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Extending Advance Care Planning to Black Americans in the Community: A Pilot Study of the PREPARE Program

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Abstract

Context: Advance care planning (ACP) is underutilized, especially among Black Americans. Yet, no ACP interventions have been tested at the community level.

Objectives: Within an established academic and community partnership, we sought to determine whether ACP is a community-identified need and if so, to conduct a pilot study of an evidence-based ACP program, PREPARE (PrepareForYourCare.org).

Methods: We conducted open discussions and in-depth interviews to determine the relevance of ACP to the community. We then conducted a pre- to 3-week post pilot study of a virtual peer facilitated brief session to introduce ACP and encourage participants to engage with PREPARE. We conducted thematic content analysis for qualitative data and used paired t-tests to assess within-participant changes in the validated ACP Engagement Survey measured on a 1-5 scale (5=greatest engagement).

Result: We conducted two discussion groups with community leaders (n=12) and key informant interviews (n=6), including leaders in aging, public health, health care and faith. We concluded that ACP is a community priority. In the pilot study, we enrolled 13 Black Americans; 85% were women and the mean age was 59.7 years (SD 15.1). There was a trend toward increased ACP

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engagement after the peer facilitated PREPARE (mean 3.2 (SD 0.6) pre vs. 3.5 (SD 0.6) post, paired t-test p=0.06). All participants found the intervention to be acceptable and were satisfied with it.

Conclusion: Community members identified ACP as important for their community. Peer facilitated PREPARE program is a promising community-based strategy to increase engagement in ACP and may promote health equity.

Keywords

Advance Care Planning; Community Based Participatory Research; Black Americans

ACP helps ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.(1) Despite these benefits, ACP engagement is low and disparities exist; White Americans are more than 4 times as likely to engage in ACP compared to Black Americans and high-income Americans are more than twice as likely to engage in ACP compared to those with low-income.(2)

One approach to increase ACP is to extend it into the community. While a vast majority of ACP interventions are delivered in medical settings, this may be suboptimal for some individuals, particularly Black and low-income Americans, who have less access to care and less trust in medical providers than their counterparts.(3-6) In addition, ACP is a process and can be time intensive, which may limit medical setting-based ACP where providers are often stretched on resources and time.(1, 7) Finally, a key recommendation of the National Academy of Medicine, Engineering and Science report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life (2014),* was to normalize end-of-life conversations through engagement of individuals and families in care planning over time and championed a 'whole community approach'.(8) Part of this normalization includes extending ACP out of the medical setting and into the community, where social norms are defined.(9, 10) While there have been pilot studies of ACP in the community, predominately church-based,(11-17) there are no evidence-based, scalable, community-level interventions to increase ACP.(18, 19)

In this context, within a long-standing academic-community partnership we first explored whether ACP was a priority of a low-income predominately Black American community. Subsequently, community and academic partners made minor adaptations to an evidence-based intervention, PREPARE, and then conducted a pilot study to assess the feasibility and acceptability of using a peer educator to facilitate the PREPARE program in the community.

Methods

Overview and Setting

We conducted key informant interviews, community discussions and a pre-post pilot study of peer facilitated PREPARE in Flint, Michigan. Flint has a population of about 100,000, 55% of whom are Black Americans and 40% live in poverty.(20) Flint is ranked 81 out of 83 Michigan counties on Robert Wood Johnson Foundation's County Health Rankings.(21) For

over a decade, utilizing a community-based participatory research approach, the academic and community partners have collaborated to improve the health of the community.

Needs Assessment

A key principle of community-based participatory research is to address a community-identified need.(22) While ACP is underutilized nationally,(2) we sought to understand whether ACP was locally relevant through discussions with Flint's centralized association of community organizations, the Community Based Organization Partners, and the Community Ethics Review Board. We also conducted key informant interviews with faith leaders, leaders in aging, public health and health care and community organization leaders. These were open discussions to assess community relevance and priorities and, as such, did not include an interview guide. Field notes were documented by the research team, including verbatim quotes, to capture the authentic voice of the community. These field notes were used to continually update the community-academic partners in order to make a determination of the relevance of ACP to the community. This work was conducted between December 2019 and June 2020 and occurred in-person prior to the COVID-19 pandemic and virtually thereafter.

PREPARE

PREPARE is a self-directed ACP program that includes an easy-to-use, patient-centered, interactive online program (PrepareForYourCare.org) that leads participants through the 5-module ACP process: 1) choose a surrogate decision maker and verify they know their role; 2) identify goals based on past experiences and personal values; 3) decide whether to grant leeway or flexibility in surrogate decision making; 4) inform medical providers and other family and friends of one's wishes, and 5) ask questions to clinicians.(23) Each module takes approximately 10 minutes. PREPARE also includes easy-to-read, state-specific Advance Directives in English and Spanish and a PREPARE pamphlet. All PREPARE materials are written at a 5th grade reading level, and the online program includes voice-overs of all text for the reading-impaired.(23) PREPARE increased ACP engagement among primary care patients,(24, 25) but has not been tested in the community or facilitated by peer educators.

Our long-standing community advisory board strongly advocated for face-to-face interaction to facilitate community member engagement in an ACP program. One strategy we have used in the community to deliver other health behavior interventions is to train non-medical laypersons as peer educators.(26) Thus we made minor adaptations to the existing PREPARE health professional facilitation guide for use by peer educators, which included expanding the description of ACP into a non-clinical setting.

Virtual Peer Facilitated PREPARE Pilot Study

The pilot study was conducted virtually given COVID-19 pandemic-related restrictions in place in Michigan during the study time period (summer/fall 2020). Recruitment was done by community partners through word-of-mouth (phone and community partner social media), followed by participant snowball sampling. Inclusion criteria included being 18 years and older with access to the internet (via phone or computer). Exclusions included

non-English speaking (less than 0.5% of community), planned move out of the community in next 2 months, self-reported dementia, blindness or deafness. This study was determined to be exempt human subjects research by the University of Michigan IRB.

Community members were contacted by phone by the research team who introduced the study, assessed eligibility and willingness to participate in the research study, provided training on the virtual platform, Zoom (i.e. how to download and use the program) if needed, and scheduled the video conference intervention. At the start of the video conference, a research team member conducted the pre-intervention assessment including the 15-item ACP engagement survey, a validated psychometrically sound tool.(27) Items were averaged into a 5-point engagement score where 5 represents the greatest engagement. We also queried sociodemographic measures including self-reported age, gender, race/ethnicity, marital status, educational attainment, health literacy,(28) and health status.(29) Inadequate health literacy was defined as a response of not at all, a little bit, or somewhat to the question, “How confident are you filling out medical forms by yourself?"(28) The peer educator then conducted the brief PREPARE session using Zoom screen share to display videos and a PowerPoint presentation.

The session began with a brief description of ACP and two short videos from the PREPARE website (https://prepareforyourcare.org/welcome and https://prepareforyourcare.org/prepare/1-2-n1) that provided scenarios of individuals discussing why preparing for medical decisions is important to them and their family members. The peer educators then reviewed the PREPARE pamphlet, an overview of the 5 PREPARE modules, and the State of Michigan easy-to-read Advance Directive (AD). Following the Zoom session, participants were mailed the PREPARE pamphlet, including instructions on how to access the online PREPARE modules and the state of Michigan AD. Then 3 weeks after the session, we assessed the 15-item ACP engagement survey again,(27) in addition to satisfaction with and perceived relevance to the community of the PREPARE intervention materials. Acceptability and appropriateness (30) were assessed via the Acceptability of Intervention Measure (AIM) and Intervention Appropriateness Measure (IAM), 4-item ordinal scales with responses ranging from 1-completely disagree to 5-completely agree. We also asked open-ended questions about the participant’s overall impressions.

Analysis

Needs assessment: Detailed field notes were taken by the academic team during the needs assessment discussions and key informant interviews. These captured the main ideas and verbatim exemplar quotes. Our team then used thematic content analysis to describe the main themes from the discussions and the interviews. The academic and community partners then met regularly to review the field notes and themes in order to update our understanding of the priorities and needs of the community related to ACP.

Pilot study: Descriptive statistics were used to characterize participant demographic and other relevant baseline information. Paired t-tests were used to compare the within-participant change in 15-item ACP engagement survey score from pre- and post-

intervention. Lastly, descriptive statistics were calculated to assess post-intervention AIM and IAM. Analyses were conducted in R version 3.5.2.

Results

Needs Assessment

We conducted two community discussions, which included 12 community members, and six key informant interviews. Community discussions lasted about 60 minutes whereas key informant interviews ranged from 15-60 minutes. We concluded that ACP was a priority for community members. One older Black woman reported that ACP is important so that "*I get some say in what happens to me*." Another Black woman mentioned the importance to *"Make a plan for if and when, because we all know when is going to come."* One White woman noted the benefits of ACP before people get sick, noting a benefit of community ACP as its *"distance from the emotion."*

A few participants described their experiences with prior ACP. An older Black man reported partaking in a facilitated ACP discussion with his father, a stroke survivor, and a social worker. He reported, *"I had it all wrong. My father said 'no' [to life sustaining treatments]. I would have said 'yes' for him*." The key informant then relayed how important that discussion was in making sure he carried forward his father's wishes. In addition, there was a consensus that ACP is applicable not only to older adults but also to younger people too. A middle-aged Black woman quoted bible scripture, "*people perish from lack of knowledge"* signifying her belief in the need for widespread ACP engagement. One discussion group believed that ACP, particularly involving young people, might be an approach to curb violence in the community, *'helping plan death might reduce violence.'* Participants also noted a few reservations about ACP. Multiple participants and a group discussion pointed out that for some community member's ACP discussions may be "*taboo*" and thus may require additional support or a longer duration of contemplation. In addition, one discussion group also noted that for many community members the definition of family is expansive and inclusivity is warranted when discussing medical decision makers. Finally, while some of the participants were familiar with clinic or hospital-based ACP, none of the participants were familiar with PREPARE or community or home-based ACP.

Peer Educator-Facilitated PREPARE Pilot Study

The pilot study was conducted from September to November, 2020. We enrolled 13 Black Americans; 85% were women and the mean age was 59.7 (standard deviation (SD): 15.1). Self-reported health was good, very good or excellent for all participants (Table 1). Educational degree attainment varied; 23% had a high school diploma or less while 38% were college graduates or had an advanced degree; 31% of participants reported inadequate health literacy.

Compared to baseline, there was an increase in mean ACP engagement after the peer facilitated PREPARE (pre: 3.2 (SD: 0.6) vs. post: 3.5 (SD: 0.6)), the within-participant change was not statistically significant (mean: 0.3, SD: 0.5, p=0.06). There was an average

of 20 days between the virtual peer educator-facilitated PREPARE intervention and the outcome assessments.

Based on self-report, 85% of participants reviewed the PREPARE pamphlet and easy-to-read AD and 30% reviewed the PREPARE online modules on their own after the session. Only one person (7%) did not engage with any of the community PREPARE components. The Acceptability of Intervention Measure (AIM) score was 4.4 out of 5 (SD:0.6) and the Intervention Appropriateness Measure (IAM) score was 4.4 out of 5 (SD:0.5). All participants found the peer facilitated PREPARE intervention acceptable and were satisfied with it. All participants agreed that everyone in their community should know this information and would recommend the intervention to others in their community. When asked to elaborate on why she felt the community would benefit, one participant stated, "*Because I feel that it's necessary. It's hard decisions [sic], but it's a place that we need to go - a place of uncomfort [sic] to be comfortable at the end. And so I believe in helping people to help themself, and this advance care helps you to help yourself."* Another participant echoed these thoughts and expressed distrust of medical providers, "*Because I think a lot of people need this. I never thought about it before, to have a voice for myself if I can't take care of myself. And a lot of people don't have that voice, or know that they need to have that voice. You don't know what a doctor will do - sit you in a corner or not pay attention to you."*

Discussion

We found that community-based ACP was a priority in a low-income, predominately Black community. There was a trend toward increased ACP engagement after participation in the peer facilitated PREPARE intervention. The facilitation of PREPARE by a peer educator was deemed highly acceptable and appropriate and all participants reported that they would recommend the intervention to others in the community. The high degree of acceptability and appropriateness is encouraging, particularly as peer facilitation was conducted virtually. Thus, peer facilitated PREPARE may be a community-based strategy to increase ACP engagement and virtual peer facilitation may offer a novel platform for ACP interactions.

Trained medical professionals typically deliver ACP programs, and often through extensive one-on-one facilitation which is labor and resource intensive and limits uptake and sustainability.(19) PREPARE has many strengths for community-based ACP. First, PREPARE has proven efficacy to increase ACP in diverse primary care settings, including low-income and Black patients.(24, 25) Second, PREPARE is self-directed, does not rely on delivery by a health professional, and is intended to be completed at home. Finally, PREPARE is free to use, removing cost barriers to the community.

Delivery of ACP by peer educators is a novel strategy for ACP delivery and may promote community sustainability. Peer educators are members of the community who share similar social backgrounds, such as race, class, culture, or life experiences with those whom they are delivering the health interventions.(31) Peer educators function across roles bridging patients and the medical system.(31) Peer educators may prompt greater trust compared to traditional approaches that rely on medical providers, which in turn might increase the dissemination

and engagement with ACP programs.(32) Furthermore, given that they are members of the community, training peer educators on ACP will increase community capacity and may facilitate community ACP program sustainability.

We found that ACP engagement increased, although the results were borderline significant likely due to the small sample size. While the change in engagement was moderate, the effect sizes seen in this study for the 15-item survey are similar to statistically significant gains seen in randomized trials.(27) The change was also greater than the validated minimal clinically important difference (ΔACP engagement score=0.20),(27) which corresponds to participants moving along the ACP continuum, for example moving from ACP precontemplation to ACP contemplation or from ACP preparation to ACP action. We anticipate greater increases in ACP engagement could be obtained via: 1) further adapting PREPARE materials for community use through community co-creation; 2) in-person brief sessions with peer educators; 3) more extensive training of peer educators; and 4) longer duration available to engage with the PREPARE program, such as the 6-12 months available in the PREPARE efficacy studies rather than 3 weeks in our pilot study;(24, 25) 5) inclusion of a quick start guide with directions to the website; and 6) development of action plans and reminders to engage in the material, which has been shown to increase behavior change.(33)

Our study has limitations. We did not include a control group and thus cannot exclude a temporal trend in ACP, although this would be unlikely given the short duration between intervention and post-intervention assessment. Due to resource constraints, our sample size was small and thus did not allow for adjustment of potential confounders or assessment of predictors of engagement. Similarly, there was a short duration between the peer educator facilitated PREPARE brief session and the outcome assessment. A longer time is warranted to give participants more opportunity to engage with the PREPARE materials and to carefully think about their values and preferences. When compared to the population of Flint, women and those with higher levels of education were overrepresented in our pilot study. In addition, most of the participants reported good health. Ensuring a representative community sample is important for future studies.

In conclusion, peer facilitated PREPARE is a promising community-based strategy to increase ACP. Further adaptation and testing with diverse communities is warranted.

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Key Message:

This pilot study indicates that peer facilitated PREPARE is a promising strategy to increase ACP in the community and promote health equity.

Table 1:

Pilot Intervention Participant Demographic and Relevant Baseline Information (N=13)

	Mean (SD) or N (%)
Age, mean (SD)	59.7 (15.1)
Sex, Woman, N (%)	11 (84.6%)
Race, N (%)	
Black or African American	13 (100.0%)
Ethnicity, Hispanic, N (%)	0 (0.0%)
Education, N (%)	
Less than high school	1 (7.7%)
High school graduate/GED	2 (15.4%)
Some college	5 (38.5%)
College or University graduate	2 (15.4%)
Advanced degree	3 (23.1%)
Self-Reported Health, N (%)	
Excellent	1 (7.7%)
Very good	2 (15.4%)
Good	10 (76.9%)
Fair	0 (0.0%)
Poor	0 (0.0%)
Confidence in ability to fill out health forms alone, N (%)	
Not at all	0 (0.0%)
A little bit	1 (7.7%)
Somewhat	3 (23.1%)
Quite a bit	2 (15.4%)
Extremely	7 (53.9%)
Marital Status, N (%)	
Now married	5 (38.5%)
Single/Never married	5 (38.5%)
Divorced	3 (23.1%)
Caregiver, N (%)	4 (30.8%)