

# Increasing African American Advance Directives: Implementing the Five Wishes Education Protocol

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**Abstract—** The completion rate of advance directives by older African Americans remains low. This pilot study evaluated attitudes related to African Americans and advance directives and the effectiveness of the Five Wishes Education Protocol to increase completion rates. The researchers used a descriptive, cross-sectional pilot study and convenience sampling. Three group sessions were conducted over a 2-month period at three senior centers. Twenty-two older African Americans participated. The mean total score on the attitude survey indicated that participants were moderately positive towards advance directives. Following the intervention, the completion rate of the advance directive Five Wishes was 77.35% (n=17), and 54.5% (n=12) of the participants provided copies of the Five Wishes advance directives to their healthcare providers.

**Index Terms—** African American; Advance Directives; attitude survey; older people

## I. INTRODUCTION

Treatment discussions and end of life decisions frequently prevent unnecessary suffering and help support individual's decisions and preferences.<sup>1</sup> Today, with the rising healthcare cost there is a need to evaluate many healthcare practices, including ways to increase completion of advance directives.<sup>2</sup> Despite efforts by healthcare facilities and laws supporting advance directives, studies consistently show that few people have advance directives.<sup>2,3</sup> Furthermore, less African American than white subjects complete advance directives. In order to increase knowledge and assist completion of advance care directives, African-American communities need increased outreach and education.<sup>4,5</sup> This pilot study helps to further develop an understanding of African American attitudes and facilitates development of a sustainable program to meet a need of African Americans. The research hypothesis was that the Five Wishes Education Protocol will be useful to obtaining completed advance directives in an African American population.

### Background

Understanding choices in decision making for end-of-life healthcare treatment includes health care providers recognizing the impact of individual attitudes toward advance directives.<sup>6</sup> Moreover, the potential influence of advance directives on treatment is a major factor for patients. For

example, a national study with over 500 respondents indicated older adults believe that having an advance directive would force medical professionals to terminate life support even when there is a chance of survival.<sup>7</sup> In addition, patients frequently want family members to be the decision makers for medical treatment and are concerned with the impact of advance directives on family.<sup>8</sup>

Many factors influence completion rates for advance directives. Older adults with higher education are more likely to complete an advance directive.<sup>8</sup> Female gender, receiving advance directive information, and being ask to complete advance directive have been found to increase advance directive completion rates.<sup>9</sup> Although, a strong family relationship, quality of life issues, and lack of autonomy may interfere with advance directive completion rates by older adults.<sup>10</sup>

African American mortality rates are often twice as high as their white counterparts.<sup>7</sup> Compared to white subjects, African Americans are twice as likely to die of serious illnesses, such as cancer. Research indicates African Americans have lower advance directive completion rates than white subjects and fear they will not receive adequate medical interventions.<sup>4</sup> Furthermore, research examining attitudes toward advance directives indicates African Americans were less likely than other ethnic groups to communicate health care desires to health care providers. In addition, they were more likely than whites not to trust healthcare professionals to honor their treatment choices.<sup>8</sup>

### Purpose

The purpose of this pilot study was to evaluate the Five Wishes Education Protocol with an African-American population in three senior citizen centers. In addition, the study assessed African American attitudes and knowledge of advance directives. A major objective was to provide a sustainable advance directive protocol for use in the senior citizen centers to increase completion rates.

### Method

A descriptive, cross-sectional pilot study was conducted using convenience sampling in three senior citizen centers. Three group sessions were conducted over a 2-month period. Since the protocol consisted of written components and the surveys required reading, participant criteria included a minimum of an eighth grade level of education. All

participants were African American. The other inclusion criteria included no history of a previously completed advance directive, fifty-five years of age or older, and attending one of the senior citizen centers. Twenty-two participants met the criteria for the study. Everyone that volunteered for the study, meet the criteria and participated in the study.

The Advance Directive Attitudes Survey (ADAS) was used to measure attitudes toward advance directives. The survey was originally developed initially by Nolan<sup>11</sup> but later Douglas and Brown<sup>6</sup> adapted the survey. Douglas and Brown used a panel of experts to revise the survey. They added questions targeting amount and quality of end-of-life care, changes in advance directives documents, and decisions about advances directives. The instrument is a 4-point Likert-type scale that asks to what extent the subject views advance directives, as either positive or negative, from 1 (strongly disagree) to 4 (strongly agree). The possible range of scores on the ADAS is 24 to 96. A higher score on the survey indicates a more favorable attitude toward advance directives. Test-retest reliability was established at 0.80 with internal consistency reliability using Cronbach's alpha of 0.74.<sup>11</sup>

The Five Wishes Education Protocol was used as an educational guide to facilitate completion of advance directives. Research findings support using the protocol to increase advance directive completion rates.<sup>11,12</sup> The protocol was created by the Florida Aging with Dignity Commission through a 1997 project funded by the Robert Wood Johnson Foundation. Non-legalistic and friendly language is used to guide individuals in making healthcare treatment preferences regarding end-of-life care, comfort measures, and personal care treatment choices.<sup>6</sup> In addition, personal, emotional, spiritual matters, proxys, and instructions relating to life support are provided.<sup>11,12</sup>

Written, verbal, and video components are included in the protocol. A 28 minute instructional DVD helps the participant complete each of the Five Wishes and answers commonly asked questions. The protocol includes a Five Wishes advance directive and includes a combination of a living will and durable power of attorney for healthcare. The participants are guided by the protocol, through the process of documenting how they would like to be cared if they could not communicate their wishes.<sup>11,12</sup>

### **Intervention**

After obtaining Institutional Review Board (IRB) approval and permission from the senior citizen centers, the researcher posted flyers in the lobby of the three senior centers. Flyers informed potential participants about the study and provided information about the dates, places and times of the study.

At each of the three senior citizen centers, the researcher started the information session with a formal introduction and description of the project. The participants met as a group in the senior citizen center. During each session, participants were provided a brief definition of an advance directive and the Five Wishes education protocol. After informed consent was obtained, demographic data were collected via a

questionnaire which included age, education, gender, ethnicity, education level, contact phone number, and knowledge of existing advance directives. To evaluate the African American participants' attitudes toward advance directives, participants completed the ADAS.

Then the researcher provided participants the Five Wishes brochure. The brochure was purchased by the researcher from Aging with Dignity.<sup>13</sup> Aging with Dignity is a national non-profit organization to support older people and to promote better end of life care. Mother Teresa's life and work was the inspiring foundation of Aging with Dignity. In 1997, Aging with Dignity introduced Five Wishes.<sup>13</sup>

Five Wishes meets the advance directive legal requirements in many states.<sup>11</sup> The Five Wishes contains simply choices that users can indicate their wishes about end-of-life care. The first four wishes cover choosing a person to make care decisions, medical treatment desired, comfort steps, and how to be cared for and treated. The last wish includes what loved ones are to know including messages of love, forgiveness, acceptance of death, funeral requests, and organ donation.<sup>11</sup>

After receiving the Five Wishes brochure, participants were shown the instructional DVD which guided them through completing the Five Wishes advance directive. One month following the information sessions, the researcher contacted each participant by phone to assess completion of the Five Wishes advance directive form and to determine whether the Five Wishes advance directive was provided to his/her primary health care provider, to be placed in his/her medical records.

### **Data Analysis**

The research question regarding attitudes related to African Americans and advance directive was analyzed using the ADAS sample data. All study variables were examined using descriptive statistics and SPSS Version 14.0 for Windows statistical package. The total scores on the ADAS were analyzed using mean scores and standard deviation. The data to evaluate the research hypothesis concerning usefulness of the Five Wishes to increase completed advance directives was obtained from the phone call responses one month following the information sessions. Additional findings were described by using descriptive and inferential statistics.

### **Results**

#### **Sample Characteristics**

A total of 22 participants volunteered and all of them met the criteria for the study. All of the participants were African American (100%, n=22). The majority of participants (40.9%, n = 9) were 66-70 years old, female (86.4%, n = 19), and reported an 8-11 grade education (50%, n = 11). Only three participants were male (13.6%, n=3), only three were 60-65 years old (13.6%, n=3), and four reported any college or technical school (18.1%, n=4), The study demographics are described in detailed in Table 1.

#### **ADAS Instrument Scores**

The ADAS Likert scale included items exploring participants' attitudes of advance directives. The survey items included attitudes toward advance directives, perception of

illness, impact of advance directives on treatment, impact of advance directives on family, and participant attitudes toward advance directives. The participants ADAS total scores ranged from 39 to 64 with a mean score of 51.90 (SD=6.68), suggesting moderately favorable attitudes towards advance directives. Frequencies for the ADAS response variables are reported in Table 2.

#### **Perception of Illness**

The majority of participants (90.9 %, n = 20) indicated agreement that it is better to make an advance directive when they are healthy. Only two participants did not agree. Slightly more than half of the participants (59.09%, n = 13) indicated that they were not sick enough to have an advance directive. Nine participants believed they were sick enough to have an advance directive.

#### **Impact of Advance Directives on Treatment**

The majority of the participants (86.3%, n = 19) felt they had choices about the treatment they would receive at the end of their life. A few (13.6%, n=3) believed they did not have a choice about treatment. Almost all of the participants, 91% (n=20) felt they would be given choices about the treatment they would receive at the end of their life. All but one participant, (95.5%, n = 21) agreed that having an advance directive would ensure that they received the treatment at the end of life that they desired.

#### **Impact of Advance Directives on Family**

The highest level of variation was the item concerning the impact of advance directives on family caring. Almost half of the participants (45.5%, n = 10) agreed that an advance directive would make family feel left out of their care, while 54.5% (n = 12) of participants did not feel that making end of life treatment wishes clear with an advance directive would impact their family. In this study, 95.4% (n = 21) of participants agreed that making end of life treatment wishes clear with an advance directive would prevent families from disagreeing when making end-of-life decision about their care. A good majority (72.7%, n = 16) of participants responded that having an advance directive would prevent costly medical expenses for their family.

#### **Completion Rate of Five Wishes Advance Directive Protocol**

One month after the information sessions, each participant was contacted by phone to assess completion of the Five Wishes advance directive form and if the Five Wishes advance directive was provided to his/her primary health care provider to be placed in his/her medical records. Prior to the intervention, 86.4% (n = 19) of the participants had never heard of the words living will, health care power of attorney or advance directive. Additionally, pre intervention only 13.6% (n = 3) reported completing any document related to end of life medical decisions and none had completed an advance directive. Post intervention, 77.3% (n = 17) of participants completed the Five Wishes advance directive and 54.5% (n = 12) actually provided copies of the completed Five Wishes advance directive to their primary care providers. Frequencies for knowledge of advance directives and pre and

post intervention data are reported in Table 3

#### **Bivariate Analysis**

Bivariate analysis was done to explore the relationship between variables. Chi-square analysis was conducted to examine differences between age and whether participants had heard the term living will or advance directive prior to the intervention. The only variables found to be significantly associated were age and whether participants had heard the terms living will, health care power of attorney, or advance directive ( $\chi^2(3) = 8.791, p < .05$ ). The older the participants, the more often they had heard of advance directives.

#### **Discussion**

The Five Wishes Education Protocol was effective in increasing advance directive completion rates. Providing participants with information in order to make an independent and informed decision concerning advance directives was an important consequence of the study, regardless if they completed an advance directive or not.

Analyzing African Americans attitudes survey data about advance directives is helpful to increasing healthcare providers understanding. The ADAS survey data indicated most participants agreed that making end-of-life treatment wishes clear with an advance directive would keep their family from disagreeing. There was essential agreement that it is better to make an advance directive when they are healthy. These findings are consistent with findings from the literature as seen in both Nolan and Bruder<sup>11</sup> and Douglas and Brown<sup>6</sup>, who found over 90% of participants responding that it was better to complete an advance directive when one is healthy. Varying responses to if they were not sick enough to have an advance directive were consistent with Nolan and Bruder<sup>11</sup>, but less participants indicated that they were not sick enough to have an advance directive from Douglas and Brown<sup>6</sup> research findings. The difference in these responses could be contributed to sample sizes, study sites, and mean age. Most participants believed they had choices about the medical treatment at the end of life and that advance directives would ensure that they received the treatment they desired.

The completion rate for advance directives in this study (77%) was higher than 63% reported by Alano and colleagues<sup>9</sup> and 26% by Salmond and David<sup>8</sup>. The higher completion rate may be that the sample included a significant number of people over age 65. The mean total score on the ADAS indicates that participants were moderately positive towards advance directives. In comparison to Douglas and Brown<sup>6</sup> study, the ADAS scores were lower than the current study, consequently indicating their participants had more negative attitudes about advance directives. If more time had lapsed, more participants might have completed the advance directive and provided advance directives to healthcare providers.

Further analysis of the post intervention completion rates indicated participants who most likely would initiate an advance directive were female, over age 65, and had 8 through 11 grade education. The number of women who completed an advance directive was three times the number of

men who completed one. It is not known why some participants did not complete the advance directives. It might be they did not have sufficient time to complete the document or an opportunity to give the form to their healthcare provider. Another finding was a significant difference between age and whether participants had heard of the words living will, health care power of attorney or advance directive. The older the participant, the more often they had heard of advance directives.

### Limitations

There were several limitations to the study that could have impacted the results such as sample size, homogeneous sample, time frame of recruitment, and the use of a single educational intervention. The small sample size could have affected the results of the statistical analysis. The participants could have responded with the generally acceptable answers, rather than their actually believes, on the ADAS survey. Moreover, completion rates were self-reported, were not verified, and consequently may not be accurate. More participants might have completed the Five Wishes at later time. More education sessions might have increased participation and subsequently increased advance directive completion rates.

### Conclusion

Health care providers are challenged to better understand cultural attitudes and increase advance directive completion rates in the African American population. In this pilot study, the Five Wishes Education Protocol was effective for older African Americans to increase advance directive completion rates. The ADAS survey provided foundational findings concerning African American attitudes. If funding is available to purchase the Five Wishes brochure, it can be easily used in any senior citizen center. More research using Five Wishes Education Protocol on specific populations could support funding initiatives. Future research is needed using sampling strategies across multiple sites with multiple education sessions to increase African American advance directive completion rates.

### References

[1]. Sessanna L. The role of spirituality in advance directive decision making among independent community dwelling older adults. *J Relig & Healt*, 2008; 47: 32-44.

[2]. Melhado L, Byers J. Patients' and surrogates' decision-making characteristics: withdrawing, withholding, and continuing life-sustaining treatments. 2011; *J Hosp & Palli Nurs*, 13: 16-30.

[3]. Morrell E, Brown B, Qi R, et al. The Do-Not-Resuscitate Order: Associations with Advance Directives, Physician Specialty and Documentation of Discussion 15 Years After the Patient Self-Determination Act. *Jf Medi Ethics*, 2008; 34: 642-647.

[4]. Bullock K. Social work series. Promoting advance directives among African Americans: a faith-based model. *Journal of Palliative Medicine*. 2006;9(1):183-195.

[5]. Johnson, K., Kuchibhatla, M., & Tulsky, J. (2008). What explains racial differences in the use of advance

directives and attitudes toward hospice care?. *Journal Of The American Geriatrics Society*, 56(10), 1953-1958. doi:10.1111/j.1532-5415.2008.01919.x.

[6]. Douglas R, Brown H. Patients' attitudes toward advance directives. *J Nurs Schola*, 2002; 34: 61-65.

[7]. Hopp F, Duffy S. Racial variations in end-of-life care. *J Ameri Geri Soc*, 2000; 48: 658-663.

[8]. Salmund S, David E. Attitudes toward advance directives and advance directive completion rates. *Ortho Nurs*, 2005; 24: 117-129.

[9]. Alano G, Pekmezaris R, Tai J, et al. Factors influencing older adults to complete advance directives. *Palli Sup Care*, 2010; 8: 267-75.

[10]. Sessanna L, Jezewski M. Advance directive decision making among independent community-dwelling older adults: a systematic review of health science literature. *J Appl Geron*, 2008; 27: 486-510.

[11]. Nolan M, Bruder M. Patients' attitudes towards advance directives and end of life treatment decisions. *Nurs Outlook*, 1997; 45: 204-208.

[12]. Sabatino C. National advance directives: One attempt to scale the barriers. *NAELA Journal*. 2005; 1: 131-64.

[13]. Aging With Dignity. 2014  
<http://www.agingwithdignity.org/index.php>