

# Community-based End-of-life Intervention for African American Dementia Caregivers

<https://www.neurodegenerationresearch.eu/survey/community-based-end-of-life-intervention-for-african-american-dementia-caregivers/>

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### Country

USA

## Title of project or programme

Community-based End-of-life Intervention for African American Dementia Caregivers

## Source of funding information

NIH (NIA)

## Total sum awarded (Euro)

€ 2,030,120.18

## Start date of award

15/08/2013

## Total duration of award in years

4

## The project/programme is most relevant to:

Alzheimer's disease & other dementias

## Keywords

Acquired Cognitive Impairment... Aging... Alzheimer's Disease... Alzheimer's Disease including Alzheimer's Disease Related Dementias (AD/ADRD)... Behavioral and Social Science... Bioengineering... Brain Disorders... Caregiving Research... Clinical Research... Clinical Research - Extramural... Clinical Trials and Supportive Activities... Dementia... Minority Health for IC Use... Neurodegenerative... Palliative Care... Prevention... Translational Research

### **Research Abstract**

DESCRIPTION (provided by applicant): End-of-life (EOL) care plans made in advance for relatives with dementia save families anguish in times of medical crises, but less than 13% of African Americans (AAs) have such plans. Yet, they have high morbidity and mortality rates from dementia. A community-based study will examine the efficacy of an education activation (EduAct) intervention for AA family caregiver healthcare proxies (HCPs) to make EOL decisions on cardiopulmonary resuscitation (CPR), mechanical ventilation (MV), and tube feeding (TF). In a pre/posttest, two condition, repeated measure, randomized design, controlled efficacy trial, HCPs with no EOL care plans will be assigned to either EduAct or attention control groups. We will deliver 9 waves of 4 weekly sessions, a 4-mo booster tailored to residual knowledge deficits. We will enroll 304 AA HCPs (n=152 per group) in 4 urban AA churches randomly assigned to EduAct (n = 2) or control (n = 2) sites, with 8-9 subjects recruited concurrently at each site. The EduAct condition will receive interactive discussions from a nurse facilitator on EOL care planning, dementia, CPR, MV, and TF treatments. The attention control condition receives interactive health-promotion from another nurse facilitator. The Theory of Reasoned Action and Kolb's Experiential Learning Theory frameworks guide both interventions to enhance knowledge, self-efficacy, intention, and behaviors. Questionnaires will be completed pre, immediately post, and 4 mo (booster) for efficacy; evaluations completed at 6 mo, 12 mo, 18 mo, and 24 mo post intervention in both groups to document EOL care when a life threatening medical crisis occurs related to CPR, MV or TF. Lay teachers (n = 8) will be trained to demonstrate feasibility for a community-based model to continue the EduAct program after completion of the study. Specific aims are to: Aim 1. Compare the effect of the EduAct and attention control interventions on HCPs': (a) knowledge (dementia, CPR, MV, TF); (b) self-efficacy about EOL care plans; (c) intentions to write an EOL care plan and (d) behavior (written EOL care plan). Controlling for pretest values and selected covariates, we hypothesize that at all time points the EduAct group will have more: (a) knowledge, (b) self-efficacy, (c) intentions and (d) behaviors (primary outcome) than the control group. Aim 2. Compare the HCPs' immediate posttest written care plan and the care provided within 2 years when any life-threatening medical crisis occurred related to CPR, MV, and TF (exploratory aim). We hypothesize that significantly more EduAct group dementia victims will receive CPR, MV, or TF treatments consistent with the immediate posttest written care plan than the control group. Aim 3. Determine the feasibility of training lay teachers to deliver the EduAct program. Feasibility is defined as retention of lay teachers, fidelity of program delivery, self-efficacy to deliver the program, and intention to deliver future programs. We expect to retain at least 50% of the lay teachers who will deliver it with high fidelity, and report high self-efficacy and intention to deliver the program.

### **Lay Summary**

PUBLIC HEALTH RELEVANCE: We developed an education program on dementia, cardiopulmonary resuscitation, tube feeding and mechanical ventilation for family caregivers' of relatives with dementia. The program is designed for caregivers to make the best end of life

treatment decisions prior to a medical emergency. We will test the program to determine if works in a church setting and determine if lay teachers can conduct the program after the study is completed.

**Further information available at:**

**Types:**

Investments > €500k

**Member States:**

United States of America

**Diseases:**

Alzheimer's disease & other dementias

**Years:**

2016

**Database Categories:**

N/A

**Database Tags:**

N/A