Published in final edited form as:

Dementia (London). 2014 January 1; 13(1): . doi:10.1177/1471301212449408.

Advance Care Treatment Plan (ACT-Plan) for African American Family Caregivers: A Pilot Study

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Abstract

Research is limited on end-of-life (EOL) treatment decisions made by African American (AA) family caregivers. In a pilot study we examined feasibility of implementing an advance care treatment plan (ACT-Plan), a group-based education intervention, with AA dementia caregivers. Cardiopulmonary resuscitation (CPR), mechanical ventilation (MV) and tube feeding (TF) were EOL treatments discussed in the ACT-Plan. In a 4-week pre/posttest two-group design at urban adult daycare centers, 68 caregivers were assigned to the ACT-Plan or attention-control health promotion conditions. Theoretically based, the ACT-Plan included strategies to enhance knowledge, self-efficacy, and behavioral skills to make EOL treatment plans in advance. Findings strongly suggest that the ACT-Plan intervention is feasible and appropriate for AA caregivers. Self-efficacy and knowledge about dementia, CPR, MV and TF increased with ACT-Plan but not attention control condition. More ACT-Plan participants than control participants developed an advance care plan for relatives with dementia. Findings warrant a randomized efficacy trial.

Keywords

African-Americans; advance care planning; dementia caregivers

Dementia is a major cause of death and disability among older African Americans (AAs). By age 65, over 10% of AAs will be diagnosed with dementia; by age 85, 50% will.^{1, 2}

Although the etiologies of dementia may vary, the disease trajectory for 90% of diagnosed victims is relatively consistent and includes insidious, progressive, irreversible, cognitive and physical deterioration that ends with death.³ Cognitive deterioration hinders informed decision making by the patient. Patients and families who make advance care plans reduce the anguish in times of medical crises and have greater satisfaction with health care received, increased confidence in decisions made, fewer hospitalizations, and decreased utilization of intensive care services than those without advance care plans.⁴⁻⁹ Unfortunately, less than 9% of AAs have made advance care plans, as opposed to 18% to 30% of white Americans (WAs).¹³⁻¹⁵ AAs are 3 times more likely to be diagnosed with dementia than WAs and disproportionately receive less dementia care and education.¹⁶⁻¹⁸ Consequently, most dementia victims must rely on family members to make their decisions about critical end-of-life (EOL) treatment, such as cardiopulmonary resuscitation (CPR), mechanical ventilation (MV), and tube feeding (TF).

In order for caregivers to make informed EOL treatment decisions for cognitively impaired relatives, they must be knowledgeable about the consequences and trajectory of the disease.¹⁰⁻¹¹ In addition, caregivers become better equipped to make these choices in advance when they are provided knowledge, such as, benefits/risks and alternative treatments.¹² Unfortunately, there is limited knowledge about how to assist AA caregivers in developing and implementing advance care plans for relatives diagnosed with dementia. The purpose of this investigation was to examine the feasibility of implementing an advance care treatment plan (ACT-Plan) with AA caregivers of relatives diagnosed with dementia. The specific aims were to describe:

Aim 1: Protocol adherence, which was defined as attrition rate, attendance, instrument completion. We expected that, by the end of the 4-week session, 85% of the subjects would be retained; 80% would attend all four sessions; 80% would arrive on time for all four sessions; and 100% would complete at least 80% of the items at pretest and posttest on each instrument.

Aim 2: Change in caregivers' outcomes including: (a) knowledge about dementia and EOL treatments (CPR, MV, and TF); (b) self-efficacy regarding their advance care decisions about CPR, MV, and TF; and (c) decision to develop an advance care plan (behavioral skills) for relatives diagnosed with dementia. Comparing pretest and posttest values within and between groups, we expected an increase in knowledge, self-efficacy and decision to develop advance care plans for the experimental condition but not for the control condition.

Method

Design

Using a two-group, pre- and posttest design, AA caregivers of relatives diagnosed with dementia participated in either a 4-week ACT-Plan condition or attention control condition focused on health promotion. The conditions were assigned to five adult day care centers; two for the ACT-Plan condition and three for the attention control condition. We did not randomly assign the centers to conditions because initially there were only two centers and one had been the site where we conducted the pre-pilot study that informed this pilot study. Participants were recruited concurrently at each ACT-Plan and attention control site. Group sessions began simultaneously at the separate sites. Each group had four-weekly sessions with from five to nine participants. Subject participation determined the number of groups conducted at each site. A total of ten groups were conducted; five at the two ACT-Plan sites and five at the three attention control sites. All groups were assessed at pretest and after completion of the intervention (4-week posttest). Approval for the study was obtained by the

Institutional Review Board (IRB) at the University of Illinois at Chicago and administrators of the adult day care centers in which the study was conducted.

Sample and Setting

Sample—The sample consisted of 68 AA caregivers whose relatives were enrolled in adult day care centers located in AA urban communities in Chicago. They were the designated family member responsible for the care of their relative. Care receivers were AAs over the age of 65 who had very high participation in center-approved activities. All care receivers had physician generated diagnosis of dementia caused by Alzheimer's disease or other related neurological disorders and were reported to be in varying stages of the disease.

Setting—The settings were five adult day care centers; two selected for the ACT-Plan condition and three for the attention control. Separate sites were chosen by convenience for the intervention to avoid between group contamination and obtain the sample size required for sufficient study power. The communities where the five centers were located were geographically comparable and were very similar in demographic and socioeconomic characteristics. The directors at each site reported having similar philosophies regarding the administration of the centers and offered equivalent education programs for clients and family caregivers. Initial site equivalence was examined and no difference between intervention and control sites was observed. Client enrollment varied by site due to physical capacity of the buildings that housed the programs and length of time programs were in operation. Total enrollment of eligible prospective participants at the five centers was 92 and 28 at the two ACT-Plan condition sites and 63, 41 and 26 at the three attention control sites. Overall, each center maintained an 80% to 85% average enrollment of eligible dementia clients at any given time throughout the year, with an 86% to 90% average weekly rate of participation, and a low annual turnover rate of 1% to 3%.

Caregivers were eligible for participation in the study if they self reported that they were: a) AAs; b) relatives of care receivers; c) the designated decision maker for the care receiver; and d) knowledgeable about the care receiver's recent and past medical history. Inclusion criteria for the care receivers were: a) AAs, b) with physician-generated diagnoses of dementia; and c) no written advance care plan.

Procedure

Recruitment—Recruitment of study subjects was initiated after approval from the IRB. Our primary source of subject recruitment was referrals by the directors of the adult day care centers. We decided to rely on the directors for referrals because mistrust in health care providers may have served as a barrier that prevented prospective subjects from participating in research. Obstacles related to sociohistorical factors may have served as barriers (e.g., Tuskegee Study).

The recruitment approach involved several steps. Step 1: *Identification of potential participants*. An initial meeting was held with the PI of this study and directors of the day care centers. The purpose of the meeting was to describe the study and request an invitation to speak at the monthly family caregiver meetings. Potential subjects who responded to the meeting invitations received an initial brief introduction and overview of the study, including eligibility requirements. Step 2: *Participation eligibility*. After the presentation, a screening questionnaire on advance directives was administered to interested participants to determine eligibility. Caregivers who did not meet the eligibility criteria were not solicited for participation. The eligible and interested caregivers received detailed information about the study to foster trust in the research. They were invited to attend the scheduled ACT-Plan meetings for actual enrollment into the study and were asked to sign the IRB-approved

consent form. Monthly presentations at caregiver meetings were conducted as needed until all 68 subjects were recruited (35 subjects from intervention sites and 33 subjects from the attention control) and prior to each group iteration. Step 3: *Assignment by site*. Consenting participants were assigned by convenience to groups at each of the ACT-Plan or attention control sites.

All participants were asked about the availability of possible dates and times for their scheduled sessions. Within two weeks of recruitment, participants received information by telephone and in the form of a letter about the schedule for their pretest, 4-week sessions (either ACT-Plan or attention control), and posttest. Each weekly group session was conducted by one of two advanced practice nurse facilitators, both of whom were AA. They were trained by the PI using a standard training protocol. The first and last sessions were 90 minutes in length for completion of the pre and posttest. The second and third sessions were 60 minutes. Immediately preceding the first session, participants completed the pretest instruments, facilitated by the trained interviewer (research assistant [RA]). Immediately after completion of the fourth session, participants completed posttest instruments. The study instruments were distributed by the trained RA who remained in the room to answer questions and observe for illiteracy while participants completed the questionnaires. All instruments were collected, counted and checked immediately for missing items. Participants were asked to complete the items if items were missed in error or because of misunderstanding. All participants received an honorarium of \$25 and a tote bag that was offered at the week 4-posttest interview.

Attrition—Recruitment procedures and enrollment were continuously implemented until the planned enrollment of 64 subjects was obtained ($n = 32$ for each site). As many as 110 subjects from the two ACT-Plan sites (92 and 28 respectively) and 130 subjects from the three attention control sites (63, 41 and 26) met eligibility criteria for inclusion in the study. We replaced subjects up to the point of the first class session and anticipated a replacement rate of less than 2% based on trust-building strategies instituted, such as, recruitment through agency directors and conducting the study in the neighborhood setting familiar to the participants.

Retention Strategies—Address and telephone numbers of secondary sources were obtained from caregivers for tracking subjects during the intervention. Incentives were given to motivate individuals to enroll in the study, maintain interest, and sustain participation for 4 weeks of the ACT-Plan or health promotion sessions. In addition, light refreshments were offered during each session for both interventions. The pretest and posttest interviews took approximately 1 hour, in order to minimize respondent burden, and were conducted at the day care centers. All interviews and interventions occurred at a time that was convenient for the group of study participants. We believed that the day care centers were places where the subjects were comfortable and wished to meet. In addition we encouraged attendance by: (1) calling subjects the day before the intervention session as a reminder; and (2) calling subjects who missed an appointment to inform them of the next planned meeting.

Interventions

Bandura's Social Cognitive Theory and Kolb's Experiential Learning Theory are the two theoretical frameworks that guided this study. Bandura's Social Cognitive Theory,¹⁹ guided the selection of intervention outcomes, specifically knowledge, behavioral skills and self-efficacy acquired through performance accomplishment, as well as the content and implementation of the intervention. Kolb's Experiential Learning Theory²⁰ was used to develop the interactive course design, including the course objectives, teaching techniques, methods, and specific learning activities. Kolb's model complimented Bandura's self-

efficacy theory in that it guided how the learning process evolved to facilitate decision making. Evidence shows that education interventions constructed with a theoretical model and within a cultural context are more likely to be successful than similar interventions without these considerations.^{21,22}

The ACT-Plan intervention included strategies such as case studies, self-reflection, storytelling, and guided discussions to enhance knowledge, self-efficacy, and behavioral skills needed to make EOL treatment plans in advance.^{24,25} Additional discussions included risks and benefits of CPR, MV, and TF at the EOL for dementia patients. Participants in the ACT-Plan condition received the ACT-Plan interactive discussions from an advanced practice nurse facilitator.

The number of sessions, frequency, education content and intervention model were derived from survey responses obtained in a small pilot study (n=7) previously conducted by the PI of this project. The education content for the ACT-Plan group consisted of the following topics provided via the Kolb's learning circle approach: a) diseases that may cause dementia and long-term progression of the disease; b) rationale for and against use of CPR, MV, or TF for persons with end-stage dementia; and c) use of advance care planning. In the educational materials, we used people of color as actors in the audio visual presentations, handouts and flyers.

Participants in the attention control condition received interactive discussions on health promotion facilitated by a second advanced practice nurse. Topics included hypertension, diabetes mellitus and exercise. Health promotion topics were chosen because family caregivers are at risk for developing chronic diseases due to stress associated with the caregiving role.^{28, 29} The attention control group participants were offered discussions on advance care planning after completion of the four sessions. Both groups received information from the regularly scheduled programs offered at each site.

Measures

Protocol adherence—Attendance was documented on all subjects for the four weekly sessions. Retention rates were calculated from the information obtained from the recorded data on attendance. Instrument completion was assessed after each participant turned in his/her questionnaire at the pre- and posttest sessions.

Change in Caregivers' Outcomes—Knowledge of dementia was assessed using the Knowledge of Dementia Scale. This scale consists of 17 dichotomous "true/false" items that address a practical understanding of dementia and yields a maximum total score of 17. The scale has demonstrated validity and adequate internal consistency with an AA caregiver sample (Cronbach's alpha = 0.76).²⁶ The internal reliability ranged from 0.84 (pre-test) to 0.92 (post-test) for the current study.

Knowledge of CPR, MV, and TF was assessed using the Comfort with Knowledge Scale developed by the PI.²⁷ This 9-item scale contains both Likert (5-point) and dichotomous (yes/no) items that measure AA caregivers' general knowledge of CPR, MV, and TF. The scale has been used with a sample of 100 AA family caregivers and has a Cronbach's alpha of 0.79. For the current study, the internal reliability of the scale ranged from 0.85 (pre-test) to 0.80 (post-test).

Self-efficacy on decisions made for CPR, MV, and TF was assessed using a modified version of the Confidence in Treatment Decisions Made questionnaire. This 4-item Likert scale was refined from individual items used in a previous study.²⁷ Internal Consistency Reliability scores ranged from 0.94 (pre-test) to 0.93 (post-test) for the current report.

Decisions made for CPR, MV, and TF was assessed using the 5-item End-of-Life Treatment Decisions questionnaire.²⁷ This tool contains dichotomous (yes/no) and open-ended items on treatment decisions made and explanations regarding the choices.

Statistical Analysis

Simple descriptive statistics were used to assess whether the projected feasibility thresholds was met. An overall intervention effect at posttest was determined by responses to items about the chances of recovery with CPR, MV and TF treatments at the end stage of dementia. A large effect was defined with a score of 2 (chances of recovery at posttest were correctly reported); a medium effect was defined with a score of 1 (chances of recovery at posttest were not correctly reported but moved in the correct direction from pre to posttest); and no effect was defined with a score of 0 (participants incorrectly stated chances of recovery at posttest and pre to posttest moved in the wrong direction).

Before final statistical analysis, preliminary data were analyzed using univariate and graphical methods wherever applicable, to facilitate inspection and interpretation of data. Data error due to data entry oversight was appropriately corrected. Descriptive statistics including means, frequencies, and standard deviations were employed to describe sample demographic characteristics and outcome variables (knowledge about dementia, knowledge about CPR, MV, and TF, self efficacy, and ACP decision). Differences in demographic characteristics and outcome variables between the two experimental groups were measured using Student's t test for continuous variables and chi-square or Fisher's exact test for categorical variables. Finally, analysis of covariance (ANCOVA) was conducted to examine the effect of ACT-Plan on increasing knowledge of dementia, CPR, MV, and TF and self-efficacy over time. Statistical significance was established at an alpha level of 0.05. All statistical analyses were performed using SAS 9.2 statistical software (SAS Inc., Cary, NC).

Results

Demographic Characteristics

The ACT-Plan and attention control groups did not differ on demographic characteristics. Most of the caregivers were retired middle age daughters with some college or higher education. Although trend differences were found for incomes ($p=0.066$), a high percentage of reported incomes were at or above \$40,000 in both groups. Also everyone in both groups had a religious affiliation and most was either Baptist or other, e.g., Pentecostal, Church of God and Christ. Both groups had similar lengths in caregiving ($p=0.21$) (Table 1).

Both groups of care receivers were similar. Most were women ($n=26$, 79% and $n=29$, 88%) with mean ages of 81.7 ± 9.3 yrs and 78.7 ± 7.4 yrs. respectively and lived with the caregiver ($n=24$, 68.6%) (Table 2). Many had Alzheimer's disease ($n=18$, 54% and $n=16$, 48%) with mild to moderate disabilities ($n=29$, 87% and $n=26$, 81%). The groups differed significantly on the length of dementia ($p=0.04$) with six in the attention control group reporting 11 or more years with the disease and none in the ACT-Plan group reporting disease for 11 years or more.

Protocol adherence

The average daily census at the five intervention sites remained constant over a one-year period; approximately 85% ($n=205$) of pooled eligible enrolled participants ($n=240$) attended the adult day care centers on a weekly basis. Of the pool of 205 eligible participants, 119 were solicited (58%), 109 verbally agreed to participate (92%), and 97 gave written consent (89%) at the first session. Of the 97 consented participants (48 to ACT-Plan and 49 to attention control), a total of 68 (70%) were retained (ACT-Plan 35/48, 73%

and attention control 33/49, 67%). Twenty-nine subjects (30%) dropped out of the study; 22 dropped out *prior* to the first session and seven *after* completion of the first session. No participants dropped out of the study after the first session. Reasons provided for the drop outs were: (a) too stressed with other family issues to attend scheduled classes (n=15); (b) no transportation (n=7); (c) conflicts in work schedule (n= 5); (d) previous commitments (n=2), e.g., graduations, respite vacation. The remaining 68 subjects attended all four sessions and arrived on time for each session. All completed the pretest and posttest with an average of 96% (SD = 9.5%) of items completed on each instrument.

Change in caregivers' outcomes

Table 3 reports the mean changes and p values in pre and posttest scores on outcome variables for both ACT-Plan and attention control groups. Knowledge of dementia increased (pre/posttest $m=12.4\pm2.2/m=13\pm1.5$) in the ACT-Plan group but not the attention control (pre/posttest $m=12.2\pm2.0/m=12.3\pm2.0$). Although not statistically significant due to the small n, trends were evident toward significance in the ACT-Plan as oppose to the attention control groups.

Trends were shown for comfort with knowledge of CPR, MV and TF for the ACT-Plan condition ($p = 0.07$) but not the attention control ($p = 0.96$). Mean values at posttest were decreased in the ACT-Plan group (8.9 ± 2.4 to 7.8 ± 2.5) but were essentially unchanged in the attention control (8.9 ± 3.4 to 8.9 ± 2.4), suggesting that as caregivers learn more about the risk/benefits of CPR, MV and TF treatments they could be more likely to become uncomfortable with making the serious decisions for relatives.

Mean pre/posttest scores for self-efficacy were 26.4 ± 8.9 to 30.6 ± 6.3 in the ACT-Plan group and 28.6 ± 11.5 to 30.3 ± 7.8 in the attention control group. Self-efficacy was significantly improved in the intervention group ($p=0.02$) but not in the attention control ($p=0.11$), suggesting that caregivers in the intervention group gained confidence in making the serious treatment decisions whereas confidence levels remained unchanged in the attention control group. However, after controlling for the baseline scores, the results of ANCOVA showed no significant difference in knowledge of dementia ($p=0.19$), comfort with knowledge of CPR, MV and TF ($p=0.07$), and self-efficacy ($p=0.83$) between ACT-Plan and attention control groups at posttest.

Participants in the ACT-Plan condition exhibited a significantly greater proportion of large (34% vs. 3.0%) and medium (22% vs. 9%) overall intervention effect than in the attention control condition for CPR ($p<.001$) (Table 4). Although the overall intervention effects for MV and TF were not statistically significant ($p = 0.14$ and 0.08 , respectively) there were definite trends toward significance and an overall intervention effect with the ACT-Plan condition but not the attention control condition (50% vs. 29%, for large effect in MV and 41% vs. 20% for large effect in TF, respectively).

Percent changes were measured at pre and posttest in CPR, MV and TF decisions made by both intervention and control groups (Table 5). Huge changes were illustrated at posttest with decisions made by the ACT-Plan participants but not attention control. For example, the ACT-Plan participants had a 32%, 43%, and 45% decrease in decisions to use CPR, MV, and TF, respectively. Conversely, there were minimal percent changes in CPR, MV, and TF decisions from pre to posttest with the attention control group. There was also dramatic increase in "will not use" category for CPR (+367%), MV (+100%), and TF (+240%) for ACT-Plan group as compared to relatively insignificant change (+38%, -6%, and +30% respectively) for retention in the control group.

Qualitative data supported the premise of an intervention effect, as well. Twenty-three out of the 35 participants (63%) in the ACT-Plan group changed one or more of their decision at posttest as opposed to 10 out of 33 (30%) subjects in the control group. The following explanations were given by ACT-Plan participants for changes in decisions to not use treatments: (a) loved one was at the end stage of dementia, therefore useless to use CPR, MV or TF; (b) CPR may break ribs because loved one is too frail; (c) loved one said she does not want CPR, TF or MV; d) treatment not beneficial to mom because she has advanced dementia; and e) will not use because loved one said “no”. Responses provided by the attention control group included: (a) not qualified to administer CPR, MV or TF (participants may have misunderstood the questions); (b) does not really understand treatments enough to answer; (c) loved one is too old and frail.

Discussion

In this research we demonstrated the feasibility of implementing an experimental study of an ACT-Plan education intervention for AA dementia caregivers and an attention control intervention focused on health promotion. Our well-developed recruitment procedures were highly successful. The attrition rate was acceptable for this vulnerable population, attendance was exceptional, and the instrument completion rate was typical but could be improved. The innovative, theory-based ACT-Plan intervention demonstrated outstanding promise as an approach for assisting caregivers of AAs with dementia to develop an advance care plan about CPR, MV and TF.

We estimated an overall attrition rate of 15% at the ACT-Plan and attention control sites by the end of the study. We obtained, however, an actual overall attrition rate of 30% (29/97). Although the rate is higher than we expected, almost all (n=22, 76%) of the participants dropped out *before* the first session began. They dropped out because they were too stressed to focus on education (n= 15) or had no transportation (n=7) to attend the sessions. No additional drop outs occurred after completion of the first session. Future studies will screen for individuals who are less likely to attend sessions based on barriers, such as, high stress levels and transportation problems. In future studies, we will explore methods to overcome transportation problems. Adjusting for these barriers may reduce the attrition rate.

Attendance in the ACT-Plan program was exceptionally high after the initial attrition. All of the remaining ACT-Plan participants (n=68) attended the 4 weekly sessions and arrived on time for each session. Such behaviors suggest a high interest rate in the ACT-Plan program and a need for the intervention and that the health promotion intervention is an acceptable approach to engage an attention control group. All completed pretest and posttest with an average 96% of completion on each instrument, far exceeding the 80% of completeness that we originally anticipated.

Although we did not find any significant differences between the ACT-Plan and attention control groups on change in knowledge and self-efficacy, our findings do suggest a trend indicating that the ACT-Plan education intervention showed positive changes in knowledge and self-efficacy as compared to attention control group. The lack of statistical significance is mostly due to the pilot nature of the study with small sample size. A study with an adequately powered sample will likely demonstrate significant findings on these key variables. Based on the effect size observed in this pilot study, we estimate that a larger sample size will be required in each group for a randomized controlled efficacy trial of the intervention.

A moderate to large intervention effect was demonstrated at posttest with the ACT-Plan participants but not the attention control when both groups were asked the chances of

recovery with CPR, MV and TF treatments at the end stage of dementia. Participants in the ACT-Plan condition more accurately reported the recovery chances than subjects in the attention control condition. Intervention effects with CPR were significant ($p=0.005$) and the effects with MV ($p=0.14$) and TF ($p=0.08$) showed definite trends. We believe the increased accuracy of responses was due to knowledge gained in the ACT-Plan condition. The participants in the ACT-Plan group also expressed a greater confidence at posttest in the choices made and succinctly expressed their EOL treatment intentions than the participants in the attention control group.

Other trends that suggest an intervention effect included huge changes from pre to posttest in decisions made by ACT-Plan participants to not use CPR, MV and TF. Participants in the control group made only a few changes at posttest. The large percent changes consisted of decreases in the “will use” category and an increase in the “will not use” category. Reasons for the changes made by ACT-Plan participants were consistent with the risk/benefit discussions about the treatment options during the end-of-life treatment sessions. In addition, the ACT-Plan participants used similar technical language used in group sessions to express their own rationale for change. For example, they stated that (a) loved one was at the end stage of dementia and (b) CPR may break frail loved ones ribs. These findings are consistent with the literature in that when caregivers and receivers learn more about the risk/benefits of the treatment and their options, they are less likely to request the treatments at the end stage of terminal illnesses.³¹ We took special precautions to avoid imposing personal beliefs onto treatment decisions made by participants. For example we conducted training sessions for the facilitators, used fidelity check lists that were scored at each session by an assistant and spot checked tape recorded sessions. Consistent with our deliberate approach, some participants in the ACT-Plan group indicated that they would use CPR, MV, and TF when their care recipient needed those interventions and cited rationale based on intervention components. Therefore, we are confident that we provided education that helped participants specify advance care plans that were consistent with their values, the overall goal of the ACT-Plan intervention.

AAs are less likely than WAs to have advance care plans^{13–15}. Community-based advance care planning interventions with WAs increased knowledge about EOL treatment choices, use of advance directives, and satisfaction with treatment decisions.^{7, 8, 9} Although our pilot study did not make a black/white comparison, our findings strongly suggest that AAs are willing to discuss and express their intentions regarding advance care planning for relatives as well. Bonner^{8, 9} demonstrated similar findings in a smaller study on advance care planning with AA caregivers of patients dying of end stage dementia. The caregivers attributed their ability to make advance care decisions to the increased self-efficacy and knowledge attained from the education intervention.

This feasibility study enriched the understanding of how a culturally sensitive education intervention on advance care planning can be successfully implemented to facilitate informed decision making by AA family caregivers. By addressing methodological issues, a culturally specific innovative education program that promotes advance care planning was refined for replication in community settings. Due to historical factors that engender mistrust by AAs in the health care system, implementing programs in the community enhances success because participants feel comfortable discussing sensitive topics in environments they trust. In addition, we believed that prospective participants were more likely to make an unbiased choice to, or not to, participate in our study if someone or a community agency they trusted referred them. Other culturally appropriate methodological considerations included the use of (a) AA advanced practice nurses education facilitators and (b) people of color as actors in the audio visual presentations, handouts and flyers.

Theory-based approach to developing and implementing the ACT-Plan intervention provides a framework from which to operationalize the study for delivery in to the community. Kolb's ELT was well received by participants and provided structure for the education content.

Limitations of the study include small sample size and homogeneity in recruitment sites (adult day care centers). Most AA care recipients do not attend adult day care centers and are cared for in home settings by relatives.³⁰ Differences in these samples may exist. However, small sample size and homogenous sites were needed because the pilot study was constructed to test the feasibility of implementing the ACT-Plan project. Therefore, generalizing to larger samples and sites was beyond the scope of the study.

Conclusion

Self-efficacy and knowledge about dementia, CPR, MV and TF increased with ACT-Plan condition but not the attention control. More participants in the ACT-Plan condition as opposed to the attention control condition developed an advance care plan for relatives with dementia, some choosing to use and others not to use CPR, MV, and TF. Findings strongly suggest that a culturally sensitive ACT-Plan intervention, framed by Bandura's Social Cognitive Theory and Kolb's ELT, is appropriate for AA caregivers and will enable them to make the best advance care plan for dementia relatives. An efficacy trial is warranted based on the strong feasibility findings in this pilot study.

Acknowledgments

This R21 Project was funded by National Institutes of Health, National Institute of Nursing Research, R21 NR010538.

We acknowledge Edna Moore-Burke, PhD^{abd}, CNP, RN; Sheon MacNeill, MSN, RN; Cynthia Henderson, MD, MPH and Neelum T. Aggarwal, MD for their contributions to this research project.

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Table 1

Caregiver Demographics

Caregiver Characteristics	Intervention (n=35)			Control (n=33)			P value
	Mean/n	SD/%		Mean/n	SD/%		
Age	59.3	10.0		58.3	10.2		0.68
Gender							0.77
Male	8	24		6	18		
Female	26	76		27	82		
Religion							0.86
None	3	10		3	11		
Baptist	11	35		13	46		
Methodist	1	3		1	4		
Catholic	6	19		6	21		
Other	13	42		8	29		
Relationship to recipient							0.11
Spouse	5	15		4	12		
Sibling	1	3		6	10		
Daughter	22	65		14	45		
Son	5	15		3	10		
Other relative	1	3		4	13		
Length of caregiving							0.21
1–3 yr	20	59		11	35		
4–6 yr	7	21		8	26		
7–10 yr	4	12		8	26		
11 or more yr	3	9		4	13		
Employment							0.96
Employed	16	56		18	58		
Retired	19	54		15	52		
Education							0.90
Less than HS	1	3		2	6		
HS graduate	8	23		7	21		

Caregiver Characteristics	Intervention (n=35)		Control (n=33)		P value
	Mean/n	SD/%	Mean/n	SD/%	
Some college or higher	26	74	24	73	0.07
Family income					
Less than \$15,000	7	22	3	9	
\$15,000–40,000	6	19	10	31	
\$40,000–70,000	7	22	12	38	
> \$70,000	7	22	2	6	
Don't know	5	16	5	16	

Table 2**Care Recipient Demographics**

Care Recipient Characteristics	Intervention (n=35)		Control (n=33)		P value
	Mean/n	SD/%	Mean/n	SD/%	
Age	81.7	9.3	78.7	7.4	0.15
Gender					0.56
Male	7	21	4	12	
Female	26	79	29	88	
Length of dementia					0.05
1–3 yr	15	45	15	47	
4–6 yr	9	27	6	19	
7–10 yr	9	27	5	16	
11 or more	0	0	6	19	
Type of dementia					0.92
Alzheimer	18	55	16	48	
Dementia caused by stroke	6	18	8	24	
Other	1	3	1	3	
D/K	8	24	8	24	
How disabled?					0.89
Severely disabled	3	9	5	16	
Moderately disabled	16	48	14	44	
Mildly disabled	13	39	12	38	
Not at all disabled	1	3	1	3	

Table 3

Outcome variable by experimental group

Variable	Intervention (n=35)						Control (n=33)					
	Pre			Post			Pre			Post		
	Mean	SD	Mean	SD	P value		Mean	SD	Mean	SD	P value	
Knowledge of dementia	12.4	2.2	13.0	1.5	0.21		12.2	2.0	12.3	2.0	0.82	
Comfortable with CPR, MV, TF knowledge	8.9	2.4	7.8	2.5	0.07		8.9	3.4	8.9	2.4	0.96	
Self-efficacy	26.4	8.9	30.6	6.3	0.02		28.6	11.5	30.3	7.8	0.11	

Table 4

Intervention effect by experimental group

Intervention effect	Intervention (n=35)		Control (n=33)		P value
	n	%	n	%	
CPR					<.001
No effect	14	43.8	29	87.9	
Medium effect	7	21.9	3	9.1	
Large effect	11	34.4	1	3.0	0.14
MV					
No effect	11	45.8	17	70.8	
Medium effect	1	4.2	0	0.0	0.08
Large effect	12	50.0	7	29.2	
TF					
No effect	16	55.2	15	60.0	0.08
Medium effect	1	3.4	5	20.0	
Large effect	12	41.4	5	20.0	

Table 5

Advanced care treatment planning decision by experimental group

ACT Decision	Intervention (n=35)				Control (n=33)			
	Pre	Post	Δ Change		Pre	Post	Δ Change	
CPR								
Will use	22	15	-32%		23	20	-13%	
Will not use	3	14	367%		8	11	38%	
Undecided	5	1	-80%		0	0	0%	
MV								
Will use	14	8	-43%		14	16	14%	
Will not use	11	22	100%		16	15	-6%	
Undecided	5	1	-80%		1	1	0%	
TF								
Will use	21	11	-45%		20	18	-10%	
Will not use	5	17	240%		10	13	30%	
Undecided	6	1	-83%		1	1	0%	