

What is Community Based Participatory Research (CBPR)?

- CBPR is often referred to as a research method. But it is not.
- CBPR is an **orientation to research** that emphasizes:
 - Mutual respect between partners (usually academia and community)
 - Building capacity within the community (and individuals in it.)
 - Balancing research & action (working towards change)



In CBPR The Community is the Unit of Identity

- The community is recognized as the unit of identity that we partner with
 - Community: group whose members share common identity (e.g., rural, southern African Americans; Urban African Americans; LGBT in Southeast [all older])
- A Community Advisory Board (CAB) partner equally with researchers



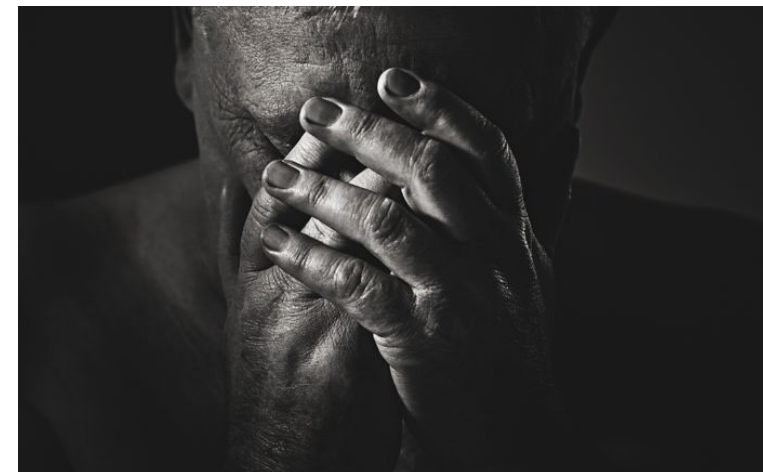
What is the relationship between CBPR and Balance of power?

- In CBPR there is a *change* in the balance of power:
 - Study respondents become more than research objects
 - They give more than informed consent & answer questions
- They participate *equally* in the research process
- They share their knowledge & experience on:
 - All aspects of the research process
 - Make recommendations for solutions
- We listen to & *accept* these recommendations
 - These form the healthcare program being created
 - Outcome benefits the community



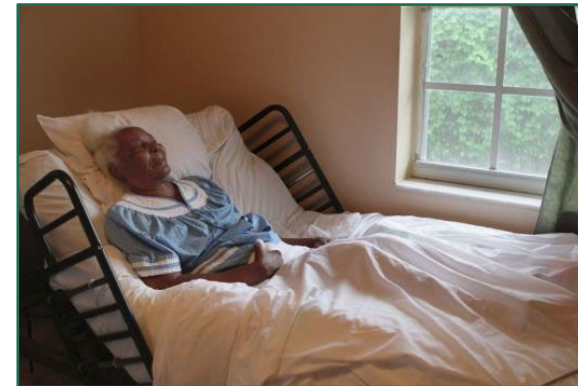
CBPR has PROVEN to reduce health disparities

- Proven to reduce health disparities
 - Over and over and over and over and....
- Widely implemented in Public Health & Cancer Prevention
 - Other than Preventive Medicine, rarely (if ever) in Medicine
 - Just started being used in Palliative Care
 - [Care for anyone w serious illness (not only at end of life)]
- Our goal is to implement this widely in Palliative Care
 - Starting w focus on older minoritized adults



Study 1: Developing the first Culturally-Concordant Palliative Care Intervention

- **Goal:** Create a culturally–concordant PC intervention
- **Why:** Culture impacts serious illness & EoL care
 - Preferences for care
 - Communication methods
 - Meaning of illness, pain and death
 - Decision-making
- **Yet in US:** EoL Care Values are based on
 - White, middle class, Christian values
- **Lack of sensitivity to or respect for cultural differences & lived experiences of racism**
 - Compromises care for minoritized patients
 - Results in significant healthcare disparities higher pain, non-goal-concordant care)



We chose to focus on Rural, Southern Older Patients w Serious Illness (W & B)

Step 1: Invited community members to join the study as our CAB:

- Equal numbers of African American and White.
- We met once every single month for 3.5 years
- The CAB guided *each and every* step of the study

Step 2: Held focus groups with community members

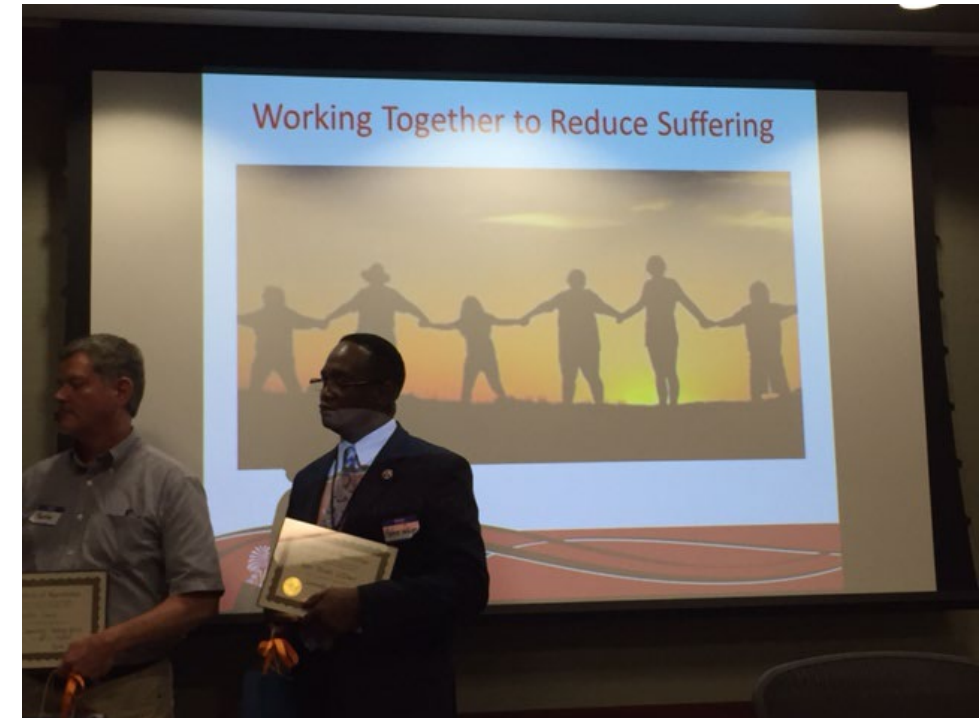
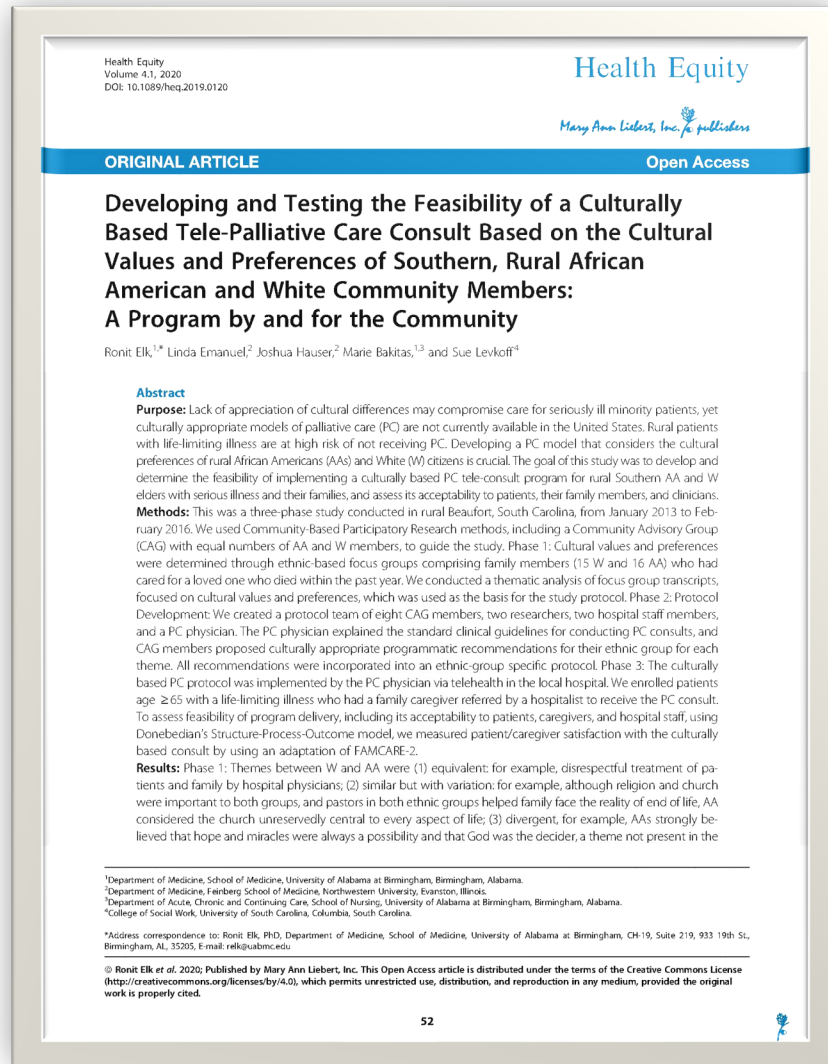
- Whose loved one had died in hospital in the last year
- To determine their experiences w healthcare system
- Per CAB: Separate focus groups for
 - White
 - African American
- We analyzed the data and reported these to the CAB



Study 1 continued

- **Step 3: CAB reviewed results, & made recommendations**
 - For how clinicians should provide care & how to communicate
 - With members of their community.
 - Many differences between African American and White
- **Step 4: Researchers incorporated these into PC Consult Guidelines**
- **Step 5: CAB members Trained The Palliative Care Physician!**
- **Step 6: Conducted pilot of this intervention in a rural hospitals to determine**
 - Feasibility of implementation in hospital
 - Patient and family recruitment recruitment
 - Patient and family satisfaction.

Result: First Culturally Concordant PC Consult



Now being replicated by mentees with a focus on older adults from other minoritized communities and those from other cultures. Need many more.

CAB Members Trained the P.C. physicians



We are now testing the efficacy of this Intervention in a RCT

3 Rural Hospitals in
3 Southern States

AL.

AA & W patients
(AL CAB)

MS.

AA & W patients
(MS CAB)

S.C.

AA & W patients
(SC CAB)

Study 2: African American Communities Speak to Healthcare Providers

- Used same approach as for Study 1
 - Different rural area
 - Only African Americans
 - Older population
- CAB created 4 videos:
 - Based on focus group results
 - How to provide culturally-concordant care for rural, southern, African American elders with serious illness
 - Each video has a different message
- Education expert added skills-based training
 - For clinicians who provide care to older African Americans with serious illness



*First such training program in the US developed by the community .
Need to be replicated in more groups (one study under way)*

This training has been provided to:

- **160** healthcare professionals around the country (to date)
 - Majority are Palliative Care professionals.
- **Preliminary data very encouraging:**
 - Increased knowledge of cultural values of Southern African Americans
 - Had the confidence to change practice
 - Majority changed their practice on 3 of 4 community recommendations

Now being replicated by mentees with a focus on older adults from other minoritized communities and those from other cultures. Need more.



Do you take care of African American patients with serious illness?
Do you sometimes wish you could better understand the cultural values of the African American community, so that you can provide them with outstanding care?

African American Communities Speak to Health Care Professionals: Caring for Southern Elder African Americans with Serious Illness

This *three-hour skills-based training* incorporates videos created by the community to elicit empathy and shed light on biases in clinical care. Self-reflection and active learning techniques provide participants the foundation needed for changed behavior and improved communication with patients and caregivers.

It is truly an honor to be part of this process



COMMUNITY BASED PARTICIPATORY RESEARCH IMMERSION TRAINING: Key Factors in Partnering with Communities to Develop Healthcare Programs (via Zoom)

July 11-15, 2022



WHO IS THIS INTENSIVE TRAINING FOR?

- Faculty with any terminal degree
- Graduate students (PhD or post-docs)

WHAT WILL APPLICANTS GAIN INSIGHT INTO?

- Privilege and disadvantage
- Egalitarian versus hierarchical relationships
- Essential differences between CBPR and other research approaches
- Social justice aspects of CBPR
- How to partner with communities equally and respectfully
- How to establish and maintain trust
- How to develop and partner with Community Advisory Groups
- The principles and practice of focus groups
- Future funding and mentoring options

APPLICATION PROCESS

- **Forty** people will be admitted to the course.
- Applications must be received by **May 13, 2022**
- Applicants will hear back by **May 27, 2022**

COST - \$850 per person

Full participation at all sessions (via Zoom) is required.

CME/CEU CREDITS will be offered.

With deep appreciation to an incredible team and NINR and NIA



Orangeburg CAG



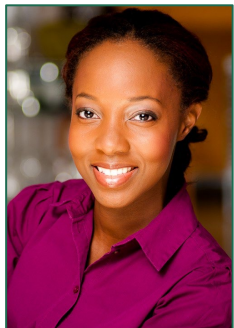
Orangeburg Pastors



Filmmaker: Roni Nicole

Elk/Bakitas: NINR
R01NR017181
“A Community-Developed, Culturally-Based PC Tele-Consult Program for African American and White Rural Southern Elders with a Life-limiting Illness”

Elk: NIA, R21AG04672
“Community-Generated Palliative Care Telemedicine for Rural Black and White Elders”



Karen Jones, MPH,
PhD
Study Manager



Gloria Eisemome,
MBChB, PhD
Graduate Assistant



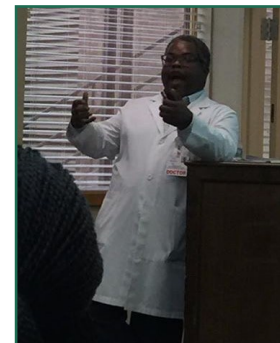
Roman Johnson, MA,
PhD student.
Graduate Assistant



Andrea Gibson, MPH
Focus group
facilitator



Akeen Hamilton, MA
PhD student
Summer Study Manager



Alvin Reaves, MD
Palliative Care Physician