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Use of a Computer Program for Advance Care Planning with African American Participants

Sarah A. Markham, M.D.,
Department of Humanities, The Pennsylvania State University, College of Medicine

Benjamin H. Levi, M.D., Ph.D.,
Department of Humanities, The Pennsylvania State University, College of Medicine

Michael J. Green, M.D.,
Department of Humanities, The Pennsylvania State University, College of Medicine

Jane R. Schubart, Ph.D.
Department of Humanities, The Pennsylvania State University, College of Medicine

Abstract

Background: For various cultural and historical reasons, African Americans are less likely than Caucasians to engage in advance care planning (ACP) for healthcare decisions.

Purpose: This pilot study tested whether an interactive computer program could help overcome barriers to effective ACP among African Americans.

Methods: African American adults were recruited from traditionally Black churches to complete an interactive computer program on ACP, pre-/post-questionnaires, and a follow-up phone interview.

Results: Eighteen adults (mean age =53.2 years, 83% female) completed the program without any problems. Knowledge about ACP significantly increased following the computer intervention (44.9% → 61.3%, p=0.0004), as did individuals' sense of self-determination. Participants were highly satisfied with the ACP process (9.4; 1 = not at all satisfied, 10 = extremely satisfied), and reported that the computer-generated advance directive accurately reflected their wishes (6.4; 1 = not at all accurate, 7 = extremely accurate). Follow-up phone interviews found that >80% of participants reported having shared their advance directives with family members and spokespeople.

Conclusion: Preliminary evidence suggests that an interactive computer program can help African Americans engage in effective advance care planning, including creating an accurate advance directive document that will be shared with loved ones.

Correspondence: Jane R. Schubart, Ph.D., Department of Surgery, 500 University Drive, CH69, Hershey, PA 17033, Tel: (717) 531-1262, Fax: (717) 531-0480, jschubart@hmc.psu.edu.

Financial disclosure: Two of the authors (BHL & MJG) have intellectual property and copyright interests for the decision aid used for this study, Making YourWishes Known: Planning YourMedical Future (MYWK). To encourage individuals to reflectively and systematically engage in advance care planning regarding end-of-life medical decisions, it is anticipated that MYWK will be made available free of charge for use by the general public, as well as for education purposes. However, users who wish to archive, revise, and electronically transmit advance directive documents will be charged a modest fee.

Keywords

advance care planning; advance directive; computer program; decision support

INTRODUCTION

Public awareness of the need to plan in advance for end-of-life healthcare issues is, increasing, spurred by an aging population and the burdens of overly aggressive medical inerventions.[1,2] Originally devised to help individuals refuse undesired life-prolonging medical treatments in the event they could not speak for themselves, more generally, advance directives provide a mechanism for promoting and respecting patients' self-determination.[2–8] But their goals have not been fully realized.[2,9–11] Only 20–30% of adults complete such documents,[12] and among African Americans, the percentage is even lower.[2–3,11] Studies have shown that, despite concerns about being over-treated at the end of life,[13] as well as being significantly more likely to have earlier encounters with life-threatening illnesses,[14–17] African Americans are less than half as likely as Whites to know about or have an advance directive.[18–22]

There are many possible explanations for this disparity, including religious and cultural attitudes regarding death and dying,[15–17,19–21] concerns about being denied needed treatment at the end of life,[14–17] and a family-oriented approach to decision-making.[14–17] Studies show that the propensity to believe that God decides when a person will die correlates with African Americans' greater desire for (and receipt of) life-prolonging treatments.[15,17,23] Other research reveals that, despite concern that life-prolonging treatments will not be fully covered by insurance companies, it is more common among African Americans to believe that requesting treatments will enhance the quality of their care.[17] Moreover, historical experiences with racism and discrimination fuels distrust in healthcare initiatives that might result in medical care being denied when it is most needed.[14–17]

These barriers speak to the need for novel interventions that can be used by African Americans to help them engage in advance care planning. We have previously described a computer-based decision aid for advance care planning that is well-accepted, accurate and effective for individuals with diverse illnesses and health statuses.[24–27] What has not been reported is whether this program can be helpful for African Americans who tend to be more hesitant than Whites to engage in advance care planning. This paper provides results from a pilot study exploring the use and acceptability of this computer program among a group of African American adults.

METHODS

Intervention:

Making Your Wishes Known: Planning Your Medical Future (*MYWK*) is a computer-based decision aid that uses audio-visual materials and plain language to unravel complex issues regarding life-or-death medical decisions.[28] This program encourages users to reflect on various clinical scenarios and potential outcomes to help them reach informed decisions about treatment preferences. Additionally, it helps users 1) articulate their general goals and values, including what "poor quality of life" means to them; 2) appoint surrogate decision makers, and specify whether the surrogate's judgment or the written advance directive should prevail if the two conflict; 3) exclude particular individuals from participating in treatment decisions; and 4) produce a printable advance directive that documents an individual's values and wishes in both broad and specific terms.

By taking a supportive and systematic approach to advance care planning, *MYWK* aims to make complex decisions less intimidating, and help individuals not only appreciate issues they may not have previously considered, but also see value in discussing these matters with others.

Procedures:

With assistance from the Community Research Outreach program at Penn State Hershey Medical Center (PSHMC), contact was made with five predominantly African American churches in Central Pennsylvania. Two pastors (both of whom ministered to inner-city, working class communities) expressed a willingness to distribute fliers that described the research study to their congregants and requested/collected contact information from interested individuals ≥ 30 years of age. Following approval from the PSHMC Human Subjects Protection Office, fliers were distributed and an initial phone call was made. Eligible individuals were invited to attend an in-person session at which informed consent was elicited and screening conducted to assure that participants had the ability to read at the 8th grade level (≥ 26 on WRAT-3),[29] were cognitively able to use the program (≥ 25 on Mini-Mental State Examination),[30] and did not have moderate/severe depression (≤ 19 on Beck Depression Inventory-II).[31] Study participants then completed a demographic questionnaire and pre-intervention instruments (ACP Knowledge;[25] Self-Determination;[32] Hopefulness;[33–34] hopelessness[35–37]). Next, all participants were provided with secure laptops and headphones, and used the MYWK computer program in a private area. A research assistant was available to provide technical assistance, but refrained from providing any substantive guidance regarding how questions should be answered. Upon completion of the program, post-intervention instruments were administered (repeat of pre-intervention measures plus Decisional Conflict;[38] Satisfaction with Decision;[39] Satisfaction with ACP; Accuracy of Advance Directive; Time and Effort), and then participants were given both paper and electronic copies of their advance directives, along with a gift certificate to thank them for their time. Finally, several weeks after the study visit, participants were contacted by phone for a brief, follow-up interview, asking if they had made any changes to their advance directive (and if so, why) or had shared or discussed their advance directive with anyone.

STATISTICAL ANALYSIS

As a pilot study, this investigation was not powered to detect statistically significant differences among measured outcomes, but rather was designed to examine whether a computer program might be useful for helping overcome barriers to advance care planning for African Americans. Nevertheless, to see if any statistically significant trends emerged, we calculated descriptive statistics of all measures, with means and standard errors provided for continuous variables, frequency distributions for categorical variables, and *t*-test results for pre-/post-intervention measures.

RESULTS

Demographics

Of the 41 people who expressed interest in the study, 18 completed the protocol (83% female, mean age = 53.2 years). Reasons for non-participation included: 11 could not be reached, 4 declined participation, 5 did not meet eligibility requirements, and 3 no-showed for their study visit. Approximately one-third of participants reported having read or heard “a lot” (5%) or “a fair amount” (28%) about advance care planning or living wills, while 67% reported having read or heard “a little” (50%) or “almost nothing” (17%). Only 2 participants already had some form of advance directive, and none had formally assigned someone to be their spokesperson. All but one participant reported owning a computer, with an average usage of 20 hours per week (range = 0–60 hours) (see Table 1).

Outcomes

Knowledge about advance care planning significantly increased following the computer intervention (mean percent correct responses = 44.9% → 61.3%, p = 0.0004), with modest increases in individuals’ sense of self-determination (35.8 → 37.1, p = 0.04), and no decrease in participants’ level of hope. In addition, participants reported low levels of decisional conflict regarding having to make choices about life-or-death medical treatments (mean=30.5; 16=very low, 80=very high), and high satisfaction with the decisions they made (mean = 10.0; 6 = not satisfied, 30 = very satisfied). Participants spent on average 60–90 minutes completing the computer program, reported that the study protocol involved little to no burden (mean = 1.3; 1 = no burden, 4 = extreme burden), and were highly satisfied with the advance care planning process (mean = 9.4; 1 = not at all satisfied, 10 = extremely satisfied). Additionally, participants reported that the computer program helped them clarify their healthcare wishes (88% of participants); prepared them to discuss their wishes with their physician (94%) and family members (100%); and generated an advance directive that accurately reflected their wishes (mean = 6.4; 1 = not at all accurate, 7 = extremely accurate) and with which they were highly satisfied (mean = 9.2; 1 = not at all, 10 = extremely) (see Table 2).

In follow-up phone interviews with 17 of the 18 participants (mean = 13.5 weeks post-study visit) most reported having shared their advance directives with family members (88%) and spokespersons (82%), but only one individual had shared her advance directive with a healthcare provider. No participant reported having changed their spokesperson, and only one individual reported changing her treatment wishes. Specifically, this one participant stated that after her spokesperson (her mother) expressed discomfort with several of her end-of-life wishes, she now wished to have her mother’s judgment supersede the preferences documented in her advance directive in the event of a conflict (though she had not yet updated her advance directive to reflect these changes).

During the phone interview, many participants expressed appreciation for the opportunity to work through the computer program. Representative remarks include that the computer program helped her put things into perspective; that while end-of-life issues were not something one ever wanted to think about, it was comforting to have an advance directive ready in the event that she could not make her own medical decisions; and that it was a relief to know that her family would not have to fight over what interventions she would want.

DISCUSSION

This pilot study provides evidence that an interactive computer program is well accepted and can be an effective tool for advance care planning (ACP) among African Americans. If our results are generalizable, then *Making Your Wishes Known: Planning Your Medical Future* (*MYWK*) has the potential to overcome some important barriers to ACP among African Americans. Participants' high satisfaction with how *MYWK* guided them through the process of ACP is particularly promising in light of concerns by some that ACP is a mechanism for racially biased denial of medical care.[14, 17]

It is also encouraging that individuals who completed *MYWK* showed significant increases in knowledge about ACP—including knowledge about healthcare powers of attorney, advance directive documents, and common end-of-life medical conditions and treatments. Relatedly, participants reported feeling more informed and more empowered regarding potential end-of-life medical decisions, with no concomitant decrease in hope. Consistent with national data,[2,13–15,17–23] three-quarters of the African Americans in this study reported knowing "almost nothing" or "a little" about ACP prior to completing *MYWK,* and only two participants (11%) had previously created an advance directive. It is known that low completion rates (across multiple populations) are partly due to the challenge of working through the many issues that must be addressed. As such, one of the strengths of *MYWK* is its ability to deconstruct complex decisions and help individuals systematically consider the pros, cons, and nuances involved in ACP—evidenced in this study by 94% of participants reporting that they felt they had made the best decisions possible and were very satisfied with them.

Because it can also be quite challenging to translate one's values and goals into treatment decisions, it is reassuring that participants indicated that both the preliminary and edited versions of the advance directive generated by *MYWK* were accurate in reflecting their end-of-life wishes, (5.7 and 6.4, respectively; 1 = not at all accurate, 7 = very accurate; see Table 3). This assessment may be related to the computer-generated advance directive articulating not only specific wishes, but also general treatment goals and conditions that participants identified as detracting from their "quality of life." If so, it also would help explain why participants reported very low levels of conflict with the difficult decisions they were asked to make throughout the program.

Taken together, these findings might also help explain why all participants in this study reported feeling prepared to discuss their wishes with family and close friends, and almost all actually had done so. If generalizable, this could be an important finding. This is because we know that 1) individuals (and African Americans in particular) are reluctant to explicitly discuss such issues with family and friends, despite relying on them to serve as surrogate decision makers;[2–4,40–42,] 2) surrogates tend to use their own criteria/priorities to make decisions and consequently predict patient preferences only slightly better than chance;[3,43–45] and 3) in the absence of a broader understanding of a person's values/goals, family and friends find surrogate decision-making both challenging and stressful.[4,46–48] Thus if *MYWK* can prepare and motivate African Americans to engage family and friends in substantive discussions, it could prove a very useful tool for ACP.

Interestingly, despite similar feelings of preparedness to discuss their wishes with their healthcare providers, only one individual reported having had such a conversation. In light of the fact that follow-up information was limited to a single brief telephone interview about 3 months after participants completed their advance directives, it is difficult to draw conclusions about this finding. Among the many possible explanations, participants may have simply lacked the opportunity to interact with a health care provider during this time period. That said, the finding that individuals felt more able to influence medical decisions after using *MYWK* (and were more knowledgeable) suggests that *MYWK* may enable users to take more ownership and responsibility for their own healthcare decisions. If so, discussions about ACP between African Americans and their doctors might be expected to increase over an extended period of time, and perhaps, so too, respecting of individuals' wishes for medical treatment.

Limitations

As with all pilot studies, this study has multiple limitations. First, due to the small number of participants, female predominance, church-based recruitment, single inner-city location, and high levels of education and comfort with computers, the findings may not be broadly generalizable. Second, the absence of a control group limits the ability to gauge the relative effectiveness of the decision aid. Third, because of the recruitment method, volunteers to this project may have been more highly motivated than those who chose not to participate. Fourth, this study did not detail participants' religious/spiritual beliefs or their views about physicians and/or the healthcare system. Nevertheless, as a pilot study the primary aim was to determine the feasibility of using an interactive, computer-based intervention to overcome barriers to effective ACP among African Americans—notably, reluctance to engage in structured ACP or explicitly communicate one's wishes to others—and this was accomplished.

CONCLUSION

Advance care planning (ACP) is an important process in healthcare that is often overlooked and under-utilized, especially among African Americans. Prior efforts have been unsuccessful at promoting effective ACP among African Americans, who demonstrate low completion rates for advance directives and a reluctance to discuss end-of-life treatment wishes with others. This study provides preliminary evidence that an interactive computer program, such as *Making Your Wishes Known: Planning Your Medical Future* (*MYWK*), may be able to overcome several important barriers to effective ACP, and thereby help African Americans make informed decisions about future healthcare, accurately articulate these wishes in a personalized advance directive, and communicate these wishes with family members and other loved ones. To determine the program's actual efficacy for overcoming barriers to ACP among African Americans, future research would need to compare *MYWK* with standard approaches to ACP using a randomized control design with a larger and more representative cohort.

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Table 1.

Participant characteristics

Characteristics	Details				
Age	Mean 53.2 years	SD 11.6 years			
Gender	Female 83%	Male 17%			
Highest level of education	High School or GED 24%	Some college or technical school 41%	Collegegraduate 11%	Graduate or professional school 24%	
Religion	Protestant or other Christian 88%	Other 6%	No formal religion 6%		
Spiritual strength	Not very strong 0%	Somewhat strong 17%	Moderatelystrong0%	Very strong 83%	
Marital status	Never married 22%	Married 39%	Divorced or legally separated 33%		
Employment status	Retired 11%	Employed part-time 6%	Employed full-time 72%	Not currently employed 6%	Other 5%
Pre-knowledge of advance directive	Almost nothing 17%	A little 50%	A fair amount 28%	A lot 5%	
Prior advance directive or living will	Yes 11%	No 89%			
Prior formal assignment of spokesperson	Yes 0%	No 100%			
Own a computer?	Yes 94%	No 6%			
Weekly computer use	Mean 20.0 hours	SD 17.6 hours			
I feel comfortable using a computer	Strongly agree 56%	Agree 33%	Neither agree nor disagree 5%	Disagree 6%	Strongly disagree 0%
Using a computer makes me nervous	Strongly agree 0%	Agree 6%	Neither agree nor disagree 17%	Disagree 21% 21%	Strongly disagree 56%
I feel confident in my ability to use a computer.	Strongly agree 56%	Agree 28%	Neither agree nor disagree 11%	Disagree 5%	Strongly disagree 0%
Overall quality of life (l=poor 7=excellent)	Mean 6.2	SD 0.8			

Characteristics	Details				
General health status	Excellent 6%	Very Good 67%	Good 27%	Fair 0%	Poor 0%

Table 2.

Summary of before/after results

Instrument	Rating Scale	Average before computer program	Average after computer program	Significant Change?
Hopefulness	12= very low 48=very high	44.4	44.2	No
Hopelessness	0=very low 7=very high	0.11	0.11	No
Self-determination	8=low level 40=high level	35.8	37.1	Yes p= 0.04
ACP knowledge	0%=no correct answers 100%=all correct answers	44.9%	61.3%	Yes p=0.0004

Table 3.

Summary of Results

Instrument	Rating Scale	Mean	SD	Other important findings
Decisional Conflict	16= very low 80=very high	30.5	10.5	94% agreed or strongly agreed that they were aware of the options they had in each decision.88% felt that they had made informed choices and were satisfied with their decisions.100% felt that their decisions reflected what was important to them.
Satisfaction with Decision	6=very satisfied 30=not satisfied	10.0	3.3	100% felt that their decisions were consistent with their personal values94% felt that they made the best decisions possible94% were satisfied with their decisions.
Satisfaction with ACP	12=not satisfied 60=very satisfied	52.9	5.5	100% felt that MYWK increased their knowledge
a) Overall satisfaction withMYWK program	l=not at all satisfied 10=extremely satisfied	9.4	0.7	88% felt that MYWK helped them clarify their healthcare wishes and feel greater control
b) Accuracy of completed advance directive in reflecting wishes for end-of-life care	1= not at all satisfied 10= extremely satisfied	9.2	1.0	94% felt that MYWK prepared them to discuss their wishes with their doctor.
c) Amount of informationprovided by MYWK	1= too little 5=about right 10=too much	7.9	1.7	100% felt that MYWK prepared them to discuss their wishes with their family.
Accuracy of ACP	l=not at all accurate	5.7	1.0	
Pre-editingPost-editing	7=very accurate	6.4	0.9	