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Main Article:

Using Culturally Informed Strategies to Enhance Recruitment of African Americans in Dementia Research: A Nurse Researcher's Experience

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Abstract

Decreased research participation hinders advancement in the understanding and treatment of dementia in African Americans. This article describes the experience of a nurse researcher using culturally informed strategies to enhance recruitment in the African American population in southern Louisiana, as part of a study on family involvement in health promotion activities for older adults with dementia. Strategies went beyond having minority recruiters and recruiting from churches to becoming familiar with the context and culture of southern Louisiana through engagement with the community and attaining buyin from formal and informal contacts. The researcher kept field notes, journals, and a record of recruitment activities to assure accountability during recruitment. An analysis of the field notes revealed the salience of six themes, namely Gaining Trust, Visibility, Networking, Follow-up, Purposeful Activity, and Community Engagement. Barriers that were overcome included knowledge deficit about dementia in the target community and the cultural unsuitability of the terminology linked to dementia. Benefits included community awareness and development of community and family partnerships, and of course, the recruitment of adequate number of research participants.

Index Terms: minority recruitment; dementia; African American; family caregiver; culturally informed recruitment strategy

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1. Introduction

They listened to her [a Caucasian researcher] because she was white and that is the tradition and custom of Southern United States: white people are right and know what they are talking about. I believe differently, that black people have to get out of the mentality that we can't do certain things and that we are not equal. I guess this goes back to the slavery days. For my [family member] to tell me "we don't do what you're doing." That was an eye opener. Is this how people feel, that I'm crazy for stepping out of my black role and doing the research, taking on the leadership, doing those things that white people do? . . . Hopefully, my current actions will be a start of many movements in Southern United States. I hope I am opening up tightly closed eyes, giving them something to think about. I don't want people to think white is better, so this black girl can't be serious. Also I want them to know that nurses can do research that can help the community just as doctors conduct clinical trials. (F. Epps, Research journal, March 16, 2014).

Challenges associated with accessing and recruiting African American research participants has been explained by a lack of trust developed because of historical ethical issues, such as the Tuskegee Syphilis Study and Henrietta Lacks' "immortal" cells (Jones & Jablonski, 2014; Kennedy, Mathis, & Woods, 2007; Williams, M., Meisel, Williams, J., & Morris, 2011). Additional barriers to African American participation in research are associated with mistrustful attitudes toward healthcare professionals based on previous negative experiences of poor communication and difficulty navigating through the health care system (Ejiogu et al., 2011; Kennedy, Mathis, & Woods, 2007). In particular, the African American communities in Louisiana, United States have an additional layer of distrust for the government and many health care institutions, which failed to serve their needs during Hurricane Katrina and its aftermath (Lowe, Lustig, & Marrow, 2011). In a recent article, McDougall, Simpson, and Friend (2015) identified recruitment barriers in ethnic groups to include educational level, stereotype threat, and stigma consciousness. These barriers result in the underrepresentation of minorities in research, thus impeding the ability and opportunity for researchers and clinicians to address health disparities effectively (Diaz. 2012).

1.1. African American Recruitment in Dementia Research

Despite African Americans having a higher incidence and prevalence of Alzheimer's disease and related dementias (Alzheimer's Association, 2015), dementia is an avoided

topic within the African American community and has been referred to as a "silent epidemic" (Jett, 2006; Monroe, 2013). In a number of minority communities, dementia is often stigmatized and family members do not discuss or share their experiences related to dementia (Aarons, 2014; Ahmed, Yates-Bolton, & Collier, 2014, McDougall, Simpson, &Friend, 2015). Stigma has been associated with negative emotions (e.g., shame and embarrassment) and behaviors (e.g., decreased involvement and concealment) among family caregivers (Werner, Goldstein, & Buchbinder, 2010). Liu, Buckwalter, and Burgener (2014) recently conducted a study that revealed a significant link between perceived stigma and increased depressive symptoms in dementia family caregivers. In fact, 35% of the study sample was African American caregivers, thus supporting the negative impact of the stigma surrounding the diagnosis of Alzheimer's disease and related dementia disorders in the African American community. In addition, Dilworth-Anderson and Gibson (2002) suggest cultural beliefs about dementia in the African American community contribute to several influential factors including who offers care, why that person offers care, and whether or not to institutionalize. These stigmas and beliefs may be significant barriers to recruitment of African Americans for dementia research (Adams, Deokar, Anderson, & Edwards, 2013; Danner, Smith, Jessa, & Hudson, 2008; Liu, Buckwalter, & Burgener, 2014). Community awareness efforts have been recommended to address these barriers (Garand, Lingler, Conner, & Dew, 2009; Williams et al., 2011).

Establishing trust in minority communities is essential to successfully recruit study volunteers (Diaz, 2012; Garand et al., 2009; Mier et al., 2006). In order to gain trust in African American communities, studies have used diverse research teams, performed community assessments, worked with gatekeepers and liaisons, and approached the church, community centers, and leaders in the African American community (Danner et al., 2008; Diaz, 2012; Ejiogu et al., 2011; Jones & Jablonski, 2014; McDougall, Simpson, &Friend, 2015; Williams et al., 2011). Community-based partnerships and establishing community advisory boards have also been successful in building a research health registry of older, urban African American volunteers (Chadiha et al., 2011; Ejiogu et al., 2011). More specifically, Chadiha et al. (2011) discussed the successful development of a volunteer registry through a community-based partnership with the Healthier Black Elders Center and Michigan Center for Urban African American Aging Research, one of the seven Resource Centers for Minority Aging Research in the United States. While building community partnerships is effective, such partnerships do not automatically take care of misconceptions about research, and minority recruitment remains challenging (Ejiogu et al., 2011; Paskett et al., 2008). Despite various recruitment efforts, there still remains a lack of African American representation in research, specifically dementia research, that hinders the understanding of the disease and quality of life for African American elders and their caregivers (Danner et al., 2008; Jones & Jablonski, 2014; Monroe, 2013). Therefore, taking into consideration the diversity of research sites and communities, it is critical for researchers to communicate effective recruitment strategies for the inclusion of minorities (Dilworth-Anderson, 2011). While not in the African American community, culturally informed community nursing practice (Dreher & Skemp, 2011) and the systematic culturally informed healthy aging model strategies have been effective in engaging and sustaining immigrant (Skemp, Surage, Maxwell, Magboul, & Poage, 2008), rural (Skemp, Maas, Umbarger-Mackey, 2014), and international (Skemp et al., 2008; Skemp, Seetharam, Surage, Peacock, & Wallis, 2014) community members in health programming and research.

1.2. Culturally Informed Healthy Aging Model Recruitment Strategies

Culturally informed strategies are used to systematically gain an understanding of the community by developing community partnerships based on trust for research and program development (Dreher & Skemp, 2011; Skemp, 2015). These strategies are grounded in epidemiology, anthropology, and nursing science. Epidemiological strategies include the bio-statistical measures of population health to include the distribution of risk factors, in addition to mortality and morbidity statistics among the populations within a community. This provides an understanding of the health issues of a group of people and, through comparison with other population groups, a better identification of the recruitment area, thus leading to a better understanding of the community's health. Anthropology provides ethnographic strategies that allow the nurse to become informed about the socio-cultural determinants of a community. Through observation, interviews, document reviews, and field notes, the nurse researcher systematically gains an understanding of the environment, population(s), and social organization of a particular group of people. Nursing science and licensure allows holistic evidence-based nursing care to individuals, groups, families, and/or communities (American Nurses Association, 2010). Prior experiences that community members have had with nurses providing intimate relationship-based care and advocacy have garnered the nursing profession the reputation of being one of the most trusted professions (Riffkin, 2014). In addition to the reputation of trust accorded the nurse, the ability to provide individualized and community nursing assessment, care, and referrals provides opportunities to better engage and "give" to the community in ways that are not related to the research project and allow potential participants to know the nurse researcher. Knowing the researcher as a nurse facilitates the development of a trusting relationship and community members' receptivity to the purpose of the research, and potential benefits/risks of participating in the research. While this has been effective in India and United States populations (Skemp et al., 2008; Skemp et al., 2014; Skemp, 2015), it has not been used for recruitment in African American populations.

2. Purpose

The purpose of this article is to describe a nurse researcher's experience of using the systematic culturally informed strategies to enhance recruitment in the African American population. In particular, lessons from the researcher's experience are synthesized so that other researchers may improve participant recruitment while working with hard-to-reach populations. The first author used these strategies over a 14-month period while conducting a study on family involvement in health promotion activities, specifically for African American older adults with dementia who live in southern Louisiana. Recruitment of this hard-to-reach population allows for the following:

- (a) clinicians and scientists to have a better understanding of the unique strengths and abilities of this population,
- (b) increase awareness of the prevalence of Alzheimer's disease in the African American population,

- (c) decrease in the stigma associated with memory loss in the African American community, and
- (d) increase in the access and availability of resources for African Americans with dementia.

3. Methods

3.1. Design

The first author was the researcher who conducted the study. She is an African American female nursing professor from southern Louisiana who had research experience with family caregivers in African American, Hispanic, and Caucasian communities (Epps, 2014). Initially, she thought that she would implement the same recruitment techniques used previously to collect survey data (i.e., recruiting through her own family, friends, and local churches). However, referrals for the current study were difficult to attain when using this familiar method despite being an African American recruiting from within her own ethnic community. It occurred to her that asking African American families to open up their homes and share their lives and stories on such a devastating disease that also has been documented as a "silent epidemic" is quite different from administering surveys. When sharing this with her research team, it was suggested she do a small-scale culturally informed community health assessment before directly approaching family, friends, and churches again.

Culturally informed strategies (Dreher & Skemp, 2011; Skemp, 2015) were used in recruiting for the study to deepen the researcher's familiarity with the context of rural and urban areas in southern Louisiana and establish a potential recruitment network, specifically in the regions surrounding Baton Rouge and New Orleans. These strategies provide a level of engagement and practicality for nurse researchers to develop relationships and a shared research purpose with community members. Culturally informed recruitment strategies for the study included:

- (a) using epidemiological and anthropological strategies to identify and describe the population health and social organization of the geographic recruitment area,
- (b) identifying key dementia organizations in the recruitment area,
- (c) interviewing members of the "nurse network" to meet key leaders of dementia focused programs in the community,
- (d) requesting and interviewing key leaders to learn more about their care program activities,
- (e) accepting invitations to observe and participate in the key leaders' care program activities,
- (f) providing hands-on nursing care by volunteering at health fairs and church events,
- (g) organizing social gatherings to create awareness and interest about the research, and
- (h) promoting the research and its benefits in all appropriate conversations.

While these strategies are similar to engaged research principles (Vukotich, Cousins, & Stebbins, 2014), the systematic use of the strategies and the nurse's role are highlighted here.

3.2. Procedure

To foster credibility of data collection and recruitment strategies, brief field notes were taken by the researcher during activities and expanded upon within an hour of the activity, along with a journal to capture immediate impressions and perceptions. Journal entries included a description of the experience, reflective notes, and the next steps toward fostering partnerships, recruitment, and referrals. Field notes and the research journal were transcribed (116 pages) to document preparation for learning about the community and recruiting members of the African American community. Additional data were also collected in interviews between the researcher and team members at the end of the study regarding the researcher's overall research experience using culturally informed recruitment strategies.

3.3. Data Analysis

Three research team members independently read the field notes and journal. Themes were identified and any differences in understanding were resolved with discussion at biweekly team meetings. A record of recruitment activities related to the research study was constructed (Miles, Huberman, & Saldana, 2014). In addition, frequency statistics were used to identify the frequency of recruitment contacts who were members of the formal and/or informal networks.

4. Results

The first author (F. Epps) systematically conducted the culturally informed community health assessment and was surprised with the results, even though she did not quite understand the culturally informed approach initially and had to trust its success with other populations. In short, the researcher established informal and formal networks within a geographic area. People from these networks participated in the research and also assisted in recruiting additional participants. Contact with this network increased the researcher's awareness of the community.

Understanding cultural groups is more than understanding race. Mapping out the geographical area and its service providers allows me to deeply understand how my research can impact the community. These are the things that I'm including in my short talking points with people I encounter. It just amazes me on how receptive they are. I wonder if they recognize the time I took to learn the community, assess their needs and that I'm not there to just take but also to make an impact. (F. Epps, Research journal, September 13, 2013)

4.1. Recruitment Area

The state of Louisiana was a French and Spanish colony that imported African slaves (Murphy, 2008). Emancipation in 1863 made slavery illegal and the Civil Rights Movement of the 1960s ended segregation. Health disparities and access to health care, however, remain an issue with approximately 34% of African Americans in Louisiana living below the poverty line (DeNavas-Walt, Proctor, & U.S. Census Bureau, 2014).

Louisiana has the third largest proportion of African Americans (1,486,885; 33%) among the U.S. states. Among them, 8.5% are 65 years of age or older (United States Census Bureau, 2011). Alzheimer's disease is the 10th leading cause of death for African Americans in the U.S. It is also associated with risk factors including lifestyle behaviors, eating habits, and the comorbidities of hypertension, diabetes mellitus, and cerebrovascular diseases (Heron, 2013).

The recruitment area included 15 parishes in southern Louisiana surrounding the Baton Rouge and the greater New Orleans area. African Americans comprise 39% of the combined population of these areas (United States Census Bureau, 2011). Within this recruitment area, following hurricane Katrina in 2005, there was a decrease in the number of organizations dedicated to providing formal dementia care services and education to families. In 2009, the Louisiana Alzheimer's Disease Task Force (2009) established the Louisiana Alzheimer's State Plan to help address this need; however, implementation has been sluggish due to state budget constraints and slow return of dementia care service organizations. Additionally, to address budget shortfalls, state hospitals that were predominantly located in African American communities, were closed in 2012 (Gregory & Neustrom, 2013). Consequently, many African Americans within the recruitment area had to travel further distances to seek care from private institutions. Furthermore, because of budget constraints and shifting economic priorities, there were strained relationships between some of the health care organizations that could have hindered engagement with the research project. Understanding the historical and political climate and interrelationship among the state and private organizations was important in identifying key community leaders and securing their participation in the research. For example:

To be told that there is a history of distrust between two of the major organizations helped me strategize on how to negotiate relationships with both; without threatening either organization. In hindsight, I realize either organization could have put major barriers up to obstruct my work. (F. Epps, Research journal, June 19, 2014)

Recruitment began by working with key nurses who then introduced the researcher to leaders at the local Alzheimer's organization (i.e., Alzheimer's Services of the Capital Area). The researcher then interviewed the director of the local Alzheimer's organization and a mutually beneficial relationship was established. This included the researcher volunteering in the programming department for the organization, where she attended training and assisted with support groups and presentations. Additionally, the organization primarily served Caucasian elders despite a goal to serve the African American community. Therefore, discussion included how this mutually beneficial relationship might assist with more African American elders participating in the local organization. Discussion also led to the researcher altering the wording on recruitment tools and for conversations to more culturally appropriate terms for African Americans (i.e., memory problems, memory loss, memory impairment, and forgetfulness). With the endorsement by the director, coordinators, group facilitators, and support group members, the researcher was able to meet with other community groups, and received invitations to participate and present in the two Alzheimer specific organizations that served the recruitment area.

4.2. Recruitment Network

Over 14 months, 83 informal and formal contacts developed into a network of persons that either assisted with recruitment, participated in the study only, or both. African Americans made up 72% (i.e., 60 persons) of this network. Informal contacts consisted of researcher's family, friends, associates, and caregivers of persons with dementia. Formal contacts consisted of individuals from faith-based organizations, service organizations, and dementia specific service organizations. The chart in Figure 1 provides the roles of these individuals that facilitated recruitment. Health care professionals comprised 36% (i.e., 30 persons) of the network, of which 47% (i.e., 14 persons) were nurses. Exploring the non-clinical roles within the network, 7% of the individuals included (i.e., 6 persons) had a role affiliated with faith-based organizations.

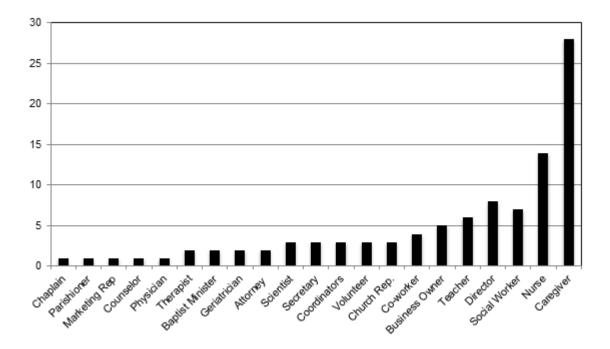


Figure 1. Diverse roles of persons who referred participants for recruitment.

Furthermore, an overlap occurred that consisted of 6% of the individuals (i.e., 5 persons) identifying with both informal and formal contact roles (Figure 2).

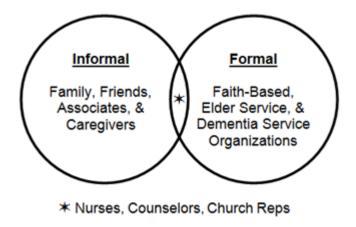


Figure 2. Informal and formal community network.

4.3. Themes

Field notes, interviews, the research journal, and the record of recruitment activities revealed the following themes: *Gaining Trust*, *Visibility*, *Networking*, *Follow-up*, *Purposeful Activity*, and *Community Engagement* (Table 1).

Table 1. Culturally Informed Recruitment Strategies

Months	Activities	Themes
1	 Identifying the geographic recruitment area and population health statistics/indicators Reviewing community documents (e.g., newspapers, television, newsletters) Identifying key African American organizations in the recruitment area (e.g., dementia service organizations, churches) Using the "nurse network" to facilitate meeting with key leaders of formal dementia care programs in the community Requesting and interviewing key leaders to learn more about their care program activities Promoting the research and its benefits in all appropriate conversations (talking points) Tracking of interviews, observations, and activities through field notes and journaling 	Networking Gaining Trust Follow-up Visibility
2	 Continuing above activities Accepting invitations to key leaders' programming events Volunteering at health fairs and church events Organizing and attending social gatherings 	Networking Gaining Trust Follow-up Visibility Purposeful Activity Community Engagement
3	Received research ethics approval	

3-5	 Continuing above activities Soliciting family participation in study Revising talking points and research forms with community participant and research team input Checking back with church leaders Volunteering for 1-2 community events per month (e.g., American Association of Retired People, Alzheimer's organizations, churches) 	All six themes
6-11	Continuing above activitiesConducting research interviews	All six themes
12-14	Continuing above activities	All six themes

4.3.1. Gaining Trust

The researcher gained trust within the community by meeting and developing relationships with key formal and informal community leaders. The researcher participated in many community activities unrelated to the research project but consistent with nursing practice. Participation involved giving a presentation at a church on breast cancer awareness, which was sponsored through their health ministry, along with volunteering for other events. Activities such as these allowed the community to see how the nurse researcher was not only interested in the proposed project but also interested in the well-being of the community.

Even though my speech wasn't on Alzheimer's disease and related dementias, this was my entry ticket into this population. I see this as having the community trust me, recognize me as someone who can and will help (F. Epps, Research journal, October 24, 2013).

The researcher also gained trust from the families that participated in the study. Snowball sampling occurred with several families once they completed the first round of interviews. Families were excited about having the opportunity to be heard and possibly being able to help others that are in similar situations. Additionally, during one of the last interviews, one family member said "we would do anything for you" and made sure that the researcher had names of others in the community to contact for her research.

On the other hand, the researcher received backlash initially from family and friends for conducting and participating in this research study. She was aware of the history of African Americans not participating in research and the ignorance surrounding the various roles of a nurse were constant reminders of the community and culture in which she lived. She found many family members who were not taking her seriously because of their unfamiliarity with nurses conducting research, especially African American nurses. Over time, as she continued to follow the culturally informed strategies, and gained the trust of family and friends.

After attending this event [educational seminar], my [family member] became more open to my research and admitted that my [elder family member] may have some type of cognitive impairment. This surprised me because before hearing me speak, she was against recognizing the signs and symptoms presented by my [elder family member]. (F. Epps, Research journal, September 26, 2013)

Amazing, this is the same [family member] that was against me doing this research in the beginning . . . I just find it amazing how people come around in time. It really meant something to me to have her give me a referral for the study without my asking her. (F. Epps, Research journal, November 19, 2014)

4.3.2. Visibility

Visibility was gained at community events where the researcher participated and made contact with program coordinators, geriatricians, caregivers, and key leaders within the community. Key leaders explained that they were pleased to see the researcher attending their community events and engaging in the community. These experiences allowed time for the community members in attendance to learn more about the research and the researcher.

I was glad to be part of this [educational seminar], putting my name out. Hoping it will soon be recognized among this community. (F. Epps, Research journal, October 22, 2013)

While attending events, meeting key community members, and visiting with family members, there were discussions about the research questions. In particular the words dementia and Alzheimer's were not well received, accepted, part of the norm, nor used in the African American community (Adams et al., 2013; Garand et al., 2009; Jones & Jablonski, 2014; McDougall, Simpson, & Friend, 2015). The researcher then worked with community members, colleagues, and the research team to revise the recruitment and research tools to be culturally appropriate for African Americans (e.g., changing "dementia" to more acceptable terms such as memory problems, memory loss, memory impairment, and forgetfulness).

Print media was used to increase visibility of the study. In addition to the researcher posting flyers on area bulletin boards, flyers were e-mailed to individuals within the recruitment network. Network contacts assisted the researcher by sharing flyers in newsletters, posting in staff lounges, handing them out at community events, and forwarding to others within their network (e.g., family, friends, co-workers, clients).

4.3.3. Networking

The researcher took every opportunity to interact with others in the community. She attended seminars to meet others in the field of aging and dementia care. She gained additional knowledge about care surrounding dementia at these seminars, where she met other scientists, volunteers, and individuals associated with Alzheimer's and elder service organizations.

This was a great opportunity for me to become more knowledgeable about the Alzheimer's disease network as I continue to develop as an expert in this area. (F. Epps, Research journal, April 16, 2014)

In addition, networking occurred in informal locations such as gas stations, personal grooming centers, and retail stores. The researcher discovered that common shopping areas within the predominant African American communities in southern Louisiana were an opportune place to share her research interest. The researcher is from southern Louisiana and has had past interaction with many healthcare professionals and members in the community. These interactions opened a gateway for her to share her program of research when individual paths crossed. The researcher had an experience in building her network in the foyer of a retail store when she met a former co-worker who was an occupational therapist and worked at an elder living center. The occupational therapist offered to make the study flyers available at her place of employment, particularly sharing it with the case management department.

This incidence lends to my recruitment efforts by also calling on/networking with past business associates. The point is, I need to share my research interest with everyone in my address book. You never know . . . (F. Epps, Research journal, December 13, 2013)

4.3.4. Follow-up

Timely follow-up proved to be valuable in the development of partnerships and receiving referrals. Follow-up notes were taken after participation in health events, nursing activities and encounters with those in the network. The researcher sent follow-up e-mails within a week after meetings with formal contacts. The follow-up e-mails served as friendly reminders in relation to particulars of any previous discussion. For example, during one of the meetings with a program coordinator, the coordinator said she preferred for the researcher to e-mail instead of calling.

I was glad to hear from her that she prefers e-mails so she can flag them, which helps her keep pertinent items on her agenda. Great! Now I know the best way to communicate with her, as she is a key player in keeping me in the loop and connected with the latest activities involving Alzheimer's. (F. Epps, Research journal, March 20, 2014)

Follow-up was also reciprocal, where some of the persons within the network followed up with the researcher. This encouraged the researcher to proceed with recruitment efforts and gave her an understanding that family members and organization representatives were interested in participating in this research because of a shared goal of enhancing and maintaining the quality of life for African American families who had an elder with dementia. For example, the researcher met a healthcare vendor at a state conference and the vendor sent a follow-up e-mail within 2 weeks, requesting more information about the study.

This was a great follow-up on her part. We had a brief conversation at the conference about my research and goal to improve the quality of life for these families. But I really didn't think she was listening or interested in what I was saying. (F. Epps, Research journal, October 8, 2014)

4.3.5. Purposeful Activity

As activities and participation were strategically planned, the research team frequently revisited the aims of the project and thought of ways and locations to contact this hard-to-reach population. Short talking points about the research that included the increased incidence and prevalence of Alzheimer's disease and related dementias in African Americans were prepared for various settings. Here is an example:

You know Blacks are two to three times more likely than Whites to develop memory problems. This disease is very prevalent in the African American community and I'm looking at ways families are involved in healthy activities to hopefully develop or tailor interventions to be culturally sensitive to enhance and/or maintain the quality of life for families that are dealing with this devastating disease.

Representatives from faith-based organizations, while interested in learning about the research, initially were not as eager and welcoming to support the participant recruitment efforts. Therefore, in addition to providing nursing services at church sponsored events, the researcher decided to introduce her research at social gatherings such as a neighborhood Halloween party. Information about the research was well received, and attendees opened up about their personal experiences with dementia, which resulted in five referrals. The success of the event led to the researcher using social gatherings as a platform to introduce the research project and recruit participants. These gatherings ranged from kids' birthday parties to socializing with friends at local bars, and having dinner with associates.

I found another effective way for me to recruit participants for my research . . . right in my backyard. Should I throw more parties? Parties with a Purpose. (F. Epps, Research journal, October 31, 2013)

4.3.6. Community Engagement

Community engagement was very significant in building an informal and formal network of contacts. Once credibility of the researcher and research purpose was established and trust was gained, community engagement led to the development of family and community partnerships.

I think volunteering to do this session [nursing educational seminar] helped my credibility among the caregivers and other practitioners. (F. Epps, Research journal, October 16, 2013)

After 12 months, three representatives from churches expressed interest in helping to recruit participants for the study. They commended the researcher for assisting with health fairs and respectfully acknowledged the researcher's willingness to wait until it was a good time for their respective churches to participate.

4.4. Recruitment Outcomes

An analysis of the recruitment process resulted in the initial 6 months focusing on purposeful activities to develop and sustain community relationships in the African American communities and the Alzheimer's organizations. Once research ethics approval was received, a growing network of support for the research had been established and family interviews were begun with African American families who were interested in participating. This recruitment process provided the research team with 33 referrals for participation in the study. However, recruitment strategies were continued and community partnerships were maintained throughout the study.

I am very grateful to my mentors to have had a step-by-step process to follow. I don't think I would have been this successful with recruitment and being accepted in the dementia and African American community if I did not. It was scary at first because I didn't see exactly how this would work with my own people. I didn't think I needed someone or a process to guide me as an African American on recruiting from my own people. However, these strategies allowed me to stay focused. Whenever I felt overwhelmed or lost, I had someone to consult and get me back on track. I am glad I trusted the documented success of these strategies in other populations. (F. Epps, Research journal, August 21, 2015)

5. Discussion

Recruitment strategies for this study supported the mission for the Resource Centers for Minority Aging Research (Ory, Darby-Lipman, Barr, Harden, & Stahl, 2000) and the National Plan to address Alzheimer's disease (United States Department of Health & Human Services, 2014). Furthermore, we believe that our additional efforts went beyond the current thinking and recommended approaches, such as having minority recruiters (Diaz, 2012; Jones & Jablonski, 2014) and focusing on African American churches (Herring, Montgomery, Yancey, Williams, & Fraser, 2004). For example, African American churches that the researcher worked with or attended in the past gave varied responses in regard to their interest in the study; some showed interest and requested for the researcher to continue her involvement in church activities and others simply did not respond. Overall, the purpose of contacting the local churches was to develop trust and provide transparency about the work that was being done in the community. Therefore, simply relying on the churches would not have produced an adequate sample for our study.

As outlined in Table 2, the culturally informed strategies that worked for this study were similar to those discussed in the community-engaged research literature (Diaz, 2012; Vukotich, Cousins, & Stebbins, 2014). However, to recruit African Americans for the study, it was necessary for the nurse to assess the community and understand the geographic context of southern Louisiana. These steps involved identifying areas that are predominantly African American, sources of health care and community services for persons with dementia, and their caregivers. The culturally informed community health assessment also helped the research team understand the political climate and purposefully identify key leaders that had influence, including engaging those persons who could help or hinder the research. Most importantly, it was essential for the

researcher to be engaged in order to gain trust and visibility in the community, which was critical to establishing a network before requesting assistance in research recruitment.

The lack of awareness of Alzheimer's disease and related dementias in the African American community (Danner et al., 2008) posed a challenge. All activities that were conducted to gain access and recruit African American families also supported the efforts of increasing the awareness of this disease in the community. Through the short talking points, information about the incidence and prevalence of dementia was found to attract the attention of the researcher's family, friends, and associates. On the other hand, because the researcher was a nurse, she was approached several times after presentations to speak privately and confidentially about the individual's personal concerns about Alzheimer's disease or "severe memory loss" experiences. This lack of awareness and the stigma associated with Alzheimer's disease are documented in the literature (Aarons, 2014; Ahmed et al., 2014; McDougall et al., 2015). African Americans avoid the subject matter and generally do not share their problems openly even within their own community.

While many of the culturally informed strategies have been used to recruit participants, use of the culturally informed healthy aging model (Skemp et al., 2008, 2014) systematically applies the strategies of population health description, ethnographic observation, interviews, document review, and nursing "hands-on" provision of care to develop a better understanding of the culture and successful recruitment in African American communities. The culturally informed model assisted the researcher to stay focused as she encountered challenges (e.g., discouraging comments from family and friends). Most importantly, the culturally informed model provided the contextual relationship in which trust was developed and the research purpose shared, garnering buy-in and informal partnerships whereby community members facilitated recruitment and the research process. We anticipate this will also foster engagement and buy-in for the next phases of the research.

The proportion of ethnically diverse older persons will continue to increase in the United States (Institute of Medicine, 2015). Limited research participation of the African American population affects the generalizability of study results and ultimately decisions related to best practices and clinical outcomes (Alzheimer's Association, 2015; Paskett et al., 2008; Williams et al., 2011). While we cannot change the checkered history of human research ethics in the recruitment of African American participants, as researchers we can, through our research relationships, better understand and build trust within African American communities. Jones and Jablonski (2014) stressed the importance of researchers modifying recruitment approaches and sharing the successful strategies for a more inclusive approach to dementia research. The culturally informed method is one approach to promoting trust, making research appealing, and increasing the participation of African Americans in health research.

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References

- Aaron, C. (2014, November). *Recruitment and retention of older African American women caregivers of persons with dementia*. Paper presented at the 67th Annual Scientific Meeting of The Gerontological Society of America, Washington, DC.
- Adams, M., Deokar, A., Anderson, L., & Edwards, V. (2013). Self-reported increased confusion or memory loss and associated functional difficulties among adults aged ≥ 60 Years: 21 States, 2011. *Morbidity and Mortality Weekly Report*, 62(18), 347-350.
- Ahmed, A., Yates-Bolton, N., & Collier, E. (2014). *Diversity and inclusiveness in dementia: Listening event report*. Salford Institute for Dementia. University of Salford, UK.
- Alzheimer's Association. (2015). 2015 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 11(3), 332-384.
- American Nurses Association. (2010). *Nursing: Scope and standards of practice*. Washington, DC: Nursebooks.org
- Chadiha, L., Washington, O., Lichtenberg, P., Green, C., Daniels, K., & Jackson, J. (2001). Building a registry of research volunteers among older urban African Americans: Recruitment processes and outcomes from a community-based partnership. *The Gerontologist*, *51*(S1), S106-S115.
- Danner, D., Smith, C., Jessa, P., & Hudson, J. (2008). African Americans with memory loss: Findings from a community clinic in Lexington, Kentucky. *Nursing Clinics of North America*, 43(3), 437-447.
- DeNavas-Walt, C., Proctor, B., & U.S. Census Bureau. (2014). *Income and poverty in the United States: 2013* (Current Population Reports, P60-249). Washington, DC: U.S. Government Printing Office. Retrieved from http://www.census.gov/content/dam/Census/library/publications/2014/demo/p60-249.pdf

- Diaz, V. (2012). Encouraging participation of minorities in research studies. *Annals of Family Medicine*, 10, 372-373.
- Dilworth-Anderson, P. (2011). Introduction to the science of recruitment and retention among ethnically diverse populations. *The Gerontologist*, 51(S1), S1-S4.
- Dilworth-Anderson, P., & Gibson, B. (2002). The cultural influence of values, norms, meanings, and perceptions in understanding dementia in ethnic minorities. *Alzheimer Disease and Associated Disorders*, 16, S56-S63.
- Dreher, M., & Skemp, L. (2011). *Healthy places, healthy people: A handbook for culturally informed community nursing practice* (2nd ed.). Indianapolis, IN: Sigma Theta Tau International.
- Ejiogu, N., Norbeck, J., Mason, M., Cromwell, B., Zonderman, Z., & Evans, M. (2011). Recruitment and retention strategies for minority or poor clinical research participants: Lessons from the healthy aging in neighborhoods of diversity across the life span study. *The Gerontologist*, *51*(S1), S33-S45.
- Epps, F. (2014). The relationship between family obligation and religiosity on caregiving. *Geriatric Nursing*, *35*(2), 126-131.
- Garand, L., Lingler, J., Conner, K., & Dew, M. (2009). Diagnostic labels, stigma, and participation in research related to dementia and mild cognitive impairment. *Research in Gerontological Nursing*, 2(2), 112-121.
- Gregory, D., & Neustrom, A. (2013, December). *A new safety net: The risk and reward of Louisiana's Charity hospital privatizations* (Publication 333). Baton Rouge, LA: Public Affairs Research Council of Louisiana. Retrieved from http://www.parlouisiana.com/dynaengine/loadDocument.cfm?site=1002087&doc=parhospital2013.pdf
- Heron, M. (2013, December 20). Deaths: Leading causes for 2010. *National Vital Statistics Reports*, 62(6). Retrieved from http://www.cdc.gov/nchs/data/nvsr/nvsr62/nvsr62_06.pdf
- Herring, P., Montgomery, S., Yancey, A., Williams, D., & Fraser, G. (2004). Understanding the challenges in recruiting blacks to a longitudinal cohort study: The Adventist health study. *Ethnicity & Disease*, *14*, 423-430.
- Institute of Medicine. (2015). Cognitive aging: Progress in understanding and opportunities for action. Washington DC: National Academies.
- Jett, K. (2006). Mind-loss in the African American community: Dementia is a normal part of aging. *Journal of Aging Studies*, 20, 1-10.
- Jones, C., & Jablonski, R. (2014). 'I don't want to be a guinea pig': Recruiting older African Americans. *Journal of Gerontological Nursing*, 40(3), 3-4.

- Kennedy, B., Mathis, C., & Woods, A. (2007). African Americans and their distrust of the health care system: Healthcare for diverse populations. *Journal of Cultural Diversity*, 14(2), 56-60.
- Liu, M., Buckwalter, K., & Burgener, S. (2014). Perceived stigma in caregivers of persons with dementia and its impact on depressive symptoms. *Journal of Depression and Anxiety*, *3*(4), 162.
- Louisiana Alzheimer's Disease Task Force. (2009, October). *The impact of Alzheimer's disease in Louisiana*. Baton Rouge, LA: Louisiana Department of Health and Hospitals. Retrieved from http://new.dhh.louisiana.gov/assets/docs/LegisReports/SCR802008RSFinal.pdf
- Lowe, S., Lustig, K., & Marrow, H. (2011). African American women's reports of racism during hurricane Katrina: Variation by interviewer race. *New School Psychology Bulletin*, 8(2), 46-57.
- McDougall, G., Simpson, G., & Friend, M. (2015). Strategies for research recruitment and retention of older adults of racial and ethnic minorities. *Journal of Gerontological Nursing*, 41(5), 14-25.
- Mier, N., Medina, A. A., Bocanegra-Alonso, A., Castillo-Ruiz, O., Acosta-Gonzalez, R. I., & Ramirez, J. A. (2006). Finding respondents from minority groups. *Journal of Research Practice*, 2(2), Article D2. Retrieved from http://jrp.icaap.org/index.php/jrp/article/view/74/74
- Miles, M., Huberman, M., & Saldana, J. (2014). *Qualitative data analysis: A methods sourcebook* (3rd ed.). Washington, DC: Sage.
- Monroe, S. (2013, October 22). Ending the disparate impact of Alzheimer's disease in African-Americans. *Leaders Engaged on Alzheimer's Disease Newsletter*. Retrieved from http://www.leadcoalition.org/2013/10/usagainstalzheimers-launches-first-national-network-devoted-ending-disparate-impact-alzheimers-disease-african-americans/
- Murphy, A. (2008). Placing Louisiana in the Francophone world: Opportunities and challenges. *Atlantic Studies*, *5*(3), 11, 363-381.
- Ory, M. G., Darby-Lipman, P. D., Barr, R., Harden, J. T., & Stahl, S. M. (2000). A national program to enhance research on minority aging and health promotion. *Journal of Mental Health and Aging*, 6, 9-18.
- Paskett, E., Reeves, K., McLaughlin, J., Katz, M., McAlearney, A., Ruffin, M., . . . Gelhert, S. (2008). Recruitment of minority and underserved populations in the United States: The centers for population health and health disparities experience. *Contemporary Clinical Trials*, 29, 847-861.

- Riffkin, R. (2014, December 18). Americans rate nurses highest on honesty, ethical standards. *Gallup Social Issues*. Retrieved from http://www.gallup.com/poll/180260/americans-rate-nurses-highest-honesty-ethical-standards.aspx
- Skemp, L. (2015, February). *Culturally informed healthy aging: From concept to research*. Speech delivered at the Proseminar on Integrative Science of Aging, University of Pennsylvania, Philadelphia, PA.
- Skemp, L., Maas, M., & Umbarger-Mackey, M. (2014). Doing it my way. *The Gerontologist*, 54(4), 693-703.
- Skemp, L., Seetharam, S., Surage, K., Peacock, A., & Wallis, A. (2014, November). *Culturally-informed community capacity programs for healthy aging cross-national exemplars*. Symposium presentation at the 67th Annual Scientific Meeting of The Gerontological Society of America, Washington, DC.
- Skemp, L., Surage, K., Maxwell, M., Magboul, R., & Poage, A. (2008, April). *Ethnographic CBPR for building community capacity for healthy aging*. Symposium presentation at the 41st Annual Communicating Nursing Research Conference, Western Institute of Nursing, Garden Grove, CA.
- United States Census Bureau. (2011). *The black population: 2010*. Retrieved from http://www.census.gov/content/dam/Census/library/publications/2011/dec/c2010br-06.pdf
- United States Department of Health & Human Services. (2014). *National plan to address Alzheimer's disease: 2014 update*. Retrieved from http://aspe.hhs.gov/daltcp/napa/NatlPlan2014.shtml
- Vukotich, C. J., Jr., Cousins, J., & Stebbins, S. (2014). Building sustainable research engagements: Lessons learned from research with schools. *Journal of Research Practice*, *10*(1). Article M1. Retrieved from http://jrp.icaap.org/index.php/jrp/article/view/381/324
- Werner, P., Goldstein, D., & Buchbinder, E. (2010). Subjective experience of family stigma as reported by children of Alzheimer's disease patients. *Qualitative Health Research*, 20, 59-169.
- Williams, M., Meisel, M., Williams, J., & Morris, J. (2011). An interdisciplinary outreach model of African American recruitment for Alzheimer's disease research. *The Gerontologist*, *51*(S1), S134-S141.

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