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Development of Personalized Health Messages to Promote Engagement in Advance Care Planning

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Abstract

Background/Objectives—Public health models of behavior change have served as the basis for intervention across a wide range of behaviors. The purpose of this study was to develop and test the acceptability of personalized intervention materials to promote advance care planning (ACP) based on the Transtheoretical Model (TTM), in which readiness to change is one key organizing construct.

Design—Development study creating an expert system delivering TTM-personalized feedback reports and stage-matched brochures with more general information on ACP, with modifications based on participant reviews.

Setting—Senior centers

Participants—A total of 77 community-living persons age 65 years and older.

Measurements—Participant ratings of length, attractiveness, trustworthiness, and reactions to reports and brochures.

Results—The expert system assessed participants' readiness to engage in each of 4 ACP behaviors: completion of a living will, naming a health care proxy, communication with loved ones about quality versus quantity of life, and communication with clinicians about quality versus quantity of life. The system also assessed pros and cons of engagement, and values/beliefs that

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influence engagement. The system provided individualized feedback based on the assessment, with brochures providing additional general information. Initial participant review indicating unacceptable length led to revision of feedback reports from full-sentence paragraph format to bulleted format. After review, the majority of participants rated the materials as easy to read, trustworthy, providing new information, making them more comfortable reading about ACP, and increasing interest in participating in ACP.

Conclusion—An expert system individualized feedback report and accompanying brochure to promote ACP engagement was highly acceptable and engaging to older persons. Additional research is necessary to examine the effects of these materials on actual behavior change.

Keywords

advance care planning; health behavior; intervention development

INTRODUCTION

Advance care planning (ACP), the process by which individuals prepare for times of decisional incapacity has been cited by patients and their surrogates in several surveys as an essential component of high-quality end-of-life care.[1–3] While ACP traditionally consisted of the completion of advance directives, contemporary approaches to ACP include components focused on facilitating communication between patients and their surrogates and with clinicians regarding patients' goals of care. Rather than having patients make treatment decisions ahead of an event, ACP may be most effective if it prepares patients and/or surrogates to be able to make decisions in real time. This can be accomplished by having a clearly identified surrogate and a shared understanding between patient and surrogate of the patients' values over time and of the surrogate's role.[4]

Regardless of how it is conceptualized, ACP is underutilized by patients and their surrogates.[5,6] Several recent randomized controlled trials have demonstrated that patient and surrogate engagement in ACP can be increased through the use of interviews facilitated by a trained moderator.[7,8] This approach to intervention is most appropriate for patients who have advanced illness, for whom the trajectory of illness can be anticipated, and who are perhaps most prepared to participate in specific ACP discussions about the health care scenarios the patient is most likely to face. The recent Institute of Medicine report, "Dying in America: Improving Quality and Honoring Individual Preferences near the End of Life" endorses an approach to ACP that begins earlier, when the individual is relatively healthy.[9] At this stage, the most relevant focus of interventions is on helping individuals to understand the importance and salience of engaging in ACP, to overcome barriers to engagement, to reinforce the positive consequences of engagement, and to provide guidance on the small, manageable next steps to proceed down the path of engagement. Because at this point in an individual's life the consideration of goals is necessarily general, this process can be done without clinical input, using a public health approach to reach a broader population of patients, including those who do not have access to a moderator or who are not ready to engage in an in-depth discussion. Engaging individuals early can help make them better prepared to participate in more intensive, clinician- or facilitator-based ACP.

The Transtheoretical Model (TTM) of behavior change provides a framework for assessing individuals' readiness to participate in ACP and for delivering feedback individualized to their readiness and their attitudes. Meta-analysis and individual studies have demonstrated the clinically significant effects of TTM-based interventions on smoking cessation, physical activity, eating a healthy diet, receiving regular mammography screening,[10] adherence to medication,[11] and reduction in multiple risk behaviors.[12,13]

The applicability of the TTM to ACP has been demonstrated in earlier studies, which have shown variability in individuals' stages of change, or readiness to engage in the different components of ACP,[14,15] and the ability to measure the attitudes and behaviors that influence readiness for engagement.[16] The objectives of the current study were: 1) to develop an expert system (a software system consisting of an assessment battery, normative data to make comparisons, decision rules for delivering feedback, and feedback components) to provide individualized, TTM-based feedback, and complementary stage-matched brochures to provide more general ACP information; and 2) to test the acceptability of these materials.

METHODS

Expert system development

The expert system was designed to assess individuals on the key constructs of the TTM and to provide individualized feedback based on that assessment. The first construct assessed was stage of change,[14] or readiness to participate in four key ACP behaviors: completion of a living will, assignment of a health care proxy, communication with loved ones about quality versus quantity of life, communication with clinicians about quality versus quantity of life. Asking about communication regarding quality versus quantity of life is an overly simplified characterization of the task of values clarification that individuals ideally undertake in the process of ACP. This process includes a consideration of values as they relate to the acceptability of diminishing states of health, the trade-offs between the benefits and burdens of interventions, and attitudes regarding uncertainty and the likelihood of different health outcomes. However, individuals early in the process of ACP engagement may not be familiar with these concepts,[17] so that the process was described in a manner most likely to be understood by diverse groups of older persons. The stages of change are Precontemplation, in which people are not ready to take action; Contemplation, in which people are intending to take action in the next six months; Preparation, in which people are intending to take action in the next month; and Action, in which people have engaged in the behavior. The second construct was decisional balance,[16] reflecting the person's weighing of the pros and cons (facilitators and barriers) of ACP. The third construct was ACP values/beliefs,[16] consisting of medical misconceptions and religious beliefs that can serve as barriers to engagement. These include the belief that ACP is unnecessary because the future is in God's hands and that ACP is unnecessary when one is old because physicians will not provide highly aggressive care.

Feedback paragraphs were developed for each stage of change for each of the four ACP behaviors as well as for decisional balance. These paragraphs serve as the building block for the personalized feedback reports, which pulled in the appropriate paragraphs corresponding

to an individual's responses to the stage of change and decisional balance assessments into a templated document. Individuals therefore received feedback specific to their stage of change for each of the four behaviors. For individuals in early stages of change for a given behavior, the feedback focused on changing attitudes, a necessary prerequisite for changing behavior, by addressing common barriers and by reminding individuals they could engage in small steps. For individuals in later stages of change, the feedback provided specific actions they could perform. In addition, if the participant had engaged in one ACP behavior but not another, the feedback provided information on how they could utilize what they had already accomplished in order to help them participate in any remaining ACP activities.

Feedback paragraphs were developed for the decisional balance scale. Cutoff scores for each stage were developed based on previous data.[16] Participants with a pros score below the cutoff received feedback suggesting additional pros they may not have realized. Participants with a pros score above the cutoff, received feedback reinforcing the pros of ACP participant. Participants with a high cons score received feedback providing general strategies for overcoming the most common barriers to ACP, and participants with a low cons score received feedback reinforcing the advantages of overcoming barriers. Feedback was also developed for each individual item on the values/beliefs scale, with participants receiving feedback for up to three items they endorsed. The content for the items included in the assessment scales and for the feedback paragraphs were based on an extensive literature review augmented by the results of focus groups conducted among over 100 older persons and their caregivers,[17] and psychometric testing performed in a cohort of 304 persons age 65 years and older.[16]

A general introduction was written to provide a common opening for the feedback report, which briefly described ACP. In addition, because a reluctance to think about death and dying is a universal phenomenon, the introduction gave a brief description of why ACP is necessary and why individuals should engage in ACP even when it seems too difficult to plan for declines in health and dying.

Stage-matched brochure development

Two brochures were developed. The first was intended for individuals who were the least ready to engage in ACP. This brochure was kept brief and focused on descriptions of strategies to overcome attitudinal barriers to engagement in ACP and the positive consequences of engagement. The brochure also included two stories, adapted from prior qualitative research.[17] One illustrated the benefits to a spouse and children of her husband's engagement in ACP, and the second described the regrets of a daughter whose mother did not engage in ACP. The second brochure was written for individuals who were ready to engage in one or more ACP activities, and provided strategies for participating in each activity. This brochure, for example, provided "words to use" to approach a health care proxy, and questions for individuals and their surrogates to discuss regarding goals of care. In addition, a quadrifold pamphlet was developed for the individual to give to his/her (potential) surrogate. This pamphlet, written from the perspective of the individual, explained to the surrogate how he/she can help the individual engage in ACP. The layout for the brochures and pamphlet was done by a graphic designer. All materials were written at

about an 8th grade reading level. Both the feedback reports and brochures are presented in large font but were reduced in size for presentation in the Appendix.

The detailed information in the later sections of the feedback reports and in the brochures goes beyond the simplified concepts utilized in the assessments and the opening paragraphs of the feedback reports. Whereas the simplified versions were written to serve as an introduction for those in the earliest stages of behavior change, the subsequent feedback is designed to provide more comprehensive information. For example, the feedback report introduces the process of ACP as "[deciding] how you feel about things like the use of machines to prolong life." While this is not consistent with the ultimate goal of preparing patients and surrogates to make high-quality "in-the-moment" decisions rather than pre-specifying their preferences,[4] it ensures that individuals who are not familiar with the term ACP obtain an immediate sense of what the feedback report is addressing. Later parts of the report refer individuals to pages in the brochure that explain the process of values clarification in greater detail, providing them with questions to ask themselves and discuss with their loved ones, such as, "Have you ever seen someone in your family, among your friends, or on TV who you think had a 'good' or 'bad' death? Why was it good or bad? Does it make you think about things you would like to see happen for you?"

Expert input

The content and wording of the feedback report and brochures were informed by input from members of the Yale Center for Clinical Investigation's cultural ambassadors, who act as resources to Yale medical researchers, providing expert advice on how to engage the community in research. The research team asked six church leaders within the AME Zion Church to discuss religious objections that have been raised to ACP and how to respond sensitively and effectively to these objections.[17–19] They were also asked to comment on the language used to talk about ACP. This discussion led to the language used to address the religious items in the Values/Beliefs scale and to the characterization of ACP on the title pages of the brochure as "Putting Your Healthcare House in Order." The focus on the AME Zion church was based on the well-characterized role of religion in influencing the treatment preferences and attitudes toward ACP among African-Americans,[20] the majority of whom belong to historically black Protestant denominations.[21]

Participants and pilot-testing

The feedback reports and brochures were pilot-tested with participants who were community-living persons age 65 years and older recruited from three senior centers selected to provide access to a diverse population. Participants, who volunteered after a brief presentation at each of the centers, completed the assessment at the senior center using a web-based interface. The assessment questions were administered by a research assistant to avoid the exclusion of persons with visual impairments. At the end of the assessment, the expert system printed the feedback report. Participants were instructed to read through the report, ask questions about any sections that were not clear, and provide comments to the research assistant regarding readability, acceptability, and any other issues they wished to speak about. They then completed a set of closed-ended questions asking them to rate different aspects of the report. When participants provided an unfavorable rating, they were

asked to give suggestions for improvement. Participants were also provided copies of the brochures and participated in a similar process of providing feedback. At the research assistant's discretion, she could limit the participant to providing feedback for just the report or just the brochures, if the participant appeared to become fatigued or overwhelmed with the material. Participants were asked about sociodemographic and health characteristics, including: age; gender; race/ethnicity; education; living arrangement; marital status; sufficiency of monthly income;[22] health literacy, assessed using REALM-SF;[23] self-rated health; and physical function, assessed using the modified Rosow-Breslau scale, which asks about the ability to perform four activities without help and which is scored on a scale of 0–4, with 1 point assigned to each activity that can be performed.[24] The protocol was approved by the Yale School of Medicine Human Investigations Committee.

RESULTS

Participants

Table 1 provides a description of the 77 participants. The majority of participants were female, approximately one-half were white, one-third had a health literacy level of < 9th grade, and one-quarter could perform only two of four physical performance tasks. While over one-half reported having discussed quality versus quantity of life with loved ones, less than one-third had named a health care proxy.

Evaluation and modifications of feedback report and brochures

The first set of feedback reports presented text in full sentences and paragraphs. The initial round of evaluation revealed that participants felt the reports were too long (Table 2). In response, the text was condensed into bullet format. An example of a report for a person who is in Precontemplation (not ready to participate in) completion of a living will, health care proxy, or communication with the physician but in Action (has participated in) communication with a loved one about quality versus quantity of life is presented in the Appendix. After revision, only a small minority of participants felt that the report was too long. In addition, this editing resulted in a larger proportion of participants reporting that they had learned new information and that they had increased interest in ACP. Nearly all participants agreed that the information was trustworthy and useful, and large proportions agreed that the report promoted comfort thinking about ACP and that they were more likely to do ACP.

Brochures underwent revisions based on the specific comments of the participants. Adjustments in the layout were made to enhance the readability of the text, and language was added to stress the importance of communication among all family members. Several screenshots from the brochures are provided in the Appendix. Participants provided highly favorable evaluations of the brochures, with large proportions (93–98%) agreeing that the brochures were easy to read, provided useful information and new things to think about, and promoted their comfort when thinking about and increased interest in ACP. A small proportion of participants agreed with the statement that the feedback report and/or brochure was anxiety-provoking.

CONCLUSION

This report describes the development of an expert system that delivers an individualized feedback report based on assessment of readiness to engage in ACP and the attitudes, values, and beliefs that can either promote or deter engagement. It also describes the development of two brochures providing additional information regarding ACP, one designed for individuals who are early in the process of preparing for engagement that focuses on attitude change, and one designed for individuals who are further along that focuses on discrete steps; and a pamphlet to help surrogates understand their role. Preliminary evaluation of the materials demonstrated their acceptability to a small but diverse cohort of older persons, with the majority indicating the materials contained useful, trustworthy information and increased comfort with and interest in ACP engagement.

The messages in the feedback report and brochures were individualized and targeted based on the TTM. A sizeable number of studies have illustrated the applicability of the TTM to ACP, demonstrating the variability in individuals' readiness to engage in different aspects of ACP,[14] the process by which individuals move through stages of change,[15] and the expected relationships among the TTM constructs, such as a decrease in the cons and an increase in the pros as individuals progress to later stages of readiness.[16,25,26] The TTM has also been proposed as a useful framework for clinicians to use for ACP discussions.[27,28] The materials developed in the current study were designed to reach beyond patients who are ready and willing to engage in structured ACP discussions. Because TTM interventions are specifically designed to engage participants at all levels of readiness, these interventions are generally characterized by higher participation rates than behavioral studies with non-individualized interventions, which may have large numbers of individuals refusing participation because they are not ready to engage in the process of behavior change.[29] In one trial of a structured interview to promote ACP, the rate of refusal among eligible patients was 52%, and an additional 7% of surrogates refused even when the patient consented to participation.[7] Even if the effect size (efficacy) of a TTM-based intervention is modest, it can achieve higher population impact through increased reach, defined as the efficacy of the intervention times its participation rate.[30] In addition to being guided by the TTM, the materials included the use of stories and specifically persuasive narratives, which are stories that contains a message, but deliver that message in a compelling context. It has been suggested that these stories may be particularly effective for those in the earliest stages of behavior change.[31]

While the materials presented in this study have strong theoretical underpinnings and were viewed favorably by an initial cohort of older persons, further evaluation in the form of a randomized controlled trial will be necessary to determine their effectiveness in promoting engagement in ACP. One limitation of the current study was the use of volunteers to review the materials. In the absence of a defined population, we cannot know how well the materials will do in reaching individuals in the earliest stages of behavior change, since only 5% of participants were in Precontemplation for all four behaviors. Additional limitations include the relatively high educational and health literacy levels of the study cohort and some missing data for individual items assessing the acceptability of the materials. We included religious experts from only a single denomination, which does not represent the

full spectrum of churches attended by African-Americans. Moreover, other religions, particularly fundamentalist ones, may influence attitudes toward ACP.[32] This limits the generalizability of the feedback on religious barriers, leaving additional work to be done to address a broader range of beliefs affecting participation in ACP. In addition, mistrust in the healthcare system is a second important factor helping to explain lower rates of participation among African Americans,[33] and our work with the religious leaders did not address this barrier. The intervention focuses on only a subset of the multiple cultural, educational, experiential, and personal factors that shape an individual's decision to engage in ACP.

In conclusion, this study demonstrates the acceptability of TTM-based intervention materials designed to promote engagement in ACP and to be suitable for use with diverse populations of older persons. Additional research will be necessary to assess the ability of these materials to help individuals move along the stages of behavior change necessary to participate in the full range of activities necessary for successful advance care planning.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Sociodemographic and health characteristics of the 77 participants and their readiness to engage in ACP

Characteristic	N (%)
Female gender	68 (88)
Age	
65–74	37 (48)
75–84	33 (43)
85+	7 (9)
Latino	2 (3)
Race	
White	38 (49)
Black	33 (43)
Other	6 (8)
Education ≤ 12 years	42 (54)
Health literacy	
< 7th grade	8 (10)
7th–8th grade	18 (23)
> 9th grade	51 (66)
Just enough/not enough money at the end of the month	47 (61)
Lives alone	50 (65)
Marital status	
Married	13 (17)
Widowed	38 (49)
Other	
Self-rated health	
Excellent	11 (14)
Very Good	31 (40)
Good	30 (39)
Fair/poor	5 (7)
Modified Rosow-Breslau scale (1 point for each of 4 functional activities that can be performed without help)	
4	28 (36)
3	30 (39)
≤2	19 (25)
Stage of change for completion of living will	
Precontemplation	14 (18)
Contemplation	36 (47)
Action	27 (35)
Stage of change for naming a health care proxy	
Precontemplation	14 (18)
Contemplation	40 (52)
Action	23 (30)
Stage of change for discussing quality of life with loved ones	45 (58)

Characteristic	N (%)
Precontemplation	19 (25)
Contemplation	13 (17)
Action	45 (59)
Stage of change for discussing quality of life with physician	
Precontemplation	47 (61)
Contemplation	17 (22)
Preparation	3 (4)
Action	10 (13)
Materials reviewed	
Feedback report only	5 (6)
Brochures only	4 (5)
Feedback report and brochures	68 (88)

Table 2

Participants responding agree/strongly agree to different aspects of individualized feedback report and brochures

Feedback reports		
Item	**Prior to major editing (n=13)**	**After major editing (n=60)**
	n (%)*	**n (%)***
Easy to read	12 (92)	57/58 (98)*
Too long	8 (62)	14 (23)
Too short	0	0
Trustworthy information	13 (100)	57 (95)
Useful information	13 (100)	58/59 (98)
New information learned	7 (54)	50 (84)
New things to think about	13 (100)	50/57 (88)
Anxiety-provoking	1 (8)	3 (5)
More comfortable thinking about ACP	12 (92)	54 (90)
Increased interest in ACP	9 (69)	56 (93)
Would recommend handout to a friend	12 (100)	54/57 (95)
More likely to do ACP after reading handout	**	56 (93)
Brochures		
Item		n (%)*
Easy to read		70 (96)
Pictures make it more attractive		61/70 (87)
Too long		6/71 (8)
Too short		0
Trustworthy information		71/71 (100)
Useful information		71 (98)
Learned new information		56/71 (79)
New things to think about		65/71 (93)
Anxiety provoking		3/70 (4)
More comfortable thinking about ACP		68 (94)
Increased interest in ACP		67/71 (94)
Would recommend to a friend		70/71 (98)
Easy to find applicable sections		65/67 (94)

* Denominator provided when data is missing to indicate number of participants responding to item.

** Question added after editing of report