

**COMIRB Protocol**

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**Protocol #: 23-0899**

**Project Title:** Underutilization of Hospice Care in Older Black Adults

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**I. Hypotheses and Specific Aims:** This research aims to recruit a nationally representative sample of older Black adults to assess their knowledge, opinions of hospice, decision making agency, and evaluate if the hospice PtDA improves these outcomes. The larger sample will support exploration of important subgroup variations such as socioeconomic status and geography (e.g., urban vs rural settings) that my prior research was unable to address.

**Aim 1:** To assess baseline hospice knowledge, opinions of hospice, and decision self-efficacy in a nationally representative sample of Black adults aged 65 and older.

**Aim 2:** To evaluate the effect of the hospice PtDA on improving hospice knowledge, opinions of hospice, and decision self-efficacy in a nationally representative population of Black adults.

**Aim 3:** To evaluate the appropriateness and acceptability of the hospice PtDA and explore specific barriers to hospice qualitatively.

**II. Background and Significance:**

**Hospice care remains underutilized.** The prevalence and severity of chronic and terminal conditions continues to grow in the US.<sup>1,2</sup> Consequently, there are a greater number of people living with these conditions who may benefit from hospice care. Yet, hospice remains an underutilized healthcare benefit. Currently fewer than 50% of hospice eligible Medicare decedents enrolled in hospice prior to death.<sup>3,4</sup> Further, one-third of all hospice recipients receive care for less than 7 days prior to death.<sup>5,6</sup> Short stays in hospice prevent patients and families from benefiting from the full spectrum of services offered by hospice care but also imposes strains on Medicare. Medicare is the primary payer for persons over the age of 65 and individuals receiving hospice care.

**Racial and ethnic disparities in hospice enrollment are striking.** The number of Black adults reaching the age of 65 is one of the fastest growing demographics in the US. Black adults make up 9% of all people over the age of 65 and this will increase to 13% of adults over age 65 in 2060.<sup>7,8</sup> Approximately 24% of all persons over the age of 65 identify as a race other than White. One-fourth of Medicare beneficiaries are racial and ethnic minorities, more than 10% of whom are Black.<sup>9</sup> Yet only about 40% of Black Medicare decedents receive hospice care while 53% of White Medicare decedents enroll in hospice.<sup>6,10</sup> Black adults experience more mortality and morbidity than their White peers and suffer disproportionately from the top three diagnoses of hospice enrollees: cancer, cardiovascular disease, and dementia.<sup>2,5,7</sup> Further, older Black adults are more likely to be diagnosed with more severe forms of disease and be diagnosed later in the disease trajectory than older White Americans,<sup>2,7,11</sup> thus making hospice care a critical healthcare service in this population. The disparities in health between Black Americans and other racial and ethnic groups is well documented in the literature.<sup>12-15</sup> With respect to hospice, there are several misperceptions and mistrust experienced in Black communities. However, there is clear evidence that it is possible to overcome these barriers and that Black adults value and benefit from the services provided by hospice care.<sup>16-20</sup> Yet disparities in knowledge and exposure to hospice

prevent many from accessing care<sup>21-23</sup> making interventions that build trust and increase knowledge and exposure to hospice important to providing the best possible care at the end of life.

**Benefits of hospice care.** Hospice provides specialized medical treatment to patients with life-limiting diseases by prioritizing quality of life over quantity of life. Research demonstrates that Black Americans benefit from hospice care, report improved quality of life outcomes, and report receiving better quality of care in hospice compared to non-hospice care,<sup>17,24,25</sup> yet very few Black adults enroll in hospice care. The reasons driving low enrollment are numerous and multifactorial. Some barriers include late referrals from providers, religious and/or cultural beliefs, a perceived inherent preference for more aggressive treatments, lack of knowledge about hospice services, a prevalence of misinformation about hospice care, and mistrust in healthcare.<sup>26-32</sup> Given the numerous medical and psychosocial benefits of hospice, the evidence that Black Americans do benefit from hospice services and the growing number of Black older black adults experiencing life-limiting conditions there is an urgent need to devise interventions to make hospice accessible to older Black adults.

**Shared Decision-Making is a proven effective strategy to improve patient outcomes in minoritized communities but is understudied.**<sup>33-35</sup> Shared decision-making (SDM) is a proven and recommended approach to improve patient-provider communication, patient agency and autonomy, to build trust, and to reduce decisional conflict in persons making complex medical decisions.<sup>35</sup> One common SDM technique is the use of patient decision aids (PtDAs). PtDAs provide information on treatment options, help elicit patient values, and facilitate deliberation between patients and providers on treatment choices.<sup>36</sup> PtDAs assume various forms including paper (e.g. leaflets, pamphlets, and booklets), electronic media (e.g. audio recordings, videos), and web-based interactive portals.<sup>35</sup> Seriously ill patients routinely express a desire for SDM at the end of life,<sup>37</sup> however, to my knowledge our hospice specific PtDA is the only freely available tool explicitly designed to support hospice decision-making.<sup>38</sup>

The National Academy of Sciences (NAS) highlighted a critical need to improve communication around end-of-life transitions and the need for better shared decision making around end of life especially among communities of color.<sup>39</sup> Additionally, SDM in Black adults is understudied<sup>33</sup> despite an expressed desire to engage in SDM with their providers.<sup>34</sup> This project can address the absence of SDM making interventions in Black adults and simultaneously gaining data on the barriers preventing Black adults from enrolling in hospice.

### **III. Preliminary Studies/Progress Report:**

My prior research, (NIA/NIH dissertation award R36AG064135), used a novel hospice specific PtDA to improve awareness and decrease misconceptions about hospice in a cohort of Black adults aged 65 and older. The hospice PtDA consist of both a paper booklet and video. This was the first to quantitatively assessing hospice knowledge in a population of older Black adults.<sup>40</sup> The findings indicated lack of knowledge and misinformation are barriers to hospice use. The PtDA reduced these barriers and increased decision-making agency. This study was limited to the Denver Metro area and not generalizable to a broader population.

### **IV. Research Methods**

**Overview:** There are two primary goals of the proposed study: The first goal is to assess baseline hospice knowledge, opinions of hospice, and self-efficacy in making decisions about hospice care as a treatment option. The second goal is to determine if a hospice specific PtDA can improve hospice knowledge, opinions of hospice, and self-efficacy in making hospice decisions. Both goals will use a nationally representative sample of Black and White adults aged 65 and older.

#### **A. Outcome Measure(s):**

- **Hospice Knowledge Test:** Hospice knowledge will be quantitatively assessed using the 23-item hospice knowledge survey.<sup>41</sup> This survey consists of true/false questions, with scores ranging from 0 to 23, awarding one point for each correct answer. A higher score indicates more knowledge of hospice. The Cronbach's  $\alpha = 0.75$  indicates a good degree of internal reliability.

- Hospice Beliefs and Attitude Scale (HBAS): Opinions of hospice care will be measured using the HBAS. The HBAS is an 8-item scale designed to measure beliefs and attitudes regarding hospice care.<sup>21</sup> The HBAS is scored from 8 to 40, with a higher score indicating more positive views of hospice care. The scale uses a 5-item Likert scale with answers ranging from “strongly disagree” to “strongly agree” for all questions. The scale reports a Cronbach’s  $\alpha = .74$ .
- The Decision Self-Efficacy Scale (DSE): DSE is an 11-item instrument using a 5-point Likert scale that measures one’s self-efficacy or confidence in making medical decisions.<sup>42,43</sup> The DSE has a Cronbach’s  $\alpha = 0.92$ .
- Medical Mistrust Index (MMI): Medical Mistrust Index (MMI) is a 17-item scale that measures mistrust of societal institutions and healthcare. The MMI answers consist of a 4-point Likert scale. Possible scores range from 5 to 75, with higher scores indicating more mistrust. This index helps to determine a correlation between the level of mistrust and hospice knowledge. The Cronbach’s  $\alpha = .76$  for the scale indicates acceptable internal reliability.

**B. Description of Population to be Enrolled:** A nationally representative sample of 400 Black adults aged at least 65 will be recruited using the IPSOS Knowledge Panel. Participants will be eligible if they are at least 65 years of age, can read and write English and self-identify as Black/African American.

**C. Study Design and Research Methods**

**Design:** The proposed project is a randomized controlled trial to determine if the hospice specific PtDA improves hospice knowledge, opinions of hospice, and decision self-efficacy in a nationally representative cohort of 400 Black adults aged 65 years or older.

**Aim 1** consists of a baseline measurement of hospice knowledge, opinions of hospice, and decision self-efficacy (survey instruments described above) in making decisions about hospice care. A total of 400 participants will be enrolled at baseline and complete the baseline surveys.

**Aim 2** Upon completion of the baseline assessment, 200 participants will be randomly assigned to review the hospice PtDA. The hospice PtDA exists as a 12-page booklet. The PtDA is available here: <https://patientdecisionaid.org/hospice/>. The control group will not view the PtDA and will be asked to review an attention control activity similar to the hospice PtDA but about dementia care not hospice. The attention control activity is a 8-page booklet that is available here <https://patientdecisionaid.org/wp-content/uploads/2022/07/Dementia-Support-Tool- FINAL 6.1.2022.pdf>. All participants will be contacted approximately 30 days after the baseline assessments to complete the follow-up surveys. Participants will receive \$5 for completing the baseline visit and an additional \$5 for completing the 30-Day Follow-Up for a total of \$10 for completing the study.

**Aim 3** consist of up to 20 qualitative interviews with participants in the intervention arm who saw the hospice decision aid. The purpose of this aim is to evaluate the PtDA for appropriateness and acceptability. The PtDA was intentionally designed to be general and not culturally tailored to any specific group or disease process. These interviews will provide data on any modifications or revisions that may make the decision aid more appropriate for use in a population of older black adults. Individuals completing the interviews will receive a \$25 gift card.

**Recruitment:** Participants will be recruited using Ipsos KnowledgePanel, which is the oldest and largest probability-based online panel in the U.S. Ipsos maintains a nationally representative panel by using address-based sampling and providing internet access to recruited individuals who do not have it. Ipsos guarantees sample demographics (gender, race, ethnicity, age, education) and will closely match U.S. census distributions. Eligibility criteria for this study include self-identifying as Black or African American and being at least 65 years of age. Participants will be excluded if they are unable to read and write English or have a cognitive impairment that prevents them from providing informed consent. At the conclusion of the 30-day follow-up visit IPSOS will ask respondents in the intervention group if they are willing to participate in a qualitative interview (Aim 3). If the respondent consents, they will contact the study PI directly to schedule the interview.

#### **D. Description, Risks and Justification of Procedures and Data Collection Tools:**

#### **E. Potential Scientific Problems:**

#### **F. Data Analysis Plan:**

**Aim 1:** To assess baseline hospice knowledge, opinions about hospice, and decision self-efficacy in a nationally representative sample of Black adults aged 65 and older.

**-Quantitative Analysis:** To achieve an alpha of 0.05 and a modest effect size of 0.3, a power analysis completed in SPSS<sup>44</sup> yielded a required sample size of 139 individuals per group. Thus, the project will recruit a total of 400 participants (200 per group) to account for potential losses to follow-up. The literature on SDM and PtDAs varies in what is an acceptable effect size for increasing patient knowledge with PtDA interventions from 10% to 65%.<sup>35</sup> I hypothesize that baseline knowledge will be low in this sample and based on the results of my prior work I am proposing a modest effect size of 0.3 for this project. Differences in mean scores between socioeconomic variables (e.g., income, education, zip code) and location (e.g., urban vs rural) will be evaluated using independent t-tests or  $\chi^2$  where appropriate. Additionally, multiple regression models will be used to assess differences between and within groups.

**Aim 2:** To evaluate the effect of the hospice PtDA on changing hospice knowledge, opinions of hospice, and decision self-efficacy in a population of Black and White adults aged 65 and older.

**-Quantitative Analysis:** Differences will be evaluated both between and within groups using paired and independent t-tests, respectively. Additionally, multiple regression models will be used to assess differences between groups pre/post-test.

**Aim 3:** To further understand the specific barriers to hospice enrollment and to elicit feedback about the appropriateness and acceptability of the PtDA I will conduct qualitative interviews with a subset of up to 20 participants in the intervention group who reviewed the PtDA.

**-Qualitative Analysis:** The interviews will be approximately 30-60 minutes. Recorded and transcribed verbatim. All interviews will be entered into Atlas.ti 9.0 (GmbH, Berlin) Atlas.ti was used for the qualitative analyses. The analysis will use inductive and deductive content analysis.<sup>45-47</sup> The deductive approach evaluate the appropriateness of the PtDA by asking questions about the length of the PtDA, the clarity of how information was presented and its utility in making decisions about hospice care. Feedback and concerns will be incorporated in future versions of the PtDA in preparation for broader dissemination and implementation of the PtDA. The inductive approach allows for other domains not previously identified to emerge, such as potential misconceptions or fallacies expressed by participants. Analysis will be done by systematically organizing the data through open coding and repeated comparisons across coded data to identify the key themes.

## **G. Summarize Knowledge to be Gained:**

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