COMIRB
APPROVED
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Principal Investigator: Channing E. Tate, MPH
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Study Title: Hospice Underutilization in Older African Americans

You are being asked to be in a research study. This form provides you with information about the study. A member of the research team will describe this study to you and answer all of your questions. Please read the information below and ask questions about anything you do not understand before deciding whether or not to take part.

Why is this study being done?

This study is designed to test whether or not hospice decisional support materials can improve hospice knowledge, attitudes, and beliefs towards hospice in older African Americans. The study will also examine how perceived discrimination and mistrust in healthcare influence the opinions of hospice care in older African Americans. You are being asked to participate in this research study because you self-identity as African American and you are 65 years of age or older.

Up to 150 people will participate in the study.

What happens if I join this study?

If you join the study, you will be asked to complete a short writing sample describing in your own words “what is hospice” as well as a series of surveys about your opinions of hospice. This will be completed in-person after you agree to be a part of the study. You will then be randomized into one of two study arms either the intervention group or the control group. If you are randomized to the intervention group, you will be given the decision aid materials and asked to review it within the next week. After that next week all intervention patients will receive a one week follow-up call where participants will be asked to complete some additional surveys about the decision aids. One month after your original enrollment date you will receive another follow-up call/email where you will be asked to complete some surveys about your opinions of hospice. Control patients will receive only the initial surveys and the one-month follow-up call/email surveys.

What are the possible discomforts or risks?

Discomforts you may experience while in this study include feeling uncomfortable discussing hospice or end-of-life decisions. You can refuse to answer any questions you do not wish to answer and may end your participation in the study at any point.

What are the possible benefits of the study?

The proposed research aims to specifically target older African Americans who are especially vulnerable to hospice underuse. The decisional support materials used in the proposed research will provide valuable insights into issues and barriers that prevent African Americans from enrolling in hospice while simultaneously evaluating whether or not hospice decisional support materials may be useful to improve hospice knowledge, attitudes, and beliefs in older African Americans.

Will I be paid for being in the study? Will I have to pay for anything?

Should you choose to participate in this study, you will be paid for your time with a Twenty-five dollar ($25) gift card after completion of the baseline and one-month follow-up survey for a total of fifty dollars ($50).

It will not cost you anything to be in the study.

Is my participation voluntary?

Taking part in this study is voluntary. You have the right to choose not to take part in this study. If you choose to take part, you have the right to stop at any time. If you refuse or decide to withdraw later, you will not lose any benefits or rights to which you are entitled. Should you decide not to participate, this will have no impact on the usual healthcare you receive.

Who do I call if I have questions?

The researcher carrying out this study is Channing Tate. You may ask any questions you have now. If you have questions later, you may call Channing Tate at 720-724-8985.

You may have questions about your rights as someone in this study. You can call Channing Tate with questions. You can also call the Multiple Institutional Review Board (IRB). You can call them at 303-724-1055.

Who will see my research information?

The University of Colorado Denver and the hospital(s) it works with have rules to protect information about you. Federal and state laws including the Health Insurance Portability and Accountability Act (HIPAA) also protect your privacy. This part of the consent form tells you what information about you may be collected in this study and who might see or use it.

The institutions involved in this study include:

- University of Colorado Denver

- University of Colorado Hospital
- Denver Health and Hospital Authority

We cannot do this study without your permission to see, use and give out your information. You do not have to give us this permission. If you do not, then you may not join this study.

We will see, use and disclose your information only as described in this form and in our Notice of Privacy Practices; however, people outside the University of Colorado Denver and its affiliate hospitals may not be covered by this promise.

We will do everything we can to keep your records a secret. It cannot be guaranteed.

The use and disclosure of your information has no time limit. You can cancel your permission to use and disclose your information at any time by writing to the study's Primary Investigator, at the name and address listed below. If you do cancel your permission to use and disclose your information, your part in this study will end and no further information about you will be collected. Your cancellation would not affect information already collected in this study.

Channing E. Tate, MPH
University of Colorado Denver
13199 E. Montview Blvd, Suite 300
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Both the research records that identify you and the consent form signed by you may be looked at by others who have a legal right to see that information.

- Federal offices such as the Food and Drug Administration (FDA) that protect research subjects like you.
- People at the Colorado Multiple Institutional Review Board (COMIRB)
- Officials at the institution where the research is being conducted and officials at other institutions involved in this study who are in charge of making sure that we follow all of the rules for research

We might talk about this research study at meetings. We might also print the results of this research study in relevant journals. But we will always keep the names of the research subjects, like you, private.

Every effort will be made to protect your privacy and confidentiality by keeping identifiable information separate from study data and keeping all data in a secure location only accessible by

study personnel, including a secure password protected online database and in a locked file cabinet.

We will do everything we can to honor and protect your privacy.

You have the right to request access to your personal health information from the Investigator.

Information about you that will be seen, collected, used and disclosed in this study:

- Name and Demographic Information (age, sex, ethnicity, address, phone number, etc.
- Research Visit and Research Test records

Agreement to be in this study and use my data

I have read this paper about the study or it was read to me. I understand the possible risks and benefits of this study. I understand and authorize the access, use and disclosure of my information as stated in this form. I know that being in this study is voluntary. I choose to be in this study: I will get a signed and dated copy of this consent form.

Signature:_____ Date:_____

Print Name:_____

Consent form explained by:_____ Date:_____

Print Name: _____

Witness:_____ Date_____

Print Name: _____

Witness of Signature

Witness of consent process