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A randomized controlled trial of strategies to improve family members' preparedness for surrogate decision-making

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Abstract

Objective—To evaluate two strategies for preparing family members for surrogate decision-making.

Design—2×2 factorial, randomized controlled trial testing whether: 1) comprehensive online advance care planning (ACP) is superior to basic ACP, and 2) having patients engage in ACP together with family members is superior to ACP done by patients alone.

Setting—Tertiary care centers in Hershey, PA and Boston, MA.

Participants—Dyads of patients with advanced, severe illness (mean age 64; 46% female; 72% white) and family members who would be their surrogate decision-makers (mean age 56; 75% female; 75% white).

Interventions—*Basic ACP*: State-approved online advance directive plus brochure. *Making Your Wishes Known (MYWK)*: Comprehensive ACP decision aid including education and values clarification.

Measurements—Pre-post changes in family member self-efficacy (100-point scale), and post-intervention concordance between patients and family members using clinical vignettes.

Results—285 dyads enrolled; 267 patients and 267 family members completed measures. Baseline self-efficacy in both MYWK and Basic ACP groups was high (90.2 and 90.1, respectively), and increased post-intervention to 92.1 for MYWK ($p=0.13$) and 93.3 for Basic ACP ($p=0.004$), with no between-group difference. Baseline self-efficacy in Alone and Together groups was also high (90.2 and 90.1, respectively), and increased to 92.6 for Alone ($p=0.03$) and 92.8 for Together ($p=0.03$), with no between-group difference. Overall adjusted concordance was higher in MYWK compared to Basic ACP (85.2% vs 79.7%; $p=0.032$), with no between-group difference.

Conclusion—The disconnect between confidence and performance raises questions about how to prepare family members to be surrogate decision-makers.

Keywords

Advance Care Planning; surrogate decision-making; self-efficacy; family caregivers

Introduction

Each year, 2.5 million people die in the U.S., and 70% lack decision-making capacity at the end of life.¹ When patients are too ill to make medical decisions, family members typically serve as surrogate decision-makers.^{1,2} But family members often feel ill-prepared for this role, describing such life and death decisions as extraordinarily stressful and emotionally burdensome,^{3–8} with the distress sometimes exceeding that experienced by survivors of natural disasters, construction accidents, and home fires.⁹ In one ICU-based study 82% of surrogates suffered post-traumatic stress disorder symptoms,¹⁰ and a meta-analysis found that the burden of surrogate decision-making is widespread and long-lasting.⁸ Though

family members experience distress for many reasons,^{11–13} often overlooked is their inadequate preparation for becoming a surrogate decision-maker.

Efforts to prepare family members to become surrogates have included “do not escalate treatment” orders,¹⁴ designating a single point of contact for the medical team,¹⁵ encouraging family members to be present for clinical rounds,¹⁶ and involving nurse specialists in ICU family meetings.¹⁷ What has not been explored is the use of online tools for advance care planning (ACP) that include both patients and their family members.

Previously, we described a comprehensive online decision aid, *Making Your Wishes Known* (MYWK), that guides people through the process of ACP,¹⁸ increases knowledge about ACP, and helps users make decisions that are more consistent with their values, goals, and preferences.^{19–21} MYWK also helps healthcare providers better understand what future medical treatments patients would want.²⁰ The present study focused on surrogate decision-making, seeking to understand whether use of MYWK was more effective than basic ACP, and whether ACP by patients and family members together was more effective than ACP done by patients alone. For clarity, we use the term “family member” to refer to individuals (related or close friends) identified by patients as potential surrogate decision-makers. Only after the family member makes a decision on behalf of a patient are they referred to as “surrogates.”

Methods

Study Design

This 2×2 randomized controlled trial at two tertiary care medical centers compared family members’ preparedness to make surrogate medical decisions after patients engaged in advance care planning using **MYWK** vs **Basic ACP**, and when patients did so **Alone** vs **Together** with their family member (Group 1 = Basic ACP Materials/Patient Alone; Group 2 = MYWK/Patient Alone; Group 3 = Basic ACP Materials/Patient and Family Member Together; and Group 4 = MYWK/Patient and Family Member Together). Hypothesis #1 was that family members in Groups 2 and 4 (MYWK Groups) would be better-prepared than those in Groups 1 and 3 (defined by greater self-efficacy and higher concordance between family members’ decisions and patients’ wishes). Hypothesis #2 was that ACP done with family members and patients together (Groups 3 and 4) would be superior to ACP done by patients alone (Groups 1 and 2), in terms of family member self-efficacy and concordance. Enrollment took place between August 2013 and June 2016 at Penn State Hershey Medical Center in Hershey, PA, and Brigham and Women’s Hospital, and Boston, MA, and was approved by IRBs at participating sites. The trial was registered at [ClincialTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT02429479) (#NCT02429479).

Study Population

The study population consisted of dyads of patients with an advanced, severe illness²² and family members (who would become surrogate decision-makers in the event of decisional incapacity). Patients were eligible if they were ≥ 18 years, and had: moderate/severe heart failure (i.e. Class III or Class IV as per NYHA);²³ chronic lung disease (i.e. Stage 3 or Stage

4 COPD per modified GOLD Classification); end stage renal disease (i.e. chronic kidney disease Stage 4 or 5 per National Kidney Foundation); or advanced cancer (i.e. Stage IV disease or estimated survival of ≤ 2 years). The Boston site exclusively recruited under-represented racial/ethnic minorities. Lists of potential patient-participants were compiled by prospectively reviewing clinic records, from which referring physicians (or their appointees) confirmed: 1) the patient had a qualifying disease, and 2) “it wouldn’t surprise you if (within 18 months) the patient had to rely on a family member to make a major medical decision on their behalf.”

Potential patient-participants were sent a letter of introduction and opt-out postcard. When feasible, research staff met with eligible patients in clinic. If no opt-out letter was returned, the patient was invited by phone to participate and asked to identify a potential surrogate who was ≥ 18 years of age and had in-person contact with them at least weekly. After the study was explained to patients and potential surrogates, these dyads were scheduled for a study visit. Basic demographic information was collected from study decliners for comparison. Participants received a \$50 gift certificate at completion of study visits.

Study Interventions

Basic ACP—Participants in this group were provided with educational materials developed by the American Hospital Association²⁴ and an online version of a simple advance directive (AD) identified as being one of the best in the US.²⁵ The AD consists of a living will form plus a prompt to select a spokesperson/surrogate. It includes brief instructions followed by space to specify whether they wish to always prolong life or to sometimes not prolong life. If the latter, users provide specific treatment directions under circumstances of an end-stage medical condition or permanent unconsciousness. Unlike MYWK (described below), there are no values clarification exercises, education about medical conditions/treatments, or decision aid. Prior research showed that users spend, on average, 26 minutes (range 10-65 minutes) to complete this AD.¹⁹

Making Your Wishes Known—Participants in the intervention group used *Making Your Wishes Known* (MYWK), a comprehensive, interactive, online decision aid for ACP (www.makingyourwishesknown.com) developed by a multidisciplinary team with expertise in medicine, geriatrics, nursing, decision analysis, law, and instructional design. MYWK was created to be user-friendly and educational, and includes audio and video simulating a conversation with a healthcare provider. The program provides tailored education (8th grade reading level) about common medical conditions that can result in decisional incapacity, as well as treatments introduced in life-or-death situations. To help with difficult decisions, the program asks users to rank and rate the importance of factors that influence choices, using a framework based on multi-attribute utility theory.^{26–29} Studies with diverse populations^{21,30,31} have demonstrated that MYWK is easy to use,³¹ effective for improving knowledge about end-of-life medical decisions,¹⁹ accurate in representing patients’ wishes,²⁰ and helpful to clinicians.³² Prior research showed that users spend, on average, 70 minutes (range 15-120 minutes) to complete MYWK.¹⁹

Study Protocol

During Study Visit 1, following informed consent, patients and family members were screened for neuro-cognitive capacity (>23 on Folstein Mini Mental State Exam)³³ and 8th grade reading level (able to read to 26th word on WRAT-3).³⁴ Patients were also screened for suicidal ideations (Beck Depression Inventory-II),³⁵ and referred to a psychologist or psychiatrist if severely depressed or suicidal (none were). Individuals not meeting screening criteria received a gift certificate and the opportunity to complete an AD, but study data were not recorded. Patients were excluded for moderate/severe depression during the first two years of the study, but this restriction was discontinued after establishing that such patients could complete the study without undue distress.

Eligible dyads were randomized into four groups: 1) Basic ACP/Patient Alone; 2) MYWK/Patient Alone; 3) Basic ACP/Patient and Family Member Together; and 4) MYWK/Patient and Family Member Together. Randomization included three stratification factors: patient disease (heart, kidney, lung, or cancer), family member gender,^{36,37} and study site (Boston or Hershey). In the “Together” groups, participants shared one computer, with the family member sitting beside the patient and assisting with the intervention. In the “Alone” groups, patients completed the intervention singlehandedly, while the family members waited in a separate room. ACP was carried out at the study site and research assistants verified that the intervention was completed. Dyads returned 3-5 weeks later for Study Visit 2. Participants knew if they were completing the intervention Together vs Alone, but were blinded as to intervention group. To avoid unconscious bias, researchers did not review participants’ group designation when gathering Visit 2 data (though not formally blinded). To further safeguard data integrity, the Principal Investigators had no access to individual data and no knowledge of participants’ enrollment group when interpreting results.

Study Outcomes

The primary outcomes were whether family members *felt* prepared to serve as surrogate decision makers (self-efficacy), and whether they *were* prepared to accurately represent patients’ wishes (concordance). Self-efficacy was assessed pre- and post-intervention using a modified version of Nolan’s 17-item scale³⁸ based on Bandura’s framework.³⁹ This instrument (available as Supplementary Figure S1) quantifies family members’ confidence (0-100, where 100=greatest self-efficacy) in accomplishing tasks associated with surrogate decision-making (e.g., determining specific treatments, overcoming communication barriers, and honoring patient’s wishes). Concordance was assessed using six previously tested clinical vignettes⁴⁰ involving situations where major medical decisions needed to be made (CPR, mechanical ventilation, surgery, hemodialysis, feeding tube, and IV antibiotics). Patients indicated which treatments they would or wouldn’t want in each scenario, and family members separately were asked “if you had to decide now what medical treatments your loved one would want in the circumstances described, which of the following do you think he/she would want and not want?” (see Supplementary Figure S2).

An overall concordance score was calculated by summing the number of treatment decisions for which patient and family members’ responses were identical, and dividing by the total number of decisions ($n=28$), all equally weighted (score range 0–28), and multiplying by

100 (score range 0-100%) (see Supplementary Figure S3). Additionally, concordance scores were calculated for the 28 separate treatment decisions.

Demographic information was collected from patients and family members, including age, gender, race, education, religion, ethnicity, marital status, employment status, computer use, and prior experience with ACP and/or surrogate decision-making. These measures were later analyzed as potential confounders.

Sample Size and Statistical Analysis

We estimated 200 dyads would be needed to detect a 5 point difference in self-efficacy scores between groups, with a two-tailed α of 0.05 and a power ($1-\beta$) of 0.80. To compensate for potential attrition, we enrolled 285 dyads.

For this 2×2 study design, analyses were conducted on data from all participants who completed Study Visits 1 and 2. A two-way analysis of variance (ANOVA) was used to test change in self-efficacy pre- to post-intervention between group means. This was done to compare basic ACP vs. MYWK, and again to compare Alone vs. Together groups. This same approach was used for concordance scores, although concordance was not analyzed for change, as it was measured only at Visit 2. For specific treatment concordance, the same main effects were tested using logistic regression, and odds ratios quantified the direction and magnitude of the likelihood of concordance. An interaction term between the two main effects was tested in all models but was not significant. The analysis included models both unadjusted and adjusted for potential confounders, including prior completion of AD by patient or family member, patient disease category, study site, patient race and ethnicity. All analyses were performed using SAS version 9.4 (SAS Institute, Cary, NC).

Results

Cohort demographics

Between August, 2013 and June, 2016, 285 patient-family member dyads were eligible and randomized, and 267 (93.7%) completed both Study Visits 1 and 2 and were included in the analysis (207 from Hershey and 60 from Boston). The refusal rate was 50% and exclusion rate was 38%. [Figure 1, Study Design and Consort Flow Chart]

For both patients and family members, baseline characteristics were similar in all four groups (see Supplementary Table S4 for detailed demographics). Because we did not see any significant overall differences in education level between groups, we did not examine differences in outcomes based on education; however, participants in Alone Group were more likely to have previously completed an AD (36.5% vs 24.1%, $p=0.027$). Compared to participants ($n=267$), *non*-participants who completed decliner surveys ($n=378$) were less educated (48.1% education beyond HS vs. 62.1%, $p=0.02$), more likely to already have completed an AD (60.0% vs. 45.8%, $p=0.001$), and less confident in their computer skills (3.8 vs 4.5 on a 1-7 scale, $p=0.02$). [Table 1, Demographics]

Self-efficacy

Family members' self-efficacy scores were high at baseline (>90 on a 0-100 scale, where 100=highest) in both the MYWK (90.2) and Basic ACP group (90.1). There was a slight post-intervention increase in both groups, which was significant in the Basic ACP Group (mean change=3.2, $p=0.004$).

Similarly, self-efficacy scores were high at baseline in both the Alone and Together groups. Again, there was a slight increase in self-efficacy post-intervention, but here the increase was significant in both groups (adjusted mean increase=2.3 for Alone and 2.5 for Together, $p=0.033$ and $p=0.026$, respectively). [Table 2, Self-Efficacy and Concordance]

Concordance

The overall adjusted concordance score was higher in the MYWK group compared to the Basic ACP group (85.2% vs 79.7%; $p=0.032$). For specific medical treatments, concordance scores were generally higher in the MYWK group than the Basic ACP group, reaching significance in individual vignettes for questions about mechanical ventilation and feeding tube placement. [Figure 2, Concordance Comparisons by Vignette]

Comparing the Alone vs. Together groups, there were no significant differences in either overall concordance scores, or concordance scores for decisions within individual vignettes (Table 2).

Discussion

As hypothesized, family members more accurately predicted patients' wishes (i.e., higher concordance) after using the comprehensive decision aid (MYWK) compared to Basic ACP materials. Surprisingly, however, this increase in concordance was not matched by a significant increase in self-efficacy in the MYWK Group, whereas those in the Basic ACP group *did* report greater self-efficacy.

What accounts for this unexpected finding? One possible explanation was keenly articulated 150 years ago by Charles Darwin, who observed that "ignorance more frequently begets confidence than does knowledge".⁴¹ This adage may help explain why family members whose loved ones engaged in basic ACP felt more confident yet were less accurate at representing patients' wishes than family members whose loved ones engaged in the more systematic and detailed MYWK. This particular cognitive bias was described by Dunning and Kruger who showed that people tend to hold overly favorable views of their abilities and, paradoxically, that improving individuals' awareness of the skills needed to successfully complete a task can result in *decreased* self-efficacy because people better recognize the limitations of their abilities.⁴²

It is also worth noting that baseline self-efficacy scores were higher than expected for *all* family members,³⁸ which may constitute a ceiling effect that artificially restricts scores at the higher end, limiting potential gains in self-efficacy.⁴³ In light of research showing that family members/surrogates are *not* actually well-prepared for making major medical decisions,⁴⁴⁻⁴⁶ participants' high baseline confidence may be unwarranted.

Perhaps more perplexing is the finding that ACP involving patients and family members *Together* did not yield superior concordance compared to ACP done by patients *Alone*. A foundational premise of ACP is that by promoting communication between patients and their loved ones, potential surrogates will have a better understanding of patients' wishes.^{8,47} So, it is counterintuitive that family members engaging in ACP side-by-side with patients would not have higher concordance scores. Though other researchers have looked at patient-surrogate concordance in the context of advance care planning, this is the first large study to evaluate the impact of a decision aid on such concordance, and no prior studies compare ACP performed together versus alone.^{48–51} Possible explanations for our negative findings include that: 1) study participation –regardless of study arm-- itself prompted discussions that informed family members about patients' wishes; 2) family members did not consider patients' wishes when making hypothetical treatment decisions; and 3) people enrolling in this study, by definition, identified family members who they trusted to represent them, leaving less opportunity for improving concordance. Our study was not designed to assess such possibilities, but future research might examine this.

The study also raises broader questions about the overall value of targeting potential surrogates with ACP interventions. MYWK was scrupulously designed to follow evidence-based guidelines for decision aids,⁵² and prior research has shown that it improves both patients' knowledge about ACP as well as healthcare providers' understanding of patients' wishes.⁴⁰ Yet, when used with family members, the increase in concordance was less than anticipated. Why? It is, of course, possible that the intervention isn't beneficial; but multiple studies suggest otherwise, including data on accuracy,^{20,30} knowledge,^{19,53} and concordance^{20,40} – which leads us to ponder other explanations. Perhaps the measures were inappropriate. Or, maybe family members require a different type of intervention than patients and healthcare providers. More radically, one might ask whether ACP interventions should target potential surrogates at all. We don't yet know which, if any, of these explanations account for our findings, thus additional research should address the surprising results that emerged from this large, systematic study of over 250 patients with severe, life-threatening illness and their named potential surrogates.

Limitations

Enrollment was challenging due to the inherent difficulty of recruiting severely ill patients and their family members into a non-therapeutic study on an uncomfortable topic, raising the possibility of selection bias. That said, the randomized controlled design helps mitigate bias, our enrollment rate is similar to other published studies on ACP,⁵⁴ and there were no differences between participants and decliners in terms of age, gender, or prior experience helping others complete ADs. Second, most non-participants did not complete decliner surveys, and among those who did, decliners had lower education and less confidence in their computer skills than participants. Further, participants tended to be well-educated and had prior experience with ACP. Taken together, the study may have a selection bias that limits generalizability. Third, the surprisingly high baseline self-efficacy scores left little room for improvement, and are contrary to prior research.³⁸ Had participants expressed lower baseline self-efficacy, the interventions may have shown a greater effect. Fourth, the concordance was based on a single post-intervention measure (rather than pre-post

comparison), hence we cannot rule out an imbalance between study groups with regard to concordance. The rationale for this approach was that introducing the vignettes prior to the intervention risked introducing bias insofar as the vignettes themselves could constitute an ACP intervention. Finally, concordance scores were higher than in prior research, which may be attributable to the large proportion of patients and family members who reported previous experience with ACP and surrogate decision-making.

Conclusions

The present findings raise foundational questions about how best to prepare family members for their role as surrogate decision-makers. While a comprehensive decision aid did improve family members' knowledge of patients' wishes, there was no correlation between such knowledge and confidence, nor did having family members engage in ACP together with patients have any discernable effect. We cannot assume that interventions shown to be effective for patients and clinicians are likewise effective for potential surrogate decision-makers.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1.
Study Design and Consort Flow Chart

Treatment Key	
MV	Mechanical ventilator
FT	Feeding tube
CPR	Cardiopulmonary resuscitation
HD	Hemodialysis
IV Abx	Intravenous antibiotics
Surg	Surgery
Vignette Summary	
A	Hemorrhagic stroke leading to chronic physical and mental impairments
B	Massive MI and you cannot breath right now
C	Fall down stairs, spinal cord injury, and quadriplegic with permanent vent
D	Car accident w/ internal bleeding and head injury, long term mental problems, total loss of independence
E	Bronchitis with unknown cause, may resolve with antibiotics or vent in 7-10 but could need longer vent/surgery
F	Scratch on arm leads to MRSA and hospitalization, sepsis, possible multiple organ failure

Figure 2.
Concordance Comparison by Vignette

Table 1**Study Participant Demographics**

Characteristics	Patients (n=267)	Family Members (n=267)	Overall (n= 534)
Gender, female N (%)	122 (45.7)	201 (75.3)	323 (60.5)
Age, mean $\pm$ SD, years	63.8 $\pm$ 13.4	55.9 $\pm$ 13.9	59.9 $\pm$ 14.2
Race/Ethnicity (%)			
Hispanic	11 (4.3)	12 (4.6)	23 (4.5)
Black	50 (19.7)	44 (17.0)	94 (18.3)
White	183 (72.1)	195 (75.3)	378 (73.7)
Other	10 (3.9)	8 (3.1)	18 (3.5)
Patient Disease Category (%)			
Cardiac	72 (27.0)		
Pulmonary	61 (22.9)		
Cancer	83 (31.1)		
Renal	51 (19.1)		
Education (%)			
<8th grade	7 (2.6)	2 (0.8)	9 (1.7)
Some HS	16 (6.0)	8 (3.0)	24 (4.5)
HS or GED	78 (29.3)	65 (24.3)	143 (26.8)
Some College or tech	83 (31.2)	86 (32.2)	169 (31.7)
College Grad	42 (15.8)	63 (23.6)	105 (19.7)
Graduate School	40 (15.0)	43 (16.1)	83 (15.6)
Marital Status (%)			
Never married	31 (11.7)	38 (14.3)	69 (13.0)
Married	166 (62.6)	184 (69.2)	350 (65.9)
Divorced/separated	31 (11.7)	22 (8.3)	53 (10.0)
Widowed	27 (10.2)	10 (3.8)	37 (7.0)
Domestic Partnership	6 (2.3)	9 (3.4)	15 (2.8)
Other	4 (1.5)	3 (1.1)	7 (1.3)
Prior experience with ACP (%) [*]			
Almost none	26 (9.8)	34 (12.7)	60 (11.3)
A little	98 (36.8)	97 (36.3)	195 (36.6)
A fair amount	96 (36.1)	95 (35.6)	191 (35.8)
A lot	46 (17.3)	41 (15.4)	87 (16.3)
Already have an AD [†]	121 (45.8)	80 (30.0)	201 (37.9)
Assigned a Proxy	152 (58.0)	102 (38.5)	254 (48.2)
Helped someone else prepare AD	55 (20.8)	80 (30.3)	135 (25.6)
Helped a family member with medical decision making		186 (69.9)	
Prior ACP conversations			

Characteristics	Patients (n=267)	Family Members (n=267)	Overall (n= 534)
“The patient is my...”			
Spouse/partner		152 (56.9)	
Parent		64 (24.0)	
Sibling		9 (3.4)	
Son/Daughter		11 (4.1)	
Other		31 (11.6)	
Lives with patient		182 (68.4)	
Own a computer (%)		194 (73.8)	222 (83.2)
Hours/week using computer, median (Q1, Q3)	6.0 (1.0, 15.0)	10.0 (3.5, 30.0)	8.0 (2.0, 20.0)

* “How much have you read or heard about advance care planning or living wills (i.e. documents that formally communicate your wishes regarding health care)?”

[†] “Prior to enrollment in this study, had you prepared an advance directive/living will for yourself?”

Table 2

Self-Efficacy and Concordance

Self-Efficacy (pre to post change by group)							
Group	N	Pre-Intervention	Post-Intervention	Raw Mean Change	Adjusted Mean Change *	P-value (within) *	P-value (between) *
Basic ACP	135	90.1 (88.3, 91.8)	93.3 (92.2, 94.4)	3.2 (1.7, 4.7)	3.2 (1.0, 5.3)	0.004	0.054
MYWK	132	90.2 (88.5, 91.9)	92.1 (90.6, 93.7)	2.0 (0.9, 3.1)	1.7 (−0.5, 3.9)	0.134	
Alone	126	90.2 (88.3, 92.1)	92.6 (81.4, 93.9)	2.5 (1.0, 4.0)	2.3 (0.2, 4.5)	0.033	0.823
Together	141	90.1 (88.6, 91.6)	92.8 (91.4, 94.2)	2.7 (1.5, 3.9)	2.5 (0.3, 4.7)	0.026	
Concordance (percentage of questions where patients and family members agree)							
Group	N	Raw (% agreement)	Adjusted (% agreement) *	P-Value (between) *			
Basic ACP	135	70.8 (67.3, 74.3)	79.7 (72.7, 86.8)	0.032			
MYWK	132	76.1 (72.8, 79.4)	85.2 (77.9, 92.4)				
Alone	126	72.3 (68.7, 75.8)	80.6 (73.5, 87.7)	0.149			
Together	141	74.4 (71.1, 77.8)	84.3 (77.0, 91.5)				

* Two-way ANOVA adjusted for the pre-measurement and confounders: prior completion of advance directive, disease, study site, race/ethnicity