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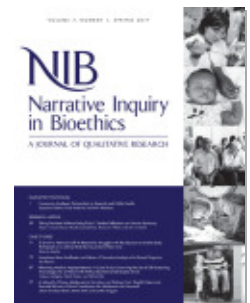
A Community–Developed, Culturally–Based Palliative Care Program for African American and White Rural Elders with a Life–Limiting Illness: A Program By The Community for the Community

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very important during the planning stages and during fieldwork. I am aware that not all graduate schools are as supportive of doctoral students doing community-engaged work as the University of Michigan, and hope that more funding opportunities and programs will become available for doctoral students hoping to engage in CBPR for their dissertations.

For me, engaging in this project and designing my dissertation in this way is likely the most important choice I have made in graduate school, and has already had a significant impact on how I think about my identity as a researcher and as a person, as well as my future career goals. I am deeply grateful for the insights I gained about my topic of academic inquiry, the interpersonal skills I learned throughout this process, and for the new intercultural professional relationships and friendships I forged by finding the courage to take my research out of the laboratory and into the Arizona desert and the Alaskan tundra.

Acknowledgements. First and foremost, I would like to express my deepest gratitude for my community partners who continue to work with me on this project and who were willing to engage in community-based participatory research project led by a graduate student. I am further eternally grateful for the guidance and advice regarding my research overall and this project in particular that my long-term research mentor Dr. Angela A. Gonzales (Arizona State University) and my dissertation committee chair Dr. Jan van den Bulck (University of Michigan) have generously provided. I also thank all funders listed below for making this project possible.

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African American and White caregivers in rural South Carolina who had been involved in the care of a loved one who had recently died, were asked what they found helpful or beneficial about the professional care (care provided by physicians, nurses, other hospital and hospice and nursing home staff) and what they considered ineffective or inadequate. Gaining an understanding of their perspective, through focus groups, was the first phase of this study. While this insight is important in and of itself, the more substantial purpose was to use this information to develop a culturally-based palliative care consult program for African American and White rural southern patients with a life-limiting diagnosis. Development of the program, in full collaboration with palliative care researchers and a team of African American and White community members, occurred in the next phase. Patient and family acceptance of this community-developed and culturally-based palliative care consult program was tested in the last phase.

Palliative care programs have been demonstrated to alleviate patient suffering and to enhance quality of life for patients with serious illness and their caregivers. Palliative care consults, in which a palliative care expert consults with the treating physician and makes recommendations for care, have been proven equally effective. Culture shapes how people make meaning out of illness, suffering and dying. Therefore, in palliative care, consideration of the culture of the patient and family is essential. Yet end-of-life care in the U.S. is rooted in values that represent the cultural and religious values of the white middle class. This was the first study to design a culturally based palliative care program for rural southern elders with life-limiting illness, and the first to do so with full community participation: "*A Palliative Care Program by the community for the community.*"

The study took place in Beaufort SC, a primarily rural southern coastal county with several small towns. Both perceived and actual differences between racial equality among African Americans and Whites are more strongly felt in the “deep South” than in other parts of the country. This is especially strongly felt in South Carolina; over 40% of African slaves were brought in to the US through this State, and during the Civil War, Beaufort County was a focal point of secessionist sentiment. Although a significant portion of the White population in Beaufort County are direct descendants of the early European settlers, or long–time residents of the area, there has been a large influx of affluent retirees who have settled in nearby Hilton Head and surrounding areas. The majority of the African American population have been in the county since they were brought over during slavery, and due to the relative geographic isolation (parts of Beaufort County includes several islands) have maintained the Gullah subculture, which includes a strong retention of indigenous African cultural elements. There is a high rate of poverty and unemployment, and associated health disparities within the African American community of Beaufort County.

Building trust within the community was the first goal of our academic palliative care research team (Study PI, two co–investigators, a palliative care physician and a research assistant.) Forming a partnership with the local hospital in which the last phase of the study would take place was the first step. The hospital’s outreach coordinator, Ms. C., had developed strong ties with many community organizations and members, both African American and White, and was deeply trusted and respected. She was instrumental in helping us invite community members, African American and White, to form a Community Advisory Group (CAG) that would guide the first phase of this study. The 14 members, equal numbers of African American and White, all residents of Beaufort County, comprised primarily of community leaders and gatekeepers. Also included were those who had recently lost a loved one, two hospital staff members not involved in the project, and two “regular” community members. These members were recommended by the

hospital outreach worker familiar with all community groups and organizations, and chosen based on an attempt to balance the group by race/ethnicity, and educational and financial level.

As study PI, I began by sharing aspects of my personal story that directly related to this study. Growing up as the child of an Israeli diplomat, I had lived in many different countries, attended many schools with diverse groups of peoples, who spoke different languages, and had varying histories, backgrounds and cultures. This had given me a deep understanding, and appreciation of, respecting the uniqueness of each culture. Later in life, I witnessed both my parents and husband become very ill and die, all within a very short time. Following a period of intense grief, I became determined to use the remainder of my career to help those who are ill or dying and their families to live the remainder of their life receiving the care that they, their families and communities wanted. My vision for this study therefore, was to create a program not only to alleviate suffering in those who are very ill or dying, but to provide the care their families, and communities wanted for them. And who better to determine how to do so, than members of the African American and White community members who lived in Beaufort, SC.

This first strong recommendation was made by the African American members of the CAG: *“If you want our people to tell you that which is in their hearts, you can’t put them in the same [focus group] with the Whites.”* We therefore planned separate focus groups. Based on recognized and justified distrust of research within the African American community, we shared our concern with the CAG that too few African Americans than we needed (10) would want to participate in the focus groups. The CAG’s recommendations for appropriate wording and artwork for the invitation to community members to participate, as well as their personal outreach in their community resulted in a higher number of eligible African American community members who wanted to participate (15) than we had planned for. Because of the strong community interest in this topic, we expanded the two focus groups to 15 members per group, and both groups

met twice in a neutral community-based setting that the CAG had recommended.

Analysis of the data (using thematic analysis, where themes are identified in each group) indicated that several aspects of preferred care for their loved ones were the same for both racial groups. For example, both groups reported confusion about pain medication provided to their loved ones, and both expressed a preference for there to be clear and easily understood communication about this. There were several key aspects of preferred care that differed between the two groups. For example, African American group members strongly appreciated doctors invoking God or a higher being, an issue not raised in the White group. Discussion of prognosis by the physician was another aspect on which the groups differed. White members wanted family members to be consulted as to whether the physician should reveal the prognosis to the patient, and their requests followed. African American members, on the other hand, did not want the prognosis to be shared—unless the family specifically asked for it—with God (not the physician) as the final determiner of impending death.

Phase 2, in which the culturally based palliative care consult program was developed, is where our story truly comes alive. To help build the program, a second Community Advisory Group of 8 members was convened. This was done in order to include some members of the focus groups, and to make the number of members more manageable. Half were members of the original CAG, and the other half were members from each of the focus groups. Two focus group members per group were chosen based on their ability to express their own opinions and reflect what the focus group had said, and the other two were members who had expressed concern or doubt about the study in order to gain a broader perspective. Here too, the group consisted of equal numbers of African American and White community members. These 8 community members, together with the team of palliative care researchers, met at the same local hospital for two hours after work one Thursday a month, for a period of *two and a half years* to develop the culturally-based palliative care protocol. Very rarely did any member

miss a meeting, most did not even miss one. Each member received a folder with the thematic results of the focus groups, and over the entire time, no one ever forgot to bring their folder to the meeting. We sat around a big table with our folders, and on the other table, a finger dinner of sandwiches, vegetables, fruit and cookies was tastefully laid out by the study coordinator. At the beginning of this phase, members were a little uncomfortable, and often sat beside other members of the same race. Over time however, a ritual developed: Ms. J, an African American retired banker who had lost her husband the previous year, became responsible for the members' sign-in sheet and gave each member the envelope with their study fees (\$25 per meeting and a \$25 gas voucher.) A natural leader, she would get up to cut up the circular sandwich wheel and everyone would then fill their plates with food and fruit and bring it to the table. Members sat wherever there was a space, no longer with regard to race, and lively conversations would begin.

Work of the group also took on a rhythm. Following an overview of all the results, at each meeting we would review one finding from Phase 1 in detail, and the group would then discuss and determine the programmatic implication of the finding. If the finding applied to both groups, the entire group discussed the recommendations and if it applied to one or other groups, that group were the primary discussants of the recommendation. Opinions were widely expressed, and although at times differences of opinions arose between members, these were always respectfully discussed. An example of recommendations made that was the same for both groups was the importance of the physician to be compassionate.

. . . the doctors were just so caring and so giving and he was up one time and it was close to the end of life . . . and the doctors and the nurses were just crying with him and hugging him. . . just because he felt so bad and they were doing everything they could. . . . When you have wonderful caring doctors and nurses, it makes it a lot easier to go through this.

Several recommendations were made that differed between the groups. For example, African Americans strongly recommended that their loved

ones remain at home and receive care from the family only, “ . . . as a family unit we had to know in our hearts that this was the right thing to do,” and “We take care of our own.” This was also one of the reasons provided for why African American family members did not want hospice staff to come to their homes to help, “ . . . it’s taken us a while to get to where we allow other people to come into our homes and do because we have always provided the care at all costs.” On the other hand, White community members appreciated the assistance of home hospice and nursing home, recognizing that taking care of a loved one at home alone, can be overwhelming and taxing.

It was apparent that although in the beginning, some White CAG members were completely unaware of several of the cultural nuances in the African American members, for example, when the concept of eternal hope and the possibility of miracles was raised, I noticed several members express surprise. Over time however, it was apparent that there was an increase in awareness and respect of, the culturally–determined wishes of the African American group, an unexpected benefit of working together.

One of the other positive outcomes of these meetings was the development of a strong sense of support among the group. On many occasions, members spoke of how participating in these sessions and working to help others, helped ease their own grief. Mr. M. a young African American man, shed tears over the loss of his beloved grandparents. Although initially embarrassed by these outward displays of feeling, he later shared with the group the support he felt in expressing these. Ms. B, a White woman in her late 60s had cared for both her dying husband and mother at home at the same time, and had experienced many instances of poor medical care, and at times rude and disrespectful communication by the physician. As a result, this gentle, dainty woman who lived in a home in the country came to the first meetings frustrated and angry. The groups’ recognition of these events, and their wish to turn it into something positive for others, as well as their ongoing support in her healing when she developed severe neck pains, was obviously very important to her. Despite her continued

pain, Ms. B drove the hour to the meeting and the hour back in order to continue to participate. When Ms. R, an affluent White woman in her late 60s whose husband had died the previous year, met a widower at church, she shared this news with the group, and when she later got engaged, the entire group exclaimed over the beauty of her large diamond ring. Ms. G., a highly respected retired Gullah nurse always made sure to call Pastor M. before the meeting to ensure his attendance. Over time, friendships began to develop across the color line. The first time I saw this was the sharing of a recipe by Ms. J. with Ms. R. and B. resulted in a discussion of various options for creating this dish.

During phase 3 of the study, we implemented the community–developed, culturally based palliative care consult program, in order to test patient and family acceptability of it. Concern was expressed by African American CAG members that African American patients and family members may not be willing to participate in a research study, and therefore recommended that they be the first to meet the patient and family and introduce the study to them, sharing that they co–created this study. In order to keep the process the same in both groups, it was decided that a CAG member would be the first to meet the patient, with African American members meeting African American patients and/or White patients, and White CAG members meeting White patients/family.

Following the completion of this phase, a study completion ceremony was held. CAG members brought their loved ones, and hospital staff and community members also attended. Following my final report of the study’s progress, CAG members in turn each spoke of how meaningful it had been to them to be a part of developing this program, and how it would help future members of their community. “*This program is a legacy to our loved ones who have passed,*” and “*We’re like the community of people that have been there before, you know, we’ve walked in these shoes before . . . This program was developed by people . . . who got together and with expert guidance, they developed a program. That’s why it’s helpful for community members to be instrumental in the program. ‘Cos palliative care happens when*

somebody's in a great deal of stress . . . you're exposed and you're dependent."

We ended the meeting with my announcement to the group of information that I had shared in the last CAG meeting; I had submitted a large, multi-state grant, based on the work of this community, and for which CAG members would serve as consultants. If and when funded, the work of this community would expand beyond their town to other rural southern states. *A program by the community for the community; work that would hopefully be expanding.*

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