

Barriers and Facilitators to End-of-Life Care Among Blacks in an Urban Setting

Amisha Parekh de Campos, PhD, MPH, RN, CHPN; Christine Dileone, PhD, RN, CNE; Denise Morris, MSN, CMSRN; School of Nursing

Background: Health disparities are prevalent among the Black community in end-of-life (EOL) and palliative care. Patients who transition from curative measures to comfort use services such as palliative and hospice care to manage symptoms, psychosocial needs, and overall well-being. However, studies have shown a substantial lack of Black patients who utilize these services, citing barriers such as access to care, mistrust of the health system, economic challenges, and transportation issues.

Purpose: This project aims to assess barriers and facilitators to EOL care among Blacks who have a serious illness or have cared for someone with a serious illness.

Methods: Phase One consisted of creating a CAB with informal and formal community leaders to discuss the project's goals and aims. Phase Two involved recruiting individuals for interviews. Inclusion criteria included that participants were 18 years and older, city residents who had a serious illness or cared for someone with a serious illness and were willing to participate in a one-hour interview. Data was collected to saturation and analyzed using the Krippendorff content analysis method.

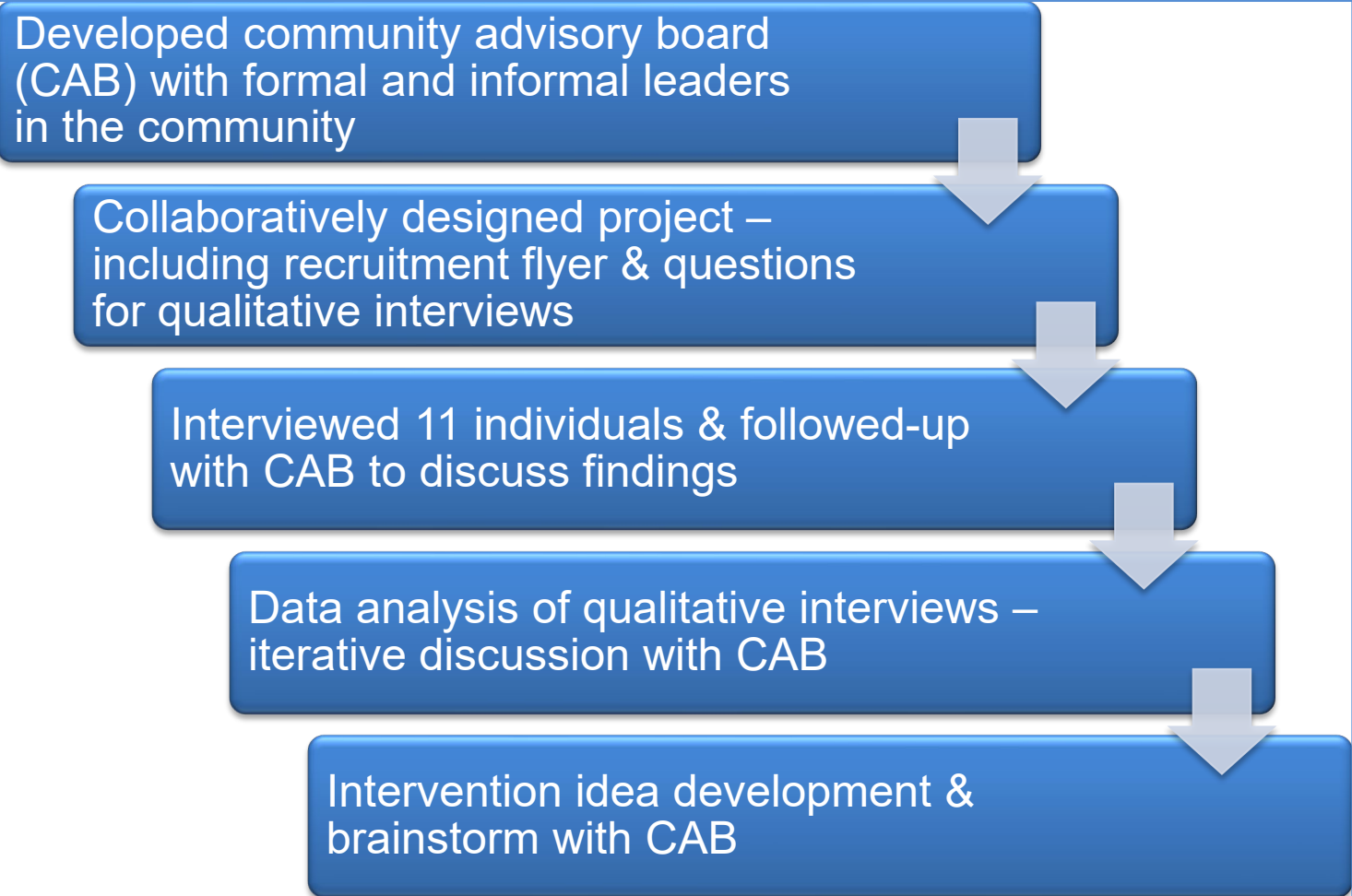


Figure 1. Timeline of study with Community Advisory Board



Theoretical Framework/Approach: CBPR (Community Based-Participatory Research). A collaborative research approach that involves community members as equal partners in all stages of the research process, aiming to address community concerns and achieve health equity (Figure 1).

Results: Eleven participants completed interviews (Table 1). Themes with sub-themes included: 1. advance care planning (planning vs. not planning), 2. health system (betrayals, advocacy, and the difference with a great clinician), 3. family (support vs. caregiving toll), 4. lack of knowing (needed to self-educate, wasn't aware, can't navigate the health system), and 5. personal struggles (how do I recover, how I've managed, letting go of formal life) (Table 2).

Table 1. Demographic Data

| | |
|------------------|---|
| Age | 55-64 years (5) |
| Ethnicity | Black or African-American (11) |
| Gender | Female (8) |
| Marital | Single (4), Widowed (1), Divorced (3), Married (3) |
| Education | Masters (4), Some College/Bachelor's (4), Associates (2), Certification (1) |
| Household Income | \$35,000 and up (9) |

Table 2. Themes with sub-themes

Advance Care Planning

- “Last year we got together with her. We got a lawyer so we did a will....
- “Who’s going to move in with her?”

Health System

- “If you don’t know how to advocate for yourself, you’re not going to know what to do.’
- “I’m just another patient among thousands.”
- “I’m tired of feeling like we’re being discriminated against.”

Family

- “My daughter is my biggest support. She would drop everything.”
- “...she needs help around the clock and I’m usually the one”

Lack of Knowing

- “And they are not giving you the resources.”
- “I was not knowledgeable on what death really was.”

Personal Struggles

- “The good thing about the memory loss is that I don’t remember the hurtful things.”
- “The managing [after] is not easy, but it is what it is.”

Conclusion & Implications: Participants expressed a more significant number of barriers, which outweighed the number of facilitators. Many participants expressed a lack of knowledge, access, or introduction to palliative or EOL services. They also stated that they needed to self-educate on resources, faced the toll of caregiving without help, and felt betrayed by the health system. Results from this study can guide programs and agencies in serving a historically ignored population. Interventions should focus on the population's needs, address these inequities, and bring palliative care into the community.