

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

Sarah A. Markham, M.D., Benjamin H. Levi, M.D., Ph.D., Michael J. Green, M.D., Jane R. Schubart, Ph.D.

Grant support: This study was funded by a grant from the NIH, National Institute of Nursing Research (1R21NR008539), and Penn State University (Social Science Research Institute, Woodward Endowment for Medical Science Education, and Tobacco Settlement Fund Award).

Financial disclosure: Two of the authors (BHL & MJG) have intellectual property and copyright interests for the decision aid used for this study, Making Your Wishes Known: Planning Your Medical 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.

Acknowledgments: The authors wish to acknowledge the support and assistance of Dr. William Lawrence for his contribution to the M.A.UT model used in the decision aid, Making Your Wishes Known: Planning Your Medical Future (MYWK), Dr. Cheryl Dellasega for her leadership in focus group activities, Charles Sabatino for his review of legal aspects of MYWK, Dr. Robert Pearlman and his collaborative team for use of the advance care planning booklet "Your Life, Your Choices," Megan Whitehead for assistance in grant preparation and project organization, and the Instructional Media Development Center at the University of Wisconsin as well as JPL Integrated Communications for production and programming of MYWK.

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.

Keywords: advance care planning ■ advance directive ■ computer program ■ decision support

Author Affiliations: 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., Departments of Surgery and Medicine, The Pennsylvania State University, College of Medicine

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

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 interventions.^{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% \rightarrow 61.3%, $p = 0.0004$), with modest increases in individuals’ sense of self-determination (35.8 \rightarrow 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

Download English Version:

<https://daneshyari.com/en/article/4199487>

Download Persian Version:

<https://daneshyari.com/article/4199487>

[Daneshyari.com](https://daneshyari.com)