Completed previously/Do not remember	0 (0.0)	1 (5.6)	1 (2.7)
Advance Directive			
Completed new advance directive	4 (21.1)	8 (44.4)	12 (32.4)
Intend to complete	0 (0.0)	1 (5.6)	1 (2.7)
Not interested	1 (5.3)	3 (16.7)	4 (10.8)
Previously completed	12 (63.2)	4 (22.2)	16 (43.2)
Do not remember	2 (10.5)	2 (11.1)	4 (10.8)
Any of Above	12 (63.1)	11 (61.1)	23 (62.1)

^aInformation reported by research staff at time of enrollment visit.

^b Delivery characteristics were not recorded for the first 3 dyads at Health System A.

^c Information reported by facilitator for participants with 1+ ACP conversation; 1 dyad at Health System A had 2 conversations.

^d Uptake of intervention components at 6 weeks refers to a composite measure for each dyad that relies on family responses for patients who were unable to report or when reports were inconsistent.

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Table 3.

Patient and Family Advance Care Planning Engagement at Baseline and 6 Weeks

	System A		System B		Combined		
	BL	6 Wks	BL	6 Wks	BL	6 Wks	Change
Overall ACP Engagement							
Patient (n=32) ^a	3.71	3.73	3.41	3.35	3.56	3.54	-0.02
Family (n=37) ^b	3.05	3.12	3.06	3.26	3.05	3.19	+0.14
Family ACP Engagement by Domain^c							
--Serving as Surrogate Decision Maker	3.41	3.50	3.41	3.63	3.41	3.56	+0.15
--Contemplation	2.39	2.42	2.35	2.29	2.37	2.36	-0.02
--Readiness	3.06	3.10	3.12	3.48	3.09	3.29	+0.20

^aMeasured with the 15-item ACP engagement survey (range: 0–4, higher scores indicate greater engagement). Results for n=32 patients responding at baseline and 6 weeks.

^bMeasured with the 17-item ACP engagement survey for surrogate decision-makers (range: 0–4, higher scores indicate greater engagement). Results for n=37 responding at baseline and 6 weeks.

^cThe domains ‘Serving as surrogate decision-maker’ and ‘Readiness’ were assessed on a scale of 0 (not at all) to 4 (extremely) and ‘Contemplation’ was assessed on a scale of 0 (never) to 4 (a lot).

Table 4:

Patient and Family Perspectives on SHARING Choices, by Therapeutic Component

1	<p><u>Letter from the Primary Care Clinic Introducing Advance Care Planning:</u></p> <p>a. "I read [the letter] and I was happy to get it. This whole thing was in the back of my mind and I've been wanting this kind of thing, but didn't know what to call it... I'm at the stage in life where I really want to cover these issues...I was thrilled that you're doing this and that <i>my</i> doctor is a part of it." (Patient age 80 who screened positive for having cognitive impairment)</p> <p>b. "[The letter] opened a discussion between my husband and I and it was very helpful. (Patient age 77 without suspected cognitive impairment)</p> <p>c. "The letter was clear and to the point. Good for someone who had not given the topic any thought." (Spouse of patient who did not screen positive for having cognitive impairment)</p>
2	<p><u>Person-Family Agenda-Setting Checklist:</u></p> <p>a. "[The checklist] was immensely helpful. We both filled that out and that was what I found to be the most helpful part of the whole process. It really focused our discussion when we went in and we were both on the same page." (Adult son of patient who screened positive for having cognitive impairment)</p> <p>b. "It [included] things I didn't really think about before...the main one was I didn't want anyone accompanying me to a certain visit. I had one that was a memory test. I really did not want my daughter in at that point because I had some fears about my memory...I didn't think before about how to say that I didn't need someone with me at that visit." (Patient age 73 who did not screen positive for having cognitive impairment)</p> <p>c. "It makes you think so you don't forget. I think it's a good idea." (Patient age 66 who did not screen positive for having cognitive impairment)</p>
3	<p><u>Facilitated Registration for Shared Access to the Patient Portal:</u></p> <p>a. "I have MyChart myself and I find it immensely helpful. My mom isn't the most technologically literate person, so I thought I'll have access and go in there and help her in case she needs it...The convenience of doing it there [in clinic] was a big plus." (Adult son of patient who screened positive for having cognitive impairment)</p> <p>b. "I know I want my husband and daughter to have access...to have a second set of eyes. If I'm in a position where I can't get the information myself, I want someone to be able to." (Patient age 74 who did not screen positive for having cognitive impairment)</p> <p>c. "It makes the whole interface with the care team easier." (Spouse of patient who screened positive for having cognitive impairment)</p>
4	<p><u>Access to a Facilitator Trained to Lead Advance Care Planning Conversations:</u></p> <p>a. "[Facilitator 1] did a really thorough job. Our attorney went over it with us, but he didn't give quite as much detail...It was a really good interview and education because while we had thought about most of that, we hadn't gotten that specific, so it was really quite helpful." (Patient age 66 who screened positive for having cognitive impairment)</p> <p>b. "The convenience was a plus side. The follow-up scheduling worked well, the meeting got a lot done. [Facilitator 2] and [Facilitator 3] helped to organize and speed up thinking about who would be involved...The conversation prompted a call to family." (Spouse of patient who screened positive for having cognitive impairment)</p> <p>c. "It was good to have someone go over it with you and the family members. We might not have talked about it otherwise." (Daughter of patient who screened positive for having cognitive impairment)</p> <p>d. "I think it's good to have someone speaking out loud and probing your desires and bringing it out into the open." (Patient age 77 who did not screen positive for having cognitive impairment)</p>