

# Health Literacy: Advance directives among the African American aging prisoner population

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**Abstract:** Recent research literature indicates that African Americans (AA) generally execute advance directives to a much lower degree than do non-Hispanic Euro-American adults. The purpose of this research study was to investigate the degree to which social and demographic variables are associated with knowledge of advance directives among AA aging prisoners. A combined sample (N=100) of AA Aging Prisoners generated from three randomly selected sub-samples were collected from three of five state correctional facilities in a Mid-Atlantic Region in the United States. Each prisoner completed the Jordan Advance Directive Measurement Scale®. Three categorical groups emerged from the combined sample. Those groups were based on the Health Status question regarding knowledge of advance directives. Null hypotheses were tested and data were analyzed using Pearson's Chi-Square Test of Independence. There was no significant degree of independence between any of the three pairs of sub-groups. The researchers informally discovered the prisoners' lack of basic knowledge of advance directives.

**Keywords:** health literacy; advance directives; African American aging prisoners; fear of death and dying; end-of-life-wishes; group work; groupwork

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## Introduction

When faced with medical emergencies individuals in the United States who have not executed advance directives – that is, have not made arrangements or expressed their wishes in the event of their incapacitation or death, risk having decisions regarding options for their medical treatment left to medical personnel, family members, or others who may not make the same decisions as the patient would. An advance directive is a legal document that expresses a patient's wishes regarding the specific end-of-life treatment options available to that patient in the unlikely event of his/her total incapacitation (Roter, Larson, Fischer, Arnold, & Tulskey, 2000; Schwartz, 2006).

According to Morrison, Zayas, Mulvihill, Baskin and Meier (1998), every American state government has enacted legislation that is a guide to protect Americans if unanticipated circumstances render those individuals unable to formulate appropriate healthcare decisions (Health Care Decision Act, 1993). Notably, American hospitals and healthcare facilities have similar but different names for these guidelines for making end-of-life healthcare decisions, names such as advance directives, Living Wills or the Five Wishes (Emanuel, 2000; Kuwahara, 2001). Unfortunately, even though such legislative acts exist to safeguard Americans in regard to their treatment at the end of their lives, many Americans have no knowledge of the benefits of executing an advance directive. Said plainly, knowledge about advance directives is not widespread among many Americans (American Medical Association, 2003; Andreasen, 2004; Barrett, 2006). Conversely, despite the existence of the HCDA (1993) and the advantages associated with having an advance directive, the vast majority of African Americans, between 83.2 % and 91.7 %, never execute such a document (Healthcare Decision Act, 1993). For those African Americans not having do-not-resuscitate orders or advance directives, the options for their medical care are frequently addressed instead by family members, close friends, or members of their religious communities (Lee, Ziegler, Sommi, Sugar, Mahmond & Lenert, 2000). Unfortunately, that individual's thought processes on medical planning and those of his/her family members, close friends, and/or religious community members are not always mutually aligned.

Knauft, Nielson, Engelberg, Patrick and Curtis (2005) propose

several barriers to advance directive completion among African American adults. They are as follows:

1. Historical mistrust of medical professionals
2. Inadequate knowledge about advance directives and their execution
3. Lack of enthusiasm about discussing the issues of death and end-of-life planning (Kübler-Ross, 1999)
4. Perceptions that advance directives are difficult to execute (Weisman, Haas & Fowler, 1999)
5. Cultural and spiritual beliefs opposing advance directives (Dancy & Dancy, 1995; Klessig, 1992), and.
6. Views that advance directives are unnecessary because there has been communication with family members and the idea that 'they will know what to do', (Munishi, 2007).

According to Alexander (2010) there are 10 million people worldwide in prison. Of that number, the United States has the highest prison population in the world, with 756 prisoners, per 100,000 population. According to Snyder, van Wormer, Chada, and Jagers (2009) with sentencing laws being modified to longer jail time, three offences and you are out mandates, and mandatory minimum sentencing rules, the aging adult prisoner population is larger than any other incarcerated group in United States history.

In the same way, Alexander (2009) contends that there are over 841,000 African Americans adults in prison. Of that number, 25% of African Americans are aging and labeled 'lifers'. Additionally, The (United States) National Assessment of Adult Literacy (2008) purports that prisoners are an undereducated class and that they have lower literacy skills that enable them to complete daily tasks thus, possibly creating a significant barrier as to why African American Aging prisoners do not complete advance directives (Williams, Goodwin, Baillargeon, Ahalt, & Walter, 2012). According to Emanuel (2000), as the aging population increases and more aging prisoners began to expire in a correctional facility, it is paramount that end-of-life education and health care literacy be offered to prisoners.

## **Health literacy**

### **The general aging population**

Ninety million Americans, one half of the adult population in the United States, lack basic literacy skills required for full contribution in American society (Sum, Kirsch, & Taggart, 2002). In the same way, a significant number of Americans lack basic health literacy status (HLS) (Speros, 2009). Specifically, inadequate health literacy disproportionately affects older adults in the United States (Speros, 2009). Health literacy has been defined as the mental and social abilities which regulate the incentive and capacity of individuals to gain access to, and comprehend, and use information in ways that encourage and preserve good health (Speros, 2009). Aging Americans process information at a slower rate, have less working memory (being able to process multiple bits of information at a given time), and have difficulty comprehending (United States Department of Health and Human Services, 2009). While many aging adults must choose to select a primary health care physician from a myriad of providers, often times fight for adequate health care, accept referrals and dissect advice given by health care professionals, choose from which prescription to get filled, if any; understand medical jargon, and the benefits of the medication, understanding health care is difficult (Speros, 2009).

### **Aging prisoners**

Many American inmates have an inexplicably low level of health literacy and a high level of chronic conditions requiring a significant amount of health care expenses and ongoing treatment and management (Young, Weinert, Kouame, Keery, & Gillispie, Personal Communication 2012). According to Snyder et al (2008) the majority of older inmates test at a sixth grade level. Those researchers also suggest that prisoners with limited and lower health literacy skills experience an increase in chronic conditions more than inmates with higher levels of health literacy. Likewise, an increased level of health literacy is a strong predictor of good health care outcomes among prisoners (The National Center for Education Statistics, 2003).

Educational attainment is highly related to literacy proficiency. Aging prisoners who have not received a high school diploma or General Education Development (GED) certification demonstrate lower levels of proficiency than those who have completed high school, earned a

GED certification, or received some postsecondary education (Price, 2007). Moreover, Swanson, Swartz, Ferron, Elbogen, & VanDorn, (2006) suggest that an increase in health literacy impacts decisions about medical incapacitation, end-of-life care, and the execution of advance directives among Americans.

### **African American aging prisoners**

Many African American aging prisoners lack basic literacy skills (Sum, Kirsch, & Taggart, 2002). Without the ability to comprehend health information, African American aging prisoners will continue to receive disproportioned care (Speros, 2009). While many African American aging prisoners test at a sixth grade level, some researchers suggest that health literacy in this population is undetermined (Washington, 2007).

Many African Americans fail to discuss the extent of their health literacy, due to the mistrust of medical professionals (Washington, 2007). In connection with this, Baugh (1999) contends that slavery, though very complicated and sometimes severe, was unsuccessful in destroying the mind and soul of African American people. However, the xenophobic memories and the suffering attached to its history have caused many African Americans and African American prisoners to doubt the traditional medical profession (Crawley, Payne, Bolden, Payne, & Washington, 2000). While many African American aging prisoners may have limited education, the idea of discussing their medical beliefs and desires with medical staff of European descent can be viewed collectively as a linkage to racial oppression (Washington, 2007).

## **Execution of advance directives**

### **The general aging population**

While many Americans plan for weddings, graduations, baby showers and other events, many do not plan for their end-of-life decisions. There have been several nationally publicized instances in which individuals who had not executed advance directives were rendered incapacitated (Barrett, 2006; Bradley, 2005; Easton, 2005; Levesque, 2003). However, even though these highly publicized cases received national attention, the rate of executing advance directives has not increased. For example, cases such as the ones that involved Ms. Terry Schiavo, Ms. Karen Quinlan and others are all examples of disquiet that occur in the absence of the execution of an advance directive.

Researchers contend that a plethora of variables have been listed as barriers to completing advance directives. Morrison, Zayas, Mulvihill, Baskin and Meier (1998) contend that reasons for the variability in completing advance directives are unclear. However, ethnic differences in knowledge about advance directives, in having available appropriate surrogates and in concern about placing undue burden on surrogates, have all been used as explanations as to why many American people in general and African American people in particular do not execute advance directives.

### **African American aging populations**

Issues surrounding the planning of end-of-life care, which essentially has caused resistance for African Americans, have ranged from racism to mistrust of medical professionals, lack of education to lack of resources (Chunn, 2002; Corbie-Smith, Thomas, & St. George, 2002; Friedman, 1998). These factors associated with the execution of advance directives have left family members with questions, economic contention, and legal fees at the point of death. In a similar way, Chunn (2007), Byrd (1992), Martin and Martin (2002) and Washington (2007) agree that based upon several factors, African Americans have a strong, emotionally? negative response to the American healthcare system generally. One factor involves the fact that, without their consent, African Americans were subjected to unpardonable medical practices as a part of medical experimentation (for example, The Tuskegee Study) (Aubrey, 2011;

Washington, 2007). A second factor involves the subjection of this group to health care that was both inferior and derisory (Chunn, 2007). Currently, in American society, African Americans experience the cultural mistrust of American healthcare because America has historically denied their desire for equality (Washington, 2007).

### **General prisoners**

In America, an advance directive is an effective tool that will allow communication between prisoners and providers to ensue in reference to health care decisions, particularly, end-of-life care decisions thus increasing the probability that prisoners' end-of-life wishes are respected and granted in the unlikely event that a prisoner is rendered incapacitated. Notwithstanding, the research literature is scant as it relates to assessing an advance directive's usefulness in a prison setting (Scheyett, Vaughn, & Francis, 2010) and less than one per cent of inmates in the United States have completed an advance directive (Scheyett, Vaughn, & Francis, 2010). America's incarcerated population has virtually no autonomy in decision making especially as it relates to medical care and treatment (Easton, 2005).

While many prisoners are not 'lifers' and may have received short sentences, it is paramount for each person entering into the penal system to execute an advance directive to ensure that the rights of each prisoner are respected (Scheyett, Vaughn, & Francis, 2010).

### **African American aging prisoners**

Progressive initiatives are necessary to bring attention to the execution of advance directives among African American aging prisoners. The current research literature has an insufficient number of studies relating to the degree to which African American aging prisoners execute advance directives. In addition, few studies indicate the degree to which African American aging prisoners in the various religious denominations engage in the execution of advance directives. Moreover, there are limited studies in the current research literature that address the multiple factors incumbent in the degree to which social and cultural variables influence the probability of African American aging prisoners completing an advance directive.

## Methods

### Participants

Participants for the current research study were comprised of a combined sample set of 100 randomly generated African American aging prisoners (50 years of age and above). There are five correctional facilities in the state of Delaware. Three out of the five were randomly selected with a view to participating in the research study. The wardens were contacted to seek permission for use of their correctional facility to administer the survey. All three agreed to participate. Thus, three random sub-samples were generated from three of five State of Delaware Correctional Facilities. Permission was gained from Delaware State University's Institutional Review Board (IRB), to conduct this study since human subjects were involved.

In communicating with the Wardens, the researcher provided basic information on the study without compromising the integrity of the data collection process. After receiving permission from the three wardens, a uniform timeframe (before noon and any educational courses offered to the prisoner, etc...), for collecting data was used in each correctional facility. The researcher explained the basic premise of the research at each facility with the proviso that, to avoid data contamination, more specific detail would be provided after the collection of primary data. One social worker/counselor from each correctional facility received a recruitment flyer to discuss with the prisoners if they visited for assistance related to social work issues. Additionally, an informational flyer was posted in the cafeteria in each correctional facility. Each prisoner who was randomly selected completed a consent form.

### Procedures

The *Jordan Advance Directive Measurement Scale*© (JADM) survey was administered to three sub- samples of prisoners from correctional facilities A, B, and C. After the participants completed the survey, the researcher debriefed each prisoner with a two page information guide on advance directives. Subsequently, the researcher met with each of the three sub-samples of prisoners and conducted an informal



discussion in reference to health care literacy regarding their personal knowledge of their rights and health care options.

Each prisoner in the sub samples was able to complete the survey without assistance from the researcher. The JADM scale is comprised of forty questions. Responses to questions are given numerical value to facilitate analysis of collected sample data. Likert scaling is used as a method of giving quantitative (numerical) value for a qualitative (descriptive) term to produce a final average score that represents the overall level of completion or approach toward the subject matter (Oxford Online Dictionary, n.d.). For example:

Table 1  
Likert Scale

Qualitative Data	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Quantitative Value	5	4	3	2	1

## **Group intervention**

After the random samples of prisoners completed the survey, the researcher held an informal group conversation with each group of prisoners to further probe, through discussion, their level of health literacy. The researcher conducted an unstructured conversational style group discussion for approximately one hour. The discussion included topics such as the health care rights of prisoners in a correctional facility, choices that prisoners make relating to their health and why health care decisions are made and the involvement of the prisoners' family members while in the penal system. The researcher met with three sub-groups at each correctional facility. The groups varied in dynamics as some prisoners were actively engaging in the conversation and some were not.

In the course of the unstructured informal group conversation, the prisoners received information about their health choices, end-of-life choices, rights to treatment, rights to deny treatment and rights to medication management from the researcher who is a social worker. Approximately one third of this discussion was spent distilling the

myths associated with the rights that the prisoners have. An additional one third of the group discussion was spent focusing on the alleged misrepresented information given to each prisoner as it relates to their health (mental, physical, spiritual, social and psychological). A third of the conversation held with the prisoners was structured. Many of the prisoners began to share experiences that introduced them to the penal system as well as physical and mental diagnosis received while being incarcerated. Prisoners expressed enthusiasm and the need to have an advance directive completed in order to assist their families in the event that they were rendered incapacitated.

### **Sampling method**

The sampling method used as the data collection strategy in this study was the random stratified random sampling method. The samples of data using the stratified random sampling method increased the probability that the results of the analysis could be generalized to the larger population from which they were derived. In addition, this approach increased the probability that the assumptions of multivariate normality will be met (Bernoulli's Law, 1935).

### **Measures**

The *Jordan Advance Directive Measurement Scale* © (40 item scale) is a standardized instrument. It was designed to measure the degree to which social and cultural variables influence the individual's perception, and associations with the individual's prior knowledge, regarding the execution of an advance directive (living will). The scale is comprised of seven domains: demographic, awareness and experience, race, cultural mistrust, spirituality, cultural competence, and the fear of death and dying.

The demographic social and cultural independent predictor variables analyzed in this study were gender, age, educational status, socio-economic status, marital status, family composition, employment status, and cultural competence. Betancourt, Green and Carillo (2002) define cultural competence as the ability of systems to offer attention to patients that is written and verbally communicated at the applicable literacy level and is specific to the language and

the cultural norms of specific populations (p.9). The execution of an advance directive was the dependent variable analyzed.

### **Analysis of data**

Based on the question regarding knowledge of advance directives, three categorical sub-groups of health literacy status emerged from the combined sample: 1. 'Yes, I know what an advance directive is' (HLS1); 2. 'No, I do not know what an advance directive is' (HLS2), and 3. 'Uncertain' (HLS3).

Data collected were analyzed using Pearson's Chi Square Test of Independence to determine the degree of independence between paired combinations of these three categorical sub-groups: (HLS1) – 'Yes, I know what an advance directive is' and (HLS2) – 'No, I do not know what an advance directive is' (HLS2); 'No, I do not know what an advance directive is' and (HLS3) – Uncertain' and (HLS1) – 'Yes, I know what an advance directive is' and (HLS3) – Uncertain. The three independent Chi Square results were summed to create a single composite index value (a representation of the addition of two or more values to create a single value (Rothman, Greenland, & Lash, 2008).

### **Research questions**

Three research questions were generated to interrogate the data:

1. Are there any significant differences associated with gender, age, educational status, socio-economic status, marital status, family composition, employment status and cultural competence regarding advance directives between HLS1 and HLS2 categorical sub-groups in samples of African American Aging Prisoners?
2. Are there any significant differences associated with gender, age, educational status, socio-economic status, marital status, family composition, employment status and cultural competence regarding advance directives between HLS1 and HLS3 categorical sub-groups in samples of African American Aging Prisoners?
3. Are there any significant differences associated with age, educational status, socio-economic status, marital status, family composition, employment status and cultural competence

regarding advance directives between HLS1 and HLS3 categorical sub-groups in samples of African American Aging prisoners?

### Null hypotheses

1. There are no significant differences associated with gender, age, educational status, social economic status, marital status, family composition, employment status, and cultural competence regarding advance directives between HLS1 and HLS2 groups of African American aging prisoners.
2. There are no significant differences associated with gender, age, educational status, social economic status, marital status, family composition, employment status, and cultural competence regarding advance directives between HLS2 and HLS3 groups of African American aging prisoners.
3. There are no significant differences associated with gender, age, educational status, social economic status, marital status, family composition, employment status, and cultural competence regarding advance directives between HLS1 and HLS3 groups of African American aging prisoners.

## Results

Table 2

Null Hypotheses Results	Jordan Advance Directive Scale Survey Chi Square test of Independence		
	Health Literacy Groups	X <sup>2</sup> Result	Critical Value
Null Hypothesis 1	HLS1 & HLS2	3.803	12.838
Null Hypothesis 2	HLS2 & HLS3	0.0634	12.838
Null Hypothesis 3	HLS1&HLS3.	0.1029	12.838

HLS1= Yes, I know what an advance directive is.

HLS2= No, I do not know what an advance directive is.

HLS3= Uncertain

The objective of the classical hypotheses testing method is to reject the null hypotheses. For the current research study, null hypotheses were tested at the .05.alpha level of significance (Durett, 1995).

- In Null Hypothesis 1 the calculated Chi Square value was 3.803. The calculated Chi Square value (3.803) does not exceed the Critical Value (12.838). Therefore, Null Hypothesis 1 was not rejected.
- In Null Hypothesis 2 the calculated Chi Square value was .0634. The calculated Chi Square value (.0634) does not exceed the Critical Value (12.838). Therefore, Null Hypothesis 2 was not rejected.
- In Null Hypothesis 3 the calculated Chi Square value was .1029. The calculated Chi Square value (.1029) does not exceed the Critical Value (12.838). Therefore, Null Hypothesis 3 was not rejected.

Overall results indicated that all three Null Hypotheses were not rejected. That means that irrespective of the differences between groups (Correctional Facilities A, B, and C), the independent variables did not make a significant difference on any group relative to the degree of health literacy regarding an advance directive. Their profiles, demographic and cultural, were basically independent of their levels of health literacy measured by knowledge of advance directives.

## **Discussion**

A key purpose within the design of the research was to inform those African American aging prisoners who participated about health choices, end-of-life choices, rights to treatment, rights to deny treatment and rights to medication management. Given that the findings suggest that the prisoner's demographic and social profiles and were basically independent of their levels of health literacy, after the research, a discussion ensued between the researcher and the correctional facility social worker as to whether the conversation with the prisoners about advance directives had been helpful. In other words, bearing in mind Betancourt, Green and Carillo's (2002)

definition of cultural competence as the ability of systems to offer attention to patients that is written and verbally communicated at the applicable literacy level and is specific to the language and the cultural norms of specific populations (p.9), should American health care professionals be doing a better job of educating African American aging prisoners on health literacy issues?

Thus many physicians may need to concentrate on ideas that will aid in the infusion of health literacy and trust between patients (Washington, 2007). For example, while several prisoners discussed their sentences, length of sentencing, whether they were guilty or not, if they had family or not, most of them discussed the fear of dying in prison. Some of the prisoners shared that when they went through the intake procedures, they were told that if anything happens in the correctional facility and someone has to make a decision on your behalf, it would be the Warden. At that point trust for the medical professionals working in the correctional facility is low. Likewise, the idea to participate in any research activities, complete any 'unnecessary' medical forms, or discuss health care wishes with the medical staff became a hotly debated subject.

While many of the prisoners discussed health literacy issues as it relates to advance directives (despite not knowing what an advance directive is, formally, never having had the form introduced to them and no one caring in the correctional facility as to whether they have executed a form or not), several of the prisoners discussed issues such as cultural mistrust and their unwillingness to complete an advance directive. The unwillingness to complete the form is one of the main reasons as to why numerous people perish without receiving sound health care (Lee et al, 2000). Additionally, several of the prisoners discussed the fear of death and dying as a major reason to avoid completing the legal document an advance directive.

## **Conclusion**

American social workers and health care professionals and social workers must begin to examine more effective ways to educate patients on the benefits of executing an advance directive. Initial arrival at a correctional facility may not be the best time to discuss

end-of-life treatment options particularly with African American aging prisoners, who may have experienced mistrust for medical professionals. Meetings, information sessions, and continued dialogue between the social worker and the prisoners should ensue in order for each patient to receive the best health care opportunity (Lanhaesser & Ziegler, 2005).

American social workers and American healthcare professionals should be required to explain the benefits of the execution of advance directives not only to the prisoner, but to the prisoners' family members. Being able to interpret an advance directive is a skill set that all American health care professionals in the correctional arena should be mandated to have.

Focused studies, along with group interventions are necessary in order to provide information and direction toward the improvement of health care literacy among American prisoners in general and African American aging prisoners, specifically. Otherwise, American physicians, health care providers, social workers, clergy, and policy makers will remain limited in their capacity to provide more effective services for prisoners. Without more health communication and health literacy in general and awareness of the benefits of advance directives in particular, the population investigated will continue to be disadvantaged. Consequently, end-of-life making decisions will be left to medical professionals, family members, American wardens and others, without the American prisoner's health care choice being respected and granted.

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