



## DOCTOR OF NURSING PRACTICE (DNP) PROGRAM

### A DNP PROJECT

# THE IMPACT OF A FAITH-BASED END OF LIFE CARE EDUCATION PROGRAM ON DECISION MAKING IN AN AFRICAN AMERICAN RELIGIOUS COMMUNITY

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African American Religious Community

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## **Abstract**

Palliative care services aim to anticipate, prevent, and treat symptoms associated with life-threatening diseases. However, research has shown African Americans are less likely to engage in end of life services when compared to their non-African American counterparts. The purpose of this project was to assess end of life knowledge of African Americans, assess African Americans' ability to make an informed decision regarding the end-of-life care, provide a faith-based end of life education session, and evaluate its effectiveness. Imogene King's general system framework was used to structure and guide this project. A demographic survey and evidence-based tools were administered before the intervention and immediately following and two weeks after the intervention. A Friedman test was used to analyze change over time with pre and posttests 1 and 2, which showed a significance level of ( $p < 0.01$ ). Results indicate there were an overall increase in the mean PaCKS scores after the educational session.

*Keywords:* Palliative Care. African Americans, End of Life Treatment, Hospice Care

# The Impact of a Faith-Based End-of-Life Care Education Program on Decision-Making in an African American Religious Community

## Introduction

End-of-Life (EOL) services are comprised of Palliative Care (PC) and Hospice Care and are significantly underutilized in the healthcare system. Many African Americans (AA) are unaware of the true meaning of palliative care and at what point in the illness trajectory to request services. According to LoPresti, Dement, & Gold (2016), nonwhite ethnic minorities tend to be less knowledgeable of End-of-Life treatment options and therefore request these services less often than their white counterparts (p. 292). African Americans and Hispanics are more likely to decline palliative care services because of religious or spiritual factors which can impact suffering related to untreated symptoms from a life-limiting disease (Apesoa-Varano, Tang-Feldman, Reinhard, Choula, & Young, 2015). Family members and caregivers also need support during this challenging time which can be addressed as part of the palliative care services. African Americans may have a different perception of Palliative Care than those of other races.

Many individuals are misinformed and acquire their information on palliative care from unreliable sources. Ramsey (2013) discovered that a majority of the participants only heard of advance directives or living wills from the media and many would like educational sessions at local churches, department stores, or pharmacies (p. 57). Instead, most AA are often questioned and educated about advanced directives and living wills during admission to the hospital which has been identified as a threatening environment for AA (Ramsey, 2013). A neutral setting such as a faith-based community is a less threatening atmosphere to introduce and educate AA on PC and hospice services.

An interview with the founder of a Church in Elizabeth, NJ (A. Gilyard, personal communication, February 1, 2018) confirmed that many members come to the Bishop with health-related questions and advice on taking medication recommended by physicians. Because of these inquiries, the church administration has developed a health ministry which disseminates monthly printed health topics and important screening tests. Recent studies have shown a strong relationship between spiritual health and physical health in the AA communities. Muresan (2018), discusses African Americans slave's adoption of Christianity during their struggle for freedom. Before the civil war began, faith-based communities pervaded the African American community. Slaves were forbidden to participate in religious practices resulting in secret meetings in slave cabins. Faith-Based communities have always been a haven for the African American community. The National Hospice and Palliative Care Organization (2008), reported 70% of African Americans attend religious services a few times a month and 80% consider themselves either very or fairly religious (p. 2.)

### **Background & Significance**

End of life care is composed of Hospice care and PC. The National Consensus Project for Quality Palliative Care (2013), defined PC as an interdisciplinary model of care aimed to anticipate, prevent, diagnose, and treat symptoms associated with life-threatening diseases to improve quality of life. Palliative care is recommended for anyone with a life-limiting illness regardless of age, religion, or ethnic background. The National Hospice and Palliative Care Organization (2017), describes Hospice care as comfort care for a patient rather than cure in a variety of settings such as home, hospital, or long-term facility. Both hospice and PC focus on quality of life and symptom management provided by an interdisciplinary team by determining the patient's preferences and goals of care. Hospice care requires a six month or less prognosis.

Croson, Keim-Malpass, Bohnenkamp, & LeBaron (2018), reports palliative care has no prognosis requirement nor has a specific eligibility criterion. PC is also provided with curative or life-prolonging therapies; unlike hospice care whose goal is comfort care. Hospice care is a Medicare benefit while Palliative Care is not a specific benefit covered by insurers.

More than 1.5 million Americans received hospice care services in 2010, and this number continues to grow each year. However, The National Hospice and Palliative Care Organization (2008), reported less than 10% of all hospice patients were African American. Research is limited on the actual percentage of AA who received non-hospice based palliative care. The exact reason for the underuse of palliative and hospice care in the African American community is unclear however, several possible causes have been identified. According to Drisdorn (2013), family, spirituality/religion, historical perspectives, physician communication, low literacy, and lack of knowledge are important factors that affect the underuse of palliative care in the African American community.

African Americans view PC and Hospice services as a decision to accept death and give up on their loved one (Drisdom, 2013). Generally, utilizing end of life services results in loved ones experiencing guilt and lack of confidence in their decision. Yancu, Farmer, & Leahman (2010) proposed that African American Christians preferred to pray for a miracle rather than accept that the disease had reached its terminal state. Embracing patient spirituality and incorporating their religious traditions around EOL care can increase participation in PC and Hospice services.

African Americans have experienced extreme neglect by our health care system in the past, leading to mistrust of the healthcare system. Drisdorn (2013), cites the effects of the Tuskegee experiment which left 399 African American males with syphilis untreated for 40



years as an example of this neglect. This study was conducted by the U.S. Public Health Service in collaboration with Tuskegee University. The African American Community often share stories of health care neglect resulting in fear of trusting the health care system. African Americans believe they will receive inferior treatment if they decided to sign an advance directive or accept PC or hospice services (Yancu, Farmer, & Leahman, 2010). According to the Nations Report Card (2015), only 17% of African American 12<sup>th</sup> graders performed at or above the proficiency level on the National Assessment of Educational Progress. Low literacy weakens the patient's ability to understand the disease process fully. Individuals with low literacy levels are more likely to accept aggressive treatment. Low literacy limits the patient and families' ability to digest each treatment outcome and provide an informed decision. Health care providers often have a challenging time explaining a patient's prognosis and palliative care options and may impose their own bias when discussing end of life options rather than actively listening to the patient's wishes or goals. Low Literacy and the inability of health care providers to communicate prognosis and treatment options contribute to African Americans' lack of knowledge concerning the available EOL services. This knowledge deficit supports findings of increased pain and unresolved symptoms frequently described by patients at the end of life.

African American families feel great pride in taking care of loved ones during terminal stages of life-threatening diseases (Drisdom, 2013). During end of life, families rely on religious communities for help and support during this challenging time. Older generations trust their loved ones to make the best end of life decisions for them. However, they never converse with their loved ones about their wishes at the end of life (Drisdom, 2013). Caregivers often come to religious leaders for advice on terminating life-prolonging measures or continuing such actions.

Studies show that accepting aggressive treatment at the end of life resulted in families feeling less guilt, anger, and loss (Ramsey, 2013).

End-of-life services has several beneficial impacts on the patient and family members. The Center to Advance Palliative Care (2017), reports palliative care develops individualized plans to minimize pain, constipation, nausea/vomiting, and shortness of breath to improve the patient's quality of life. Family members and caregivers are a vital piece of the palliative care team which in turn promotes improved confidence and coping skills (Croson, Keim-Malpass, Bohnenkamp, & LeBaron, 2018). PC often reduces hospital readmission rates by anticipating, preventing, diagnosing, and treating people with poorly controlled symptoms at the end of life as an outpatient. A study by Taylor et al., (2007) assessed the health care costs of individuals with a life-limiting illness and the utilization of hospice care. There were 1,819 patients in hospice care and 3,638 patients in the control group who did not utilize hospice services. The maximum cost reduction was \$7000 in Medicare expenditures of cancer patients who used hospice in the last 58-103 days of life compared to the control group. Hospice care reduced expenses by an average of \$2309 per hospice patient during the last year of life (Taylor, Ostermann, Van Houtven, Tulsky, & Steinhauser, 2007).

The National Consensus Project objective was to standardize PC into core concepts. When to initiate PC is frequently debated amongst providers, for fear of introducing PC too early in the illness trajectory. This fear is unwarranted as the literature shows that the earlier PC is begun, the better the patient outcome (Temel et, al., 2010). There is no secure nor standardized approach to educating patients and family members about PC. The 2013 National Consensus Project for Quality Palliative Care describes the different components of PC but does not explain how to approach family members about starting EOL services.

According to the National Consensus Project for Quality Palliative Care (2013), hospice and palliative education has reached many millstones since 2009. The Accreditation Council for Graduate Medical Education announced hospice and palliative care as a subspecialty of eleven different parent boards (ACGME, 2014). Physician fellowships are now a requirement for the palliative care medicine board examination. Palliative care curriculums are now incorporated into many nursing programs throughout the United States. Advanced practice nurses now have access to more palliative nursing fellowships. The National Board of Certification of Hospice and Palliative Nurses have palliative care board certifications for RNs and for APNs and have developed two new examinations, one for pediatric hospice/palliative care registered nurses and hospice palliative care administrators. PC has become a critical part of the healthcare team and determining an efficient way to help African American Christians make an informed decision regarding end of life care is essential.

Finding an appropriate way to approach and educate African American Christians on PC is imperative. Transitioning from teaching in the hospital to educating in a trusted environment such as a church may be beneficial. A guide titled “African American Outreach Guide” was published to help educate African Americans on palliative care by Caring Connection which is a program of the National Hospice and Palliative Care Organizations (The National Hospice and Palliative Care Organization, 2008). Incorporating family members and the church into decision making supports healthcare providers’ knowledge of African American history and tradition. Using the right words and being patient are helpful tips to relieve suspicion concerning African American mistrust of the healthcare system (The National Hospice and Palliative Care Organization, 2008). The VNAs of Vermont established a website to discuss end of life care at [Starttheconversationvt.org](http://Starttheconversationvt.org) (2018). This public initiative program provided by Vermont’s VNAs

and home care services focuses on how family members can start the conversation on end of life care with loved ones. One recommendation for beginning the conversation suggests various strategies depending on the circumstance such as 1) An adult child who wants to know their parent's wishes; 2) Someone coping with a life-limiting illness; 3) Someone starting a new family; and 4) A young adult who may need to make decisions due to unexpected injury or illness.

This project aimed to develop a faith-based educational approach on EOL services for AA communities and focused on AAs knowledge and perception of EOL care services, comfort with discussing EOL care, ability to communicate EOL care goals and consideration of EOL services for themselves or a loved one. The findings of this project provides support for transitioning EOL education programs for AAs from the hospital to the faith-based community to improve the perception of PC and hospice services, facilitate early understanding of such services and improve the quality of life for AAs suffering from symptoms of a life-limiting disease. What could happen if we provided PC education to AAs in environments that they trust such as local churches rather than in the hospital or doctor's office? Song et al. (2008), studied interventions to improve communication concerning End-of-life care among African American patients with chronic kidney disease (CKD) and found that palliative care interventions should address the influence of spirituality on patient's decision making. The findings of this study suggest, "relationship-centered, person to person approach, which is consistent with oral traditions" when communicating end of life treatment options (p. 71).

### **Needs Assessment**

According to the World Health Organization (2017), an estimated 40 million people were in need of EOL services such as PC with the majority of them living in low and middle-income countries. On average only 14% of this population received PC services. Lack of training and knowledge of PC is a significant barrier to improving access to such services. Only 20 countries of 234 had well-established palliative care services; it is recommended for all health system policies to integrate palliative care services into national health care systems (WHO, 2017). Millions of Americans with severe illness are living without adequate access to End-of-Life care services (National Palliative Care Research Center, 2015). Approximately 68% of Medicare dollars are spent on patients with four or more chronic illness, which describes your typical palliative care patient. According to the National Hospice and Palliative Care Organization (2016) “1,381,182 Medicare beneficiaries were enrolled in hospice care for one day or more in 2015 (pg. 3). New Jersey reported 91.2% of all hospitals had a palliative care team (National Palliative Care Research Center, 2015). Barriers such as lack of awareness amongst policy-makers, cultural/social beliefs, and misconceptions concerning palliative care restrict the advancement of palliative care programs. In an attempt to address such barriers, the World Health Organization recommends: 1) integrating PC services into structure and financing of national health systems; 2) policies to strengthen training professionals and to incorporate PC into core curricula of all health care providers; and 3) ensure the availability of essential medication to manage end of life symptoms such as pain medication. The Center to Advance Palliative Care has made a significant impact on the substantial increase in inpatient and outpatient programs throughout the United States (Center to Advance Palliative Care, 2014).

An interview with the founder of a Church in Elizabeth, NJ confirmed the need for End-of-Life education for this congregation. Over the last 15 years, the bishop has been the sole guide

for the congregation when members or family members become terminally ill. They seek him for direction concerning end of life decisions from a spiritual aspect. The bishop estimated that 90% of the situations he encountered included family members who were not aware of EOL treatment services nor had end of life care been discussed with their loved ones (A. Gilyard, personal communication, February 1, 2018). Several members of the church discussed their experiences with life-limiting illness. A story of a married couple of 30 years stood out to me. The husband suddenly became terminally ill, and after a six-month hospital course, he ultimately died. As the conversation progressed, the wife discussed her husband's history of End-Stage Renal Disease (ESRD), heart failure and peritoneal dialysis. Several physicians routinely saw him, and no one had ever spoken to him about PC or hospice services. His wife described him as completely independent and happy with his life which is why she states they never discussed end of life care. They felt that death seem so far away and at 63 years of age he was admitted, walked into the hospital and never came home. She explained how lost she was and that she was not in a state to retain any information that was given to her by doctors during such a difficult time. She also expressed that this time could have been more comfortable for her if she had guidance from her husband on his end of life wishes (, personal communication, January 2018). It is essential to educate patients on the need to discuss end of life care for patients and their families with chronic, life-limiting diseases.

### **Problem Statement**

Many African Americans are unaware of the true meaning of EOL services and when to start such a process. As a result, many African Americans with life-limiting diseases experience unbearable pain and poor management of their life-threatening conditions. Mistrust of the healthcare system from past experiences such as the Tuskegee Experiment in 1932 has

established fear in the African American Community of not receiving adequate care if they decide to participate in EOL services. The National Hospice and Palliative Care Organization (2008), reported less than 10% of all hospice patients were African American. Poor communication from healthcare providers concerning end of life care limits African Americans ability to process each treatment option and make an informed decision on care.

New techniques regarding educating African Americans on EOL services and its importance during terminal stages of life-limiting diseases are needed. Individuals are often questioned about advanced directives and living wills during admission to the hospital which African Americans identified as a threatening environment (Ramsey, 2013). Educating African Americans in threatening environments will promote further resistance to end of life treatment. Transitioning the environment to one that they trust such as local churches, department stores, or pharmacies would allow AAs to decrease their fear and adequately process the information they are receiving. Utilization of the End of Life Nursing Education Consortium (ELNEC) PowerPoint slides for community education was used as the educational training tool. In addition, MulitVu (2015) “palliative care provides more moments” YouTube video was also used. This guide provided an educational session blueprint to assess, The Impact of a Faith-Based End-of-Life Care Education Program on Decision-Making in an African American Religious Community.

### **Aims & Objectives**

The clear understanding of End-of-Life services for a Christian congregation of African Americans was the ultimate purpose of this DNP Project. This facility is a 300-person church in Elizabeth, NJ. The primary goal of this project was to provide end-of-life education in an environment that is less threatening to AA. This project attempted to determine the ability of

African American Christians (AACs) to make an informed decision regarding end of life care after receiving an educational End-of-Life care session. This project used End of Life Nursing Education Consortium (ELNEC) educational slides to provide a foundation for educating AACs on EOL services. It also included a three minute YouTube video titled “Palliative Care Provides More Moments” (Mutlivu, 2015). POLST forms was distributed and reviewed with the audience.

There were three primary objectives of this DNP project which disseminated evidence-based information on end of life care and evaluated : 1) AACs ability to make informed decisions regarding end of life care; 2) AACs knowledge regarding end of life care 3) the relationship between gender, age group, educational level, marital status, income, and average score changes on the pre, post survey, and 2 week follow up survey.

### **Review of Literature**

A literature review was conducted to explore three critical positions: 1) AA perception and usage of End-of-Life care; 2) PC effectiveness during end of life; and 3) end of life care communication interventions. Many research and non-research sources were available from nursing journals, community practices, expert opinions, clinical guidelines, and organization websites. A professional search of two databases included CINAHL and PubMed. A total of 156 potential sources on CINAHL and nine references on PubMed were recognized using keywords: African Americans, Palliative Care, End of Life Treatment and perception. Keywords were used in several different combinations to yield the best results. Filters used to narrow selection including full text, Scholarly/peer reviewed, 2006-2018, and Evidence-Based Practice. Articles that did not focus primarily on adult PC were excluded. Items that did not include AA were also excluded.

Table 1
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Evidence Table						
Article #	Author & Date	Study Method	Interventions	Outcomes	Comments	Evidence Level & Quality
1	LoPresti, M. A., Dement, F., & Gold, H. T. (2016)	Systemic review 5 qualitative analyses with descriptive data, 7 prospective observational cohort studies, 4 cross sectional studies, 9 retrospective cohort studies	Examined databases to review End-Of-Life care use, preferences, and beliefs for cancer patients	Religion and spirituality are topics discussed but do not consistently influence decision making. Palliative consultation is strongly associated with an increased likelihood of code status change to DNR. Patients who did not have an ACP document commonly cited the reason was “no one has brought it up to me” or “it hasn’t come up.” The preference for aggressive treatment and more life-sustaining measures at the EOL were greater among African Americans	Most of the studies were in urban areas. Only 2 studies included data from actual caregivers, most of the information came from national databases or chart reviews.	Level III High Quality
2	Ramsey, C. P. (2013).	A mixed method of quantitative design and qualitative design	The study surveyed 112 young, adult African American family	Lack of trust in Health care results decrease completion of Advance Directives	Majority of the sample did not have Advance directives	Level III High Quality

			<p>members, ages 21-40 years, to explore their perceptions, knowledge, and attitudes toward utilizing ADs, as well as to determine whether there was a relationship between gender, education level, marital status, and occupation in making this decision.</p>	<p>Having the needed knowledge would decrease caregiver's uncertainty of which treatment option their loved ones would prefer. Recommended to duplicate study but include an educational study.</p> <p>Some participants expressed the importance of having an AD and that it would decrease stress on the family.</p> <p>The majority of the participants agreed with the purpose of a LW and would consider completing one. Of the participants, 23% (n = 26) experienced having to make the decision to withdraw life support for a family member, and 12.5% (n = 14) experienced being in intensive care. Despite these factors, the majority of participants in this study did not</p>	<p>Lack of End of Life knowledge No intervention</p>	
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				have ADs in place.		
3	Smith-Howell, E. R., Hickman, S. E., Meghani, S. H., Perkins, S. M., & Rawl, S. M. (2016)	Cross-sectional descriptive study design	49 AA bereaved family members had script guided interviews and were given demographic survey, belief & Value scale survey, decisional regret survey, decisional conflict scale survey.	Family members held strong religious beliefs and values (M= 64.63, SD = 10.4) A majority (63.3%) of decedents received comfort focused care versus life-prolonging treatments (36.7%). Family members reported relatively low decision regret (M= 22.24, SD = 17.77) and decisional conflict (M= 25.41, SD = 26.24), indicating many family members did not feel uncertain about nor did they regret the choices made for decedents' care. These findings suggest that when African American bereaved family members experience poor quality of general and end-of-life communication with HCPs,	Convenience sample, Sample limited knowledge of advance directives and hospice care, excluding those without telephones, the question lacks clarity as to how directly family members were involved in the care and decision making process, limited access to patient medical records	Level III Low Quality

				family members feel more uncertain about end-of-life decisions.		
4	Song, M., Donovan, H., Piraino, B., Choi, J., Bernardini, J., Verosky, D., & Ward, S. (2010).	RCT	Nineteen African Americans with stage 5 CKD and their surrogates were randomized to either patient-centered advance care planning (PC-ACP) or usual care. PC- ACP was an in-depth interview with the patient–surrogate dyad, delivered by a trained nurse interventionist who had nearly 20 years of clinical experience in medical–surgical nursing and had completed 2.5 days of	Both groups showed difficulty in making end-of-life choices at baseline (mean score N2), and the before–after changes in decisional conflict in the two groups were not significantly different ( $d = .47$ ). The perceived quality of communication about end-of-life care reported by the intervention patients was significantly higher than that of the control group ( $d = .84$ , $p = .05$ ). However, there were no significant group differences in either the patient–clinician interaction index ( $d < .30$ ) or the clinician's cultural sensitivity ( $\phi = .34$	PC-ACP intervention has not been evaluated in African Americans, Small sample size, Only 1 week follow up to observe changes too short of an interval	Level I Low Quality

			PC-ACP training.			
5	Johnson, J., Hayden, T., True, J., Simkin, D., Colbert, L., Thompson, B., & ... Martin, L. (2016).	Qualitative Focus group design	Seven focus group of 51 African Americans from two churches in Philadelphia to determine what would allow church members to effectively communicate with other members who are making end of life decisions	Caregivers and family members of the church need more information on End of Life care Members keep beliefs and thought about death and dying from healthcare providers and family members, Participants want health professionals to use terms that they can understand and they want “not to be ignored or feel ignored when being given information about their condition. Participants expressed uncertainty as to how to approach health care providers and what questions to ask.	focus group participants were Baptists. Members of other denominations may have different views based on church doctrine or have different structures to support persons with life-limiting illnesses, pastors and ministers were not included in focus groups because of concern that they would influence the views of the other participants.	Level III Good Quality

6	Taxis, J. (2006).	Qualitative study- Focus group	28 patients in two focus groups to determine the values, attitudes, & participation in hospice programs	Many did not choose hospice because that equated to death and giving up., it is significant that at the conclusion of the groups, 89% described feeling as though they understood the goals and services of hospice and 96% reported that if the situation presented itself, they would consider hospice for themselves or a loved one	Sample were all females, all participants were church members	Level III High Quality
7	Hendricks Sloan, D., Peters, T., Johnson, K. S., Bowie, J. V., Ting, Y., & Aslakson, R. (2016).	Cross Sectional descriptive Survey	5 question Likert scale survey given at 4 services to assess parishioner experiences with, and desire for, church based education concerning End-of-Life Care.	A majority (93%) would welcome church-provided information about end of life care, an association was not found between age groups, our results support that surveyed black parishioners value EOLC and would welcome a church-based intervention addressing such care.	Only two churches were included, both churches are Baptist, there was potential response bias with only those who care about the topic of EOLC responding.	Level III High Quality

8	Song, M., Ward, S., Happ, M., Piraino, B., Donovan, H., Shields, A., & Connolly, M. (2009).	RCT	Surveys and semi-structured interviews to determine the feasibility, acceptability, and preliminary effects of Sharing Patients Illness Representation to Increase Trust (SPIRIT) on patient and surrogate outcomes at 1 week and 3 months post-intervention.	the outcome variables for the two groups over time. Intervention dyads' congruence at T2 was significantly improved from baseline ( $\chi^2 [1, n = 57] = 4.29, p = .04$ , odds ratio = 3.30). However, dyads' congruence at T3 was not significantly improved from baseline ( $\chi^2 [1, n = 54] = 2.64, p = .10$ ). Patients' decisional conflict did not change over time; there were no group differences in changes (T1 - T2 and T1 - T3). In summary, we found SPIRIT to promote communication between African American dialysis patients and their chosen surrogates was effective and well received.	the lack of intervention effect on decisional conflict could be due to a need for more than a one-time intervention, only a small number of deaths occurred during the study, we were unable to examine surrogates' experiences during the time of actual end-of-life decision making, the lack of intervention effect on psychosocial-spiritual well-being could suggest the need for further evaluation of the instrument's validity when used with African American samples. Its lack of variability	Level I High Quality
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					and high baseline scores might have resulted in ceiling effects and limited sensitivity to change over time, small number of dyads studied	
9	Apesoa-Varano, E. C., Tang-Feldman, Y., Reinhard, S. C., Choula, R., & Young, H. M. (2015)	Systemic Review of 238 articles 218 descriptive or observational, 20 interventional studies	Examined databases to review multi-Cultural caregiving and caregiver's interventions .	Latinos prefer home care, distrust of institutions, African Americans value tradition, family integrity and role modeling, complex web of support extending into community, caregiver support and use of formal resources is shaped by prior knowledge and reputation of services as culturally appropriate Asian Americans pride/shame in asking for help Native Americans experience anxiety regarding complex medical problems and ensuing family conflicts	Interventions at the community and policy levels that address barriers and optimize supportive environments have a potentially broader impact for improving outcomes for individuals and families.	Level III High Quality



10	Palliative Care Network of Wisconsin	Community Standard		Provide information and document preferences: Inform patients about the range of care options, including hospice and palliative care. Explore beliefs, and dispel myths. Even if African Americans choose not to complete advance directives, document treatment preferences and encourage them to identify a trusted decision-maker.	n/a	Level V Low Quality
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## Perceptions

Taxis (2006), conducted a study on the perceptions and attitudes of African Americans in a local church. A focus group held contained 27 church members who were all females and had no life-threatening diseases. After this engagement, it was concluded that hospice care was equated to giving up. As a believer, giving up is not an option and fighting until the last minute is common. However, 96% of the women would consider hospice for themselves if they were presented with a life-threatening illness. Common barriers described in this study were lack of information on palliative care, cultural norms, and institutional barriers such as mistrust. Recommendation for health care providers to provide further respect to religious beliefs when making end of life decision may increase participation. Providing PC information via brochures

or videos in the AA community would be beneficial. Johnson et al., (2016) presented a focus group to 51 African Americans from two churches in Philadelphia. Similarities from Taxis (2006) study included a lack of knowledge of palliative care, mistrust in the health care system, and religious concerns being overlooked. It was discovered that AA believers prefer to keep their thoughts on death from health care providers and family members. They are more likely to express such concerns to pastors of churches. Participants are more comfortable approaching their pastor and are uncertain on how to approach health care providers and what questions to ask. Some participants were unsure of the definition of PC and hospice care while others had actual positive experiences with such services. They expressed hospice care programs gives a chance for family members to say goodbye, provides comfort to the patient, and provides family support.

Ramsey (2013) conducted a mixed method quantitative and qualitative design to obtain the perceptions and knowledge of AA towards advance directives. A total of 112 people from three different churches were provided with a questionnaire and participated in a focus group. Lack of knowledge was one common barrier with the majority of the participants informed of advance directives from non-health sources. Fear of death was an essential factor that contributed to AA not participating in end of life decisions. It was concluded that family members make decisions together and they would not want their family member to suffer. AA also agreed that having an advance directive would decrease stress on the family during that difficult time. Ramsey (2013) discovered that majority of the participants only heard of advance directives or living wills from the media and many would like educational sessions at local churches, department stores, or pharmacies (p. 57). Apesoa-Varano, Tang-Feldman, Reinhard, Choula, & Young (2015) reviewed the literature and concluded AA are more likely to involve family

members and community members to care for terminally ill family members because of mistrust in the healthcare system.

### **Communication Interventions**

Song et al., (2010) tested a communication intervention entitled Patient-Centered advanced care planning (PC-ACP) to increase communication between AA and their decision makers regarding end of life treatments. A total of 19 patients with chronic kidney disease stage 5 were selected to participate. Baseline data concerning difficulty in making choices were assessed via phone. After phone interviews, members were randomly selected to receive the PC-ACP intervention. This intervention was designed to help patients and their surrogates understand the course of the illness better and review their values on life-sustaining treatments in the case of low survival rate. Both groups expressed difficulty making end of life choices at baseline. Using the decisional conflict scale the two groups before and after the intervention were not significantly different ( $d < .30$ ). Recommendations from this study for future study were a focus on the influence of spirituality on end of life care decisions. Relationship-centered education which is delivered by someone you trust and have a relationship with could be more efficient. This complies with “oral traditions” of talking with someone you trust to obtain information. Limitations included small sample size and follow up was done one week after the intervention.

Hendricks et al., (2016) proposed a church-based Advance Care Program (ACP) to increase education and understanding end of life treatment options amongst African American Baptist churches. A cross-sectional survey was collected from 930 members of two different Baptist churches. Of the 930 surveys, 865 members would like information about end of life care made available in the church and 40% of the population had not appointed someone to make

decisions for them in the event they were not able to make it themselves. It was evident that church members would be opened to a church-based EOL care educational intervention. Surveys were given to 2,000 members, and only 930 responded, there was potential response bias with only those who were interested responding.

Song et al., (2009) performed a randomized control trial which included 125 African Americans from six different dialysis clinics. Sharing Patients Illness Representation to Increase Trust (SPIRIT) intervention was used to increase communication between African Americans with CKD and their surrogates. A one-hour session of SPIRIT was performed followed by a one week and three months follow up. Other participants received usual care which consisted of an advanced directive handout from a social worker. The Decisional Conflict Scale was used to determine difficulty in making end of life choices. Although there was no significant difference in groups, the SPIRIT intervention was well received and promoted communication. Limitations included the intervention was only given once and therefore may have a higher effect if more than one encounter was given. Smith-Howell, Hickman, Meghani, Perkins, & Rawl (2016) investigated communication between 49 bereaved African American family members and healthcare providers. Participants were selected from a palliative care program. Family members reported a high quality of communication overall but expressed a lower quality of end of life communication. National Hospice and Palliative Care Organization, (2008) describes an outreach approach to communicating with AA concerning End-of-Life care. This approach stressed the need to build a relationship with those being educated. A discussion on healthcare disparities, religion, death, and palliative care was seen as difficult with community involvement essential. The inclusion of the patient and caregivers was stressed as well as active listening.

To summarize, the review of literature provided African Americans' perceptions and attitudes towards end-of-life care, recommendations on what to include when discussing end of life care, and interventions aimed to increase communication concerning end of life care. Common perceptions throughout the literature review were: 1) mistrust in the health care system; 2) misconception of not receiving any care if he/she agrees to palliative care; 3) not understanding the concept of palliative care, and 4) lack of understanding due to poor communication. Several communication interventions have been implemented to increase communication among patients, family members, and healthcare providers. Several studies such as Hendricks et al., (2016) recommended providing education in an environment African Americans trust such as a religious establishment. However, the African American teaching approach is novel in health care, and an exact method has not been described in the literature to date.

### **Theoretical Framework**

Imogene King constructed a nursing framework which was published in 1971 (Appendix H). The structure encompasses a systems approach including personal, interpersonal, and social. Personal includes perception, growth and development, body image, space, learning, and self-awareness. Everyone has their own perception regarding End-of-Life care. Perception is explained as a process of gathering and interpreting information from an experience that influences one's behavior. Learning is a critical component which allows the personal aspect to gain knowledge. The interpersonal system embraces interactions, communication, transactions, stress, role, and coping. This represents the healthcare providers, patients, and families' interaction and communication with one another. Communication may be verbal or nonverbal; it is essential that your nonverbal language is not contradictory to your spoken language.

Communication is imperative when educating patients. Being an active listener is a necessary component of communication. When teaching AA on end of life treatment options, it is essential to make sure they understand the terminology that is used. Increasing communication and understanding regarding PC is one aim of this DNP project. The social system portrays the community or society that share common goals, values, and interest. An organization such as a church is an important piece of the social network. Individuals in a similar social system often influence other persons within the same social system. Therefore, if one person experiences a poor encounter, the social system as a whole will reflect on this experience. This study utilized the personal, interpersonal, and social networks as a starting point in educating African American Christians on end of life care.

## **Methodology**

### **Design of Project**

This pilot study assessed the association of an End-of-life educational session, provided in a local Christian church, on AAC ability to make informed decisions regarding PC and hospice care. A letter of agreement to participate in this study was obtained from a local church in Elizabeth (Appendix J) the study was approved by the Rutgers Institutional Review Board, and members of this church were recruited for the study. Participants received a pre-education session packet that included the consent (Appendix F), demographic survey (Appendix A), a pre-survey Palliative Care Knowledge Survey (PaCKS) (Appendix D), POLST form (Appendix E) and a pre-survey Decisional Conflict Scale questionnaire (DCS) (Appendix B). The primary investigator then delivered a PowerPoint presentation on palliative care provided by the End of Life Nursing Education Consortium (Appendix G) and “Palliative Care Provides More Moments” <https://www.youtube.com/watch?v=MhYvgtMPYEU>. Immediately following the

educational session, participants completed the post-test 1 which consisted of the PaCKS post-survey# 1 and DCS scale post-survey #1. Two weeks following the educational training, participants completed the post-test 2 which included the PaCKS post-survey # 2 and DCS scale post-survey #2. Using descriptive statistics, the data was collected and analyzed.

### **Instrumentation**

The PaCKS and DCS are two instruments used in this pilot study. The PaCKS is a 13-item true or false scale used to evaluate PC knowledge. Kozlov, Reid, & Carpenter (2017) reports this survey tests a variety of PC topics that palliative care professionals reported as imperative (p. 3). Scores range from 0 to 100 with higher scores representing greater knowledge of palliative care. For example, one item from PaCKS questionnaire includes, “When people receive palliative care, they must give up their other doctors” (false). Results are from 0% lowest knowledge set to 100% highest score.

There are four versions of the Decisional Conflict Scale, one for clinical practice and three for research. The primary investigator decided to utilize the research low literacy 10 item decisional conflict scale version. This ten-item scale measured decisional conflict with questions with three response options which include yes, unsure, or no. According to Brehaut et al. (2006) decisional conflict is uncertainty in choosing between multiple options because of risk associated with each opportunity and the need to make a sound judgment during the decision-making process. The Decisional Conflict Scale was constructed on an eighth-grade reading level making it easy to use with low literacy populations. The Decisional Conflict Scale had three response point values, yes for zero points, unsure for two points, and no for four points. To analyze the decisional conflict scale, all ten answers were summed together, divided by 10 and multiplied by

25. Scores may range from 0 defining no decisional conflict to 100 determining extremely high decisional conflict.

### **Reliability and Validity of Instruments.**

The PaCKS was determined to be internally consistent, valid, and brief (Kozlov, Reid, & Carpenter, 2017, p. 3). Kozlov (2016) conducted a study to develop and determine the validity of the PaCKS survey. It was determined PaCKs could be used to inform the public to close knowledge gaps concerning palliative care. According to Kozlov (2016), palliative care professionals and individuals who experienced palliative care scored high on the PaCKS survey and it was seen as a good tool to evaluate educational initiatives for health care professionals. Kozlov (2016) reported a Cronbach's alpha of 0.7-0.9 indicating good internal consistency (p.19). PaCKS validity correlation revealed  $p < .01$  and R-squared greater than 0.39 (Kozlov, 2016, p. 53).

Linder et al. (2011) used baseline data from a randomized control trial on prostate cancer screening to assess the validity and reliability of the DCS. Cronbach's alpha for this scale was higher than 0.80 and R-square greater than 0.40 indicating good internal consistency and reliability. Overall, this study demonstrated construct and discriminant validity. According to O'Connor (1995), this scale is stress-free to administer and maintains acceptable standards of reliability and validity. O'Connor (1995) conducted a study on breast cancer screening. Reliability of the scale was tested by correlating the test and retest scores using Pearson correlation and by reviewing the internal consistency of the scale using Cronbach alpha. Subjects who had higher DCS scores had less knowledge of breast cancer risks.

### **Setting**



Data was collected at one local community church in Elizabeth, New Jersey which has 300 male and female members. Members of this church live in various areas ranging from New York to Philadelphia. The population within this church consists of primarily African American families with 1% Hispanic and less than 3% Caribbean families. This information was provided to me by the church's secretary.

### **Population & Recruitment**

In January of 2018, the church consisted of 300 members. Convenience sampling was used to recruit subjects for this study. The purpose of using this population was to get a suitable representation of AAC knowledge of PC and hospice care. All subjects were at least 18-89 years-old, Christian, English speaking, able to read English and African American. Participants did not need to have a chronic disease to participate. Both healthy participants and participants with chronic illnesses were welcome. Participants with relatives who have a chronic illness and participants who do not have a relative with a chronic illness were both welcome to participate. Exclusion criteria included non-African Americans, non-Christians, those who are 17-years of age or younger, 90-years of age or older, and those where English is a second language. Using this convenience population, subjects were recruited by word of mouth from the church's wellness ministry, handouts during services and by public announcement during 9 am and 12noon Sunday services. A total of eight public statements were delivered, two per Sunday for a total of four Sundays starting a month before the scheduled educational sessions. Posters and handouts (Appendix I) designed by the primary investigator were displayed in the front and back entrance of the church. All signs and handouts had the primary investigator's phone number for additional questions or concerns. The goal was to obtain 37 subjects to provide reliable descriptive results. According to Hertzog (2008), 25 participants should be the minimum sample

size when conducting a pilot study, however, 35-40 participants per group is the preferable size when estimating test-retest reliability of a pilot study.

### **Ethics, Consent Procedure, & Compensation**

Religion, racial, and ethnic groups are vulnerable populations and protecting their human rights is a significant concern for the primary investigator. Rutgers IRB approval was obtained before project implementation to ensure the safety of each subject. Rutgers IRB adult consent template form was used for this project. This consent form (Appendix F) was completed using a six to eighth-grade reading level and customized to fit the objectives and aims of the project. The consent was given at the beginning of the educational session and reviewed with the subjects before starting the informative session. A review and breakdown of the consent form and project was provided to the entire group in the gym. Subjects was given the opportunity to ask questions regarding the study privately. The primary investigator discussed individual questions in a private room located next to the gym inside the church. After all questions were answered, subjects signed the consent form and were given a copy of the consent form. Subjects who decided not to participate in this study were not subject to any consequences. The participant's decision to engage in the study or withdraw from the study was not disclosed to anyone, including the pastor. Participants were not compensated for their participation.

### **Timeline**

Table 1 Project Timeline				
Completion Date	Planning	Pre-Implementation	Implementation	Evaluation
1/1/18		Start Interviewing church members for needs assessment		

2/1/2018	Meet with Pastor of the church for approval of the project and meet with Dr. Barberio for chair approval			
2/15/18	First planning meeting			
2/18/18	Submit Proposal part 1			
2/28/18	Begin developing educational session material, posters, handouts, and PowerPoint			
3/1/18		Complete all interviews with members of the church for needs assessment		
3/27/18		Attend palliative care symposium at SBMC and finalize educational session material		
4/8/18	Submit Proposal part 2			
01/2019		Submit IRB application		
1/2019		Handout flyers, Hang up Posters in church, Public announcements during church services		

4/2/2019			Conduct educational Session in church	
4-17-2019				Complete analysis of all pre-survey, post-survey, 2 week follow up and evaluations
Table 1 Project Timeline				

## **Budget**

The budget for the implementation of this project had only a few expenses. All printed material including 300 handouts and 37 educational training packages (8 pages per package) was \$0.27 per page totaling \$156.60. One pack of ballpoint pens was purchased for \$6.49 to use during educational training. The church gym was complimentary for the educational training. A palliative care symposium provided by Saint Barnabas Medical Center was presented at no cost to the primary investigator since she's an employee of RWJ Barnabas Healthcare System.

## **Evaluation Plan**

### **Data Collection**

A background survey (Appendix A) developed by the primary investigator was utilized to describe the study population. Background survey questions included the age, sex, race, educational level, income, marital status, and primary language of each subject. Each participant was assigned a number and this number was the only identifying information on all forms completed by the participant. A master list of numbers associated with each participant's name and phone number was locked in a file cabinet and only accessed by the primary investigator. Background survey and any other forms had the subjects number located on them but not their

names. All information was locked away until the end of the study and was destroyed as per Rutgers IRB protocol

The Palliative Care Knowledge Survey contains thirteen items to assess the subject's understanding of palliative care (Appendix D). Completion of the PaCKS pre-survey, post-test #1 and post-test #2 were evaluated for an increase in knowledge and retention of knowledge regarding palliative care. A survey that assessed the ability of African Americans to make clear informed decisions between palliative care, hospice care, and usual treatment options was warranted. This was evaluated by having the subjects complete the questionnaire "Decisional Conflict Scale" (Appendix B) prior to the presentation, after the educational session post-test #1 and post-test #2. Conducting a post-test 1 and post-test 2 enabled the primary investigator to see if the educational session was effective by increased scores on the pretest and post-test 1, pretest and post-test 2 and between post-test 1 and post-test 2.

### **Data Analysis Plan**

The Decisional Conflict Scale has three responses, yes for zero points, unsure for two points, and no for four points. To analyze the decisional conflict scale, all ten answers were summed together, divided by 10 and multiplied by 25. Scores ranged from 0 defining no decisional conflict to 100 determining extremely high decisional conflict. Ratings for pre-survey, post-test #1, and post-test #2 were determined by the primary investigator. The Palliative Care Knowledge Survey was given pre-survey, and post-test #1, and post-test #2 were given after the educational training to evaluate for an increase and retention of knowledge and was analyzed by the primary investigator. Categorical data was obtained from the demographic survey. A descriptive bivariate analysis of the data was conducted based on the pretest and post-tests 1 and 2 for both sets of questionnaires and entered in the statistical analysis program SPSS version 24. An

analysis of skews and normal distribution was conducted, which could be affected by the sum of participants and collected data. A repeated measures analysis of variance (ANOVA) was considered for analysis, however, due to the small sample size, a non-parametric test and a standard mean and deviation were used to analyze the data.

## **Results**

A total of 46 people were recruited to participate in this project, which accounted for 15% of the total population of the church. After reviewing the data collected only 37 surveys were selected for analysis due to the studies inclusion and exclusion criteria. The findings of this project are discussed in sections: 1) results of Background Survey; 2) Results of Pre-Test Survey, Post-Test #1, and Post-Test 2 Follow-Up; and 3) Results of the Educational Session Evaluation. After the educational project, all survey information was scored and plotted into Microsoft Excel. This data was reviewed to ensure proper transfer of information. The data collected were de-identified; Results are reported from a group perspective not individualized. To protect the participant's privacy, tracking of their responses were avoided. Participants completed the Decisional Conflict Scale and the Packs survey before the educational session, after the session, and 2-weeks post session. The Pre-Test Survey had a response rate of 100% (n=37), the Post-Test #1 had a response rate of 100% (n=37), and the 2-week follow-up had a response rate of 78% (n=29).

### **Results of Background Survey**

Thirty-seven participants completed the Background survey. Characteristics of the demographic survey showed that all participants were African American and reported English as their primary language. The majority of participants (n=10, 27%) were between the ages of 36-45, followed by ages 46-55 and 56-68 (n=8, 22%) for both groups, ages 26-35 accounted for

(n=7, 19%) and the smallest group 19-25 (n=4, 10%) (Table 1). The mean age of all 37 participants was 43 years old. Results indicated 59% of the participants were single, followed by 27% married, 11% classified as a widow, and 3% reported separated as their marital status (Table 2). There were a total of 29 females and eight males that participated in this study. Income was listed in intervals and participants were asked to select the income that best suited their mean household income. The largest group (n=10, 27%) reported an income of \$42,381-\$54,999 and the smallest group (n=3, 8%) reported an income of less than \$20,000 a year (Table 3). In regard to educational status majority of participants (n=15, 41%) had their high school diploma, followed by (n=10, 27%) contained a bachelors' degree, (n=7, 19%) represented participants with an associate degree, (n=4, 11%) contained a master's degree, and lastly (n=1, 2%) did not complete high school (Table 4).

During end of life, families rely on religious communities for help and support during challenging time. For this reason, the primary investigator decided to perform the study in a religious community. This demographic survey also questioned participants on their religious attendance and spiritual time. Recruitment and facilitation of this pilot study were performed at a religious institution. Thirty percent of the study population reported they participant in private spiritual time more than once a day (Table 5). Forty-one percent of the people also said they attend religious meetings two or more times a week (Table 6). Only 14% of participants reported they had a chronic illness.

Table 1
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<i>Age of Study Participants</i>		
Group	Frequency	Percent
19-25	4	10%
26-35	7	19%
36-45	10	27%
46-55	8	22%
56-68	8	22%
Total	37	100%

Table 2		
<i>Marital Status</i>		
Group	Frequency	Percent
Married	10	27%
Separated	1	3%
Single	22	59%
Widow	4	11%
Total	37	100%

Table 3
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<i>Income of Study Participants</i>		
Group	Frequency	Percent
Below \$20,000	3	8%
\$20,000-\$29,999	2	5.4%
\$30,000-42,380	4	11%
\$42,381-\$54,999	10	27%
\$55,000-\$75,000	6	16.2%
\$75,001-\$100,000	6	16.2%
Above \$100,000	6	16.2%
Total	37	100%

Table 4		
<i>Education Level</i>		
Group	Frequency	Percent
Did not complete HS	1	2%
High School	15	41%
Associate Degree	7	19%
Bachelors' Degree	10	27%
Master's Degree	4	11%
Total	37	100%

Table 5
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<i>Religious Attendance</i>		
Time	Frequency	Percent
More than 1/day	5	13%
Daily	2	5%
Once a week	7	19%
2 or more/week	15	41%
Few Times/month	3	8%
Rarely or Never	5	14%
Total	37	100%

Table 6		
<i>Spiritual Time</i>		
Time	Frequency	Percent
More than 1/day	11	30%
Daily	11	30%
Once a week	5	13%
2 or more/week	7	19%
Few Times/month	2	5%
Rarely or Never	1	3%
Total	37	100%

### Decisional Conflict Scale Findings

The Decisional Conflict Scale has three responses, yes for zero points, unsure for two points, and no for four points. To analyze the decisional conflict scale, all ten answers were summed together, divided by 10 and multiplied by 25. Scores ranged from 0% defining no decisional conflict to 100% determining extremely high decisional conflict.

Pretest scores showed a range of 0% to 100% in decisional conflict prior to the educational session. Pretest scores showed a range of 0% to 46%, post-tests # 1 showed a range of 0% to 15% and # 2 showed a range of 0% to 10%. A mean and standard deviation was calculated to show differences between pretest, posttest #1 and posttest #2. Pretest mean score ( $M= 46, SD =0.28$ ). Posttest #1 score was ( $M=2, SD = 0.04$ ). Posttest #2 score was ( $M= 0 SD = 0.02$ ). Results indicate there was an overall decrease in mean scores after the educational session. A Friedman test was used to analyze change over time. A Wilcoxon test was used as a post hoc test to look for change within the pre and post- tests 1 and 2. The Friedman test showed statistically significant difference within the pre, post test 1 and post test 2 ( $p < 0.00001$ ). Wilcoxon rank test run as post hoc test to show that there is a statistically significant difference between pre and post 1 DCS scores ( $p=0.000013$ ). In addition, there is also a statistically significant difference between pre and post 2 DCS scores ( $p=0.000017$ ). There is no statistically significant difference between post test 1 and post test 2-week follow up surveys ( $p=0.09$ ).

Table 9			
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<i>Changes in DCS over time</i>					
	Pretest	Post test 1	Post test 2	$\chi^2$	<i>p</i> -value
Mean $\pm$ SD	46 $\pm$ 0.28	2 $\pm$ 0.04	0 $\pm$ 0.02	44.517	0.00001

### **The Palliative Care Knowledge Survey Findings**

All participants completed the PaCKS (Appendix D) as part of the pretest, and post-tests # 1 and # 2. The Palliative Care Knowledge Survey contained thirteen items to assess the subject's understanding of palliative care and responses included True or False. The correct response for each question scored one point and an incorrect response scored zero points. Results ranged from 0% which represents the lowest knowledge score to 100% representing the highest knowledge score. Completion of the PaCKS pre-survey, post-test #1 and post-test #2 were evaluated for an increase in knowledge and retention of knowledge regarding palliative care. A mean and standard deviation was calculated to show differences between pretest, posttest #1 and posttest #2. Pretest total score ( $M= 77$ ,  $SD =0.21$ ). Posttest #1 score was ( $M=98$ ,  $SD = 0.02$ ). Posttest #2 score was ( $M= 97$   $SD = 0.05$ ). Results indicate there was an overall increase the mean scores after the educational session. A Friedman test was used to analyze change over time. A Wilcoxon test was used as a post hoc test to look for change within the pre and post-tests 1 and 2. The Friedman test showed statistically significant difference within the pre, post test 1 and post test 2 ( $p < 0.00001$ ). Wilcoxon rank test run as post hoc test to show that there is a statistically significant difference between pre and post 1 PaCKS scores ( $p=0.000017$ ). In addition, there is also a statistically significant difference between pre and post 2 PaCKS scores

( $p=0.00015$ ). There is no statistically significant difference between post test 1 and post test 2-week follow up surveys ( $p=0.23$ ).

Table 9					
<i>Changes in PaCKS over time</i>					
	Pretest	Post test 1	Post test 2	$\chi^2$	$p$ -value
Mean $\pm$ SD	77 $\pm$ 0.21	98 $\pm$ 0.02	97 $\pm$ 0.05	27.553	0.00001

### Results of the Educational Session Evaluation

After the educational session participants were asked to fill out an evaluation form, the Educational Evaluation assessed the subject's perspective of the educational session and their overall learning experience. The overall response rate of this survey was 86% ( $n=32$ ). Evaluations response points were calculated on a Likert scale ranging from Strongly agree to strongly disagree (4-0). The average score was 99.5%, this response supports the need for additional PC educational sessions within the African American Christian community.

### Discussion

End of Life services are comprised of PC and Hospice Care and are significantly underutilized in the healthcare system. Many African Americans are unaware of the true meaning of palliative care and at what point in the illness trajectory to request services. Therefore, the purpose of this project was to assess the effect of an educational session on PC knowledge and level of confidence in End-of-Life decision making. Several studies such as Hendricks et al., (2016) recommended providing education in an environment African Americans trust such as a religious establishment. Baseline assessments of members of this

church by the Bishop revealed that 90% of family members were not aware of End-of-Life treatment services nor had end of life care been discussed with their loved ones (A. Gilyard, personal communication, February 1, 2018).

The sample represented about thirteen percent of a local Christian church in central New Jersey. The majority of participants were between the ages of 36-45 and thirty percent reported they participated in private spiritual time more than once a day. The initial educational session along with data collection lasted for one hour. Thirty-seven people participated in the pilot study and 29 continued throughout the entire study. As anticipated the quantitative data of the PaCKs mean scores were increased after the educational session which represents an increase in Palliative Care knowledge. Participants also had a decrease in conflict when making an informed end of life decision after the study implementation. These findings validate the need for outpatient educational sessions in nonmedical setting such as churches. In Summary, this pilot study is a foundation for larger studies to assess the impact of a faith based educational plan on African American Christians knowledge and involvement of PC.

## **Implications**

### **Policy**

Recommendations for palliative care education policy changes are organization based and national. National policies are the foundation for facilitating palliative care educational programs that will provide the missing outpatient educational component to African American Christians. Raising awareness for the lack of palliative care knowledge in African American Christian communities is imperative. The lack of standardized palliative care national policies could lead to additional symptomatic suffering of patients with life long illness. The first step is to increase awareness of the lack of educational outpatient programs for the Christian

community. Advocating for this population and increasing awareness will attract the attention of critical stakeholders. In return, national organizations such as the National Consensus Project for Quality Palliative Care, The National Hospice and Palliative Care Organization, and National Coalition for Hospice and Palliative Care can provide policy guidelines for educating African American Christians in religious settings. The National Consensus Project for Quality Palliative Care & National Coalition for Hospice and Palliative Care (2018), provided clinical guidelines for educational training of the interdisciplinary care team. The addition of clinical guidelines specific to different racial and ethnic populations may increase access and acceptance by these groups. For African American Christians an added guideline specific to this population could be education on PC in a nonhospital setting such as a place of worship. At present, there are enormous variations in palliative care educational programs varying from organization to organization and state to state.

After extensive research no policies for pastors or religious leaders to incorporate palliative care teaching to their congregation were discovered. The National Consensus Project for Quality Palliative Care (2013) recommends that chaplains be included in the PC team; however, there is no recommendation for adding teaching in a faith-based setting. Educating spiritual leaders and African American leaders on the lack of African American Christians' knowledge of palliative care may increase awareness. Health ministries can integrate palliative care pamphlets and educational tools into their religious services. Currently there does not appear to be a guideline for religious leaders to incorporate palliative care education into their religious ceremonies.

### **Best-Practices**

The National Hospice and Palliative Care Organization (2008) provided an African American Outreach guide focusing primarily on Hospice care. This guideline recommended getting to know the community, evaluating your resources, and gathering support before implementing an outreach program. There are no practice guidelines for educating African American Christians in an outpatient setting such as a religious institution. The End of Life Nursing Education Consortium PowerPoint could be used to teach African Americans in churches. Educating the African American community in non-threatening environments can increase their knowledge and change their perception of palliative care.

### **Dissemination and Future Trials**

This study is a pilot study and the results can only be descriptive of the study population. However, it can serve as information for larger randomized studies in the future. Disseminating the results of this pilot study may prompt more palliative care community education research. The results of this study cannot be generalized to all African American Christians, which is one limitation to this study. Future studies should allow longer follow-up time such as 3 months and 6 months to assess for retention of information. Palliative care team members can partner with a religious leader to explore and conduct randomized control studies on palliative care education in the African American Christian community.

### **Professional Reporting**

This project and results will be reported to the Rutgers School of Nursing faculty, and the findings will be published after approval by the DNP project committee. Secondly, the outcomes will be posted on the Rutgers library database. Manuscript and presentation submission to a professional organization is imperative. The 2019 International Conference on Palliative Care and Hospice are currently accepting abstracts and presentation applications. An application for



this conference along with submission of the abstract will be completed upon approval of the DNP project. SAGE Palliative Medicine Journal is a peer-reviewed scholarly journal used to improve palliative care. An online application will be submitted to Palliative Medicine editors since this would be an excellent match for project dissemination. Lastly, findings will be reviewed with the Bishop and congregation to encourage teaching in other faith-based facilities. Pamphlets and posters can be displayed at the 112th National Holy Convocation which is a more extensive gathering to celebrate Christians.

### **Conclusions**

Palliative Care clinicians must develop an appropriate outpatient educational plan to increase palliative care knowledge in the African American Christian community. This project discovered that African American Christians are not only open to learning more about PC but also to become more involved in PC. To ensure best practices, future palliative care educational sessions should take place in an outpatient setting and include End of Life Nursing Education Consortium PowerPoint slides. National palliative care organizations should incorporate educational outreach guides for African American Christians.

There were three barriers mentioned that limited African American Christians participation in PC: 1) healthcare mistrust; 2) misconception; and 3) poor communication. Educating African American Christians in religious institutions should ultimately lead to improved healthcare trust, communication, and understanding of PC. This is imperative to improve the quality of life of individuals with chronic illness and to prevent symptomatic suffering.

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