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Ethical Dimensions within Qualitative Research

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Abstract

Throughout history people have relied on their culture for healing practices and ways of caring. Healing began in Africa thousands of years ago with herbs and plants that were used for healing and rituals. As African people came to America they brought with them cultural ways which were practiced throughout slavery. Thereafter, elders passed down the healing remedies until today.

The purpose of this study was to discover beliefs, meanings, and practices of healing with botanicals (plant, root, or bark parts) recalled by African American women 80 years of age or older that were born and resided in the Mississippi Delta. The goal of the study was to provide insight into the cultural beliefs and ways of the people by identifying generic practices of the elders; thereby, providing additional knowledge needed to design and implement culturally congruent care. The knowledge obtained is posited to assist other nurses in the care of African Americans and highlight the importance of generic care awareness.

This study discovered that the elders in the Mississippi Delta depend now on professional care and less on the remembered botanical healing ways of the past. Many botanical healing methods were remembered but few used today. However, women remain the healers in the family units and are considered important in care. African American elders view God as the center of life and healing. Health was defined by the elders and younger informants as the ability to get up and do normal things and is maintained by taking care of oneself. Illness is viewed as the inability to do normal activities. This finding may shed light on the late presentation of symptoms in health care within this culture.

As population demographics shift, people and nurses are more mobile now than ever before. Because of this mobility, cultural care research is important to ensure provision of culturally competent care. This research provides additional resources toward understanding the elder African American culture in the Delta as it relates to provision of culturally congruent care. Ultimately, through culturally competent care, the client will receive care that is respectful, safe and not offensive.

Keywords: Ethics, Qualitative, Ethno-nursing, Findings

Ethical Dimensions within Qualitative Research

In a recent qualitative study of current and past healing ways with botanicals as recalled by African American female elders in the Mississippi Delta, this researcher considered, recognized, and experienced ethical questions and issues. There is a history of unethical treatment of participants in research that imposes on all research today. There was a desire to maintain an ethical study and much forehand thought was given to ethical treatment in this study involving African American elders as participants. But even with planning and design, issues arose in narrative collection that deserved reflection for future studies. Eight key elder and sixteen general informants were asked what healing practices with botanicals were in use today and what practices were remembered from the past. In addition an ethno history was collected from each of the eight key participants to obtain a better understanding of the elder's worldview.

The need to protect human subjects participating in research resulted from past studies and not as a fore thought (Tuskegee University, 1981). Trochim (2006) cited two studies that were partially responsible for a new look at ethical issues and the formalization of some ethical rules when humans are involved. The Nuremberg Trials in which Germans used humans for experimentation and the mid 1900 Tuskegee Syphilis Study that involved African American participants set a precedent for studies that followed. The Institutional Review Boards have been established to prevent the tragedy that occurred with these two studies from occurring again.

The Tuskegee Study was recorded as a "one of the most horrendous examples of research carried out in disregard of basic ethical principles of conduct" (Tuskegee University, 2003, para. 1). In the mid 1900's, African Americans often did not have sufficient health care and many participated in studies as a way of obtaining health care. With the loss of funding during the depression, the Tuskegee study was altered to study the effects of syphilis on humans. Clients were not told they had syphilis nor given the treatment of penicillin even after penicillin was identified as the treatment (Freimuth et. al., 2000, Background sect., para. 9). The Tuskegee study resulted in a formalized plan for human subject protection but the plan did not mend the distrust. As a result of past research with African American participants, distrust often exists today and this distrust extends to care providers as well as researchers (Tuskegee University, 2003).

When a researcher considers ethical considerations today, several principles come to mind such as: voluntary participation, informed consent, protection from harm, and confidentiality (Trochim, 2006). Ethical principles identified by the National commission for the Protection of Human Subjects of biomedical and Behavioral Research included: the principle of respect for the person, beneficence, and justice (Burns & Grove, 2002). In a recent ethno nursing research study involving African American elders, steps were taken before research began and during the process to ensure ethical treatment. Participants were asked if they would like to participate free of pressure. An introductory letter and consent to audiotape were presented to the informants, and as much as is possible, participants were protected from identification. The research was also aimed at doing good avoiding harm and showed respect for the individual. But in spite of preparation for these ethical principles and with much given forethought, additional ethical issues arose.

In fact, there were four additional issues that came to light from the interviews as the research progressed. First, elders were asked to share their life history from earliest memories forward; many memories were happy and many unhappy (facing memories). Secondly, a discussion came forth involving the use of the term African American (African American or Black); one of the participants voiced a preference to be referred to as Black while another declined to be called African American. The third issue involved a disassociation with the past (being modern). The elders expressed a strong desire to be treated in a modern way but while the association with the old ways of healing was remembered fondly, the ways were not desired today. And fourth, the researcher recognized this group of elder women was protected by their children and communities; one daughter did not want her mother to participate because she believed she had given enough already to whites (given enough). Respect and ethical treatment of research participants is paramount; how best do we recognize harm and unethical treatment, and how do we protect our participants? Even sufficient planning for ethical issues will not prevent new issues from arising in the process.

Facing Memories

Most institutional review boards are accustomed to reviewing quantitative studies which are controlled, but qualitative research interviews give more control to the interview process “creating a different risk profile” (Corbin & Morse, 2003, p. 335). Although an interview may bring up stressful memories, Corbin and Morse found in such interviews there was “no indication that this distress is any greater than in everyday life” if the interview is guided by a skillful researcher and ethical practices. “When research is conducted with sensitivity and guided by ethics, it becomes a process with benefits to both participants and researchers” (p. 335).

In Ethnonursing, a qualitative method based on anthropology, the collection of an ethnohistory is recognized as an important tool in understanding participants (Leininger, 1991). In this study, elders were asked to recall their life history and all did so eagerly, recalling happy as well as painful memories very candidly. The painful memories were often of oppression and poverty. Most all the elders recalled stories of mistreatment by whites. The accounts included walking to school while white children rode the bus, working for less than adequate, treatment as an inferior people, and other oppressive experiences. The accounts often began in the early 1900s and many recalled stories of slavery from their grandparents.

Yellow school buses

Frost lay on the grass, mud puddle water frozen solid, and the air sharp and cold,
Bundled in the coat Momma made me; we walked to school
Down the dirt road for two miles to the church, that was our school.
Laughing and talking, carrying our lunch, a biscuit and some meat
Maybe blackberry cobbler, if any was left, but we always had food.
That was one thing we had, even with twelve kids, we had plenty of food.
And the bus rattled down the road leaving a dust trail behind it
As the white kids rode to school, not our school but the white school,
From the window they called us names sometimes, and one spit upon us, while others
just made faces and I can’t remember if we made them back, or did we just walk
That’s what it means to have been black in those days, when I was a child in the 20s.
At school we sang songs, can’t remember the words,
Sally went round the sun and Molly around the moon…

And I forget the rest of the forgotten song
But the words and faces will never be forgotten
That came from the dusty school bus that rambled down the road
That cold winters day on our way to school,
Frost lay on the grass, mud puddle water frozen solid, and the air sharp and cold.

The principle of beneficence means participants have the right to be protected from harm (Burns & Grove, 2002). The principle reminds the researcher “one should do good and, above all, do no harm” (p. 214). The researcher questioned if this recall of painful memories would do harm or provide comfort as it allowed an opportunity to be heard when conducting the interviews. Richards and Schwartz (2002) identified anxiety and distress as a potential risk area for participants. Questions are intended to be deep reaching to bring forth information. The very questions used to seek out the desired information may provoke these feelings and outcomes cannot be easily determined before hand.

Shellman (2004) in a study of life experiences of African American elders also recorded stories of discrimination and pain. Analysis revealed no one had asked before about the elder’s worldview and hurt did exist from past experiences. Nurses through these studies can “gain insight into the cultural worldviews, and life experiences of African American elders and improve their ability to provide culturally competent care” to the population (p. 308). With research that elicits these stories, understanding and healing may begin to occur.

As the stories poured forth, the researcher experienced sadness. Participants were more eager to talk about the past than the use of botanicals. Some elders expressed the importance of telling their story and of the occurrences they remembered and they specifically wanted the stories passed on to be heard by others. It was a catharsis for the elders; someone had finally asked and was listening to what they said. The research became much more than a botanical study; it became a way of releasing and sharing. The researcher was aware the results of the study would not include the ethnohistory narratives but knew the importance of those narratives. The narratives would be published at a different time, in a different venue, as a way of fulfilling the request of the elders, a request to be heard.

African American or Black

The act of referencing race, culture, or color for research purposes became an ethical question. The title of the research and the domain of inquiry included the title African American. Most key participants preferred to be called African American, although one elder preferred to be identified as Black. A general participant reminded the researcher that only he could determine what he wished to be called, and that no one else could call him African American. What is the correct way to identify people in a specific group, race, or culture in research? If the correct reference comes from the group, culture, or race of the people, then how might researchers know the right title to use? Will including persons on the research team from that group, culture, or race assist in identifying correct and respectful titles? When answering these questions becomes too difficult, it may be easy to avoid studying specific groups, but “the participation of African Americans in clinical and public health research is essential for addressing disparities in health status” (Freimuth et. al., 2001, p. 797). If researchers believe the barriers to participation are severe enough, minorities might become limited in research studies. This imbalance would create further ethical issues.

Airhihenbuwa and King (2001) wrote the “use of the taxonomic category African American, either in public or health or other disciplines, fundamentally reflects the racial stratification in American society” (African Americans sect., para. 1). The title originated from the early 1900s when free Black people began to move north to “reunite with their African heritage” (para. 2.). What does the title African American mean to the participant or to the reader of research? Does the term allow African Americans to self identify in an “expression of identity, power, defiance, pride, and the struggle for human rights?” (para. 1). Is it a classification believed to be based on white power? Earlier terms referred to the skin tone such as Colored, Negro, and Black, while African American refers to geographic origins. Other reported “scientific research about so-called racial group differences (e.g., eugenics) was highly influential in promoting white supremacy” (African American sect., para. 5).

During the interviews, the researcher grew conscious of the term African American. The participants were asked if they preferred to be referred to as African American or Black. One elder stated being called Black was fine because she was black and she was not an African American but an American, because she wasn’t sure she came from Africa. In an effort to provide respect, the preference of the participant was observed during the interview.

Does the use of the term African American or Black bring forth the past? Physicians in earlier times believed black “physiology was inferior to whites and thus differed with regard to intelligence, sexuality, and sensitivity to pain” (Airhihenbuwa &

King, 2001, para. 6). Dr. Sims operated on three African American women without any anesthesia because of this belief. Multiple times on the same women, surgery was carried out in an attempt to perfect a surgical technique. In spite of the connection with the title African American to a negative connotation by some, it is "unlikely that serious consideration can be given to eliminating the use of racial designations" (para. 12).

Are we on the verge of a change from the African American designation to other more specific designations or no titles at all? Titles such as African American, white or non-white bring forth a multiple of identities. "Being classed as African American is quite significant because it reflects an important social group transformation and reality in terms of group identity, political orientation, life chances or social opportunity, normative standards and lifestyles, and discriminatory behavior" and these are related to "disease susceptibility, quality of life, morbidity and mortality, and longevity" (Airhihenbuwa & King, 2001, para. 12).

Being Modern

Overwhelmingly, the elders voiced the desire to be modern and to be treated clinically by trained health care providers. Does this modern treatment indicate the elders specifically want to be treated as members of other races are treated? Airhihenbuwa and King (2002) identified reasons for African Americans not to seek health care as "institutional racism" of the past, fear of "inferior treatment" from providers, fear of experimentation in care, and a "disparity of health outcomes between African Americans and the white population" that resulted in higher death rates for African Americans (para. 7).

Benkert and Peters (2005) in a study that looked at coping with health care prejudices in African American women, discovered strategies for coping with poor treatment included “getting angry, learning to be assertive, and walking away” (p. 863). In this Ethnonursing study, the elders did not voice any concerns or experiences of current mistreatment by providers, but instead recounted over and over they wanted to see doctors and nurses in the clinic and to be treated like everyone else. They concluded the old ways just do not work like the new medical ways.

Given Enough

Any doubts concerning participation during the preparatory research planning stages were unfounded. There was a tremendous willingness to participate. Although Friemuth, 2001, found that African Americans “needed to be very cautious about when and how they interacted with the medical system or government agencies” most people asked to participate in this study were willing (Results sect., para. 1). Of the twenty-six participants contacted for this study, only two declined to participate. The first elder declined because she was too busy with daily activities of canning vegetables. Another elder declined to participate because her daughter did not want her to share her stories. That refusal came from her daughter to a gatekeeper. She said her mother had given enough and she did not want her stories of the past taken as well. Both were offered appreciation but neither were approached again or included in the study. It brought to mind that researchers are not assured trust from participants and that past experiences impact present feelings.

Two elders who did not fit the qualifications of the study because they were born outside of Mississippi were so adamant about the researcher hearing their stories that they were interviewed and their stories recorded, but excluded from this study. As they were told they could not participate because they did not fit the criteria they became sad and expressed feelings of being left out. The researcher then listened to their life histories anyway, in an effort to do no harm, and their stories will be published at a later date as well in an effort to fulfill their wish of being heard and included.

African American elders have given enough. “In this country, the social reality of African American individuals is experienced through the color of their skin” and “their identity is bound with racial inequalities of our society” (Carlos and Chamberlain, 2004, p. 372). One way to assist in the recovery may be to have more conversation because there has been “little honest dialogue about how race and racism influences health” (p. 372). The researcher found through ethnohistory collection that many want to tell their stories if someone will simply listen.

A Willing Participant

She stood in the doorway smiling,
Trusting, inviting, and translucent;
Her hand was open in her blue apron pocket.
I asked to hear her story
And without hesitation she opened the door
To research and science and a stranger.
Looking into her brown marble eyes
I saw the world as she saw it
The worldview she eagerly shared.
A white researcher and an African American elder

Sat down together under the umbrella
Of broken trust, history, and new promises
Frayed from the storms that passed.
And the knowledge came forth
From her lips as she trusted I would do no harm
And I wondered how not to…

Trust and Risk

Friemuth, et. al., (2001) examined how African Americans viewed research and found "accurate knowledge about research was limited; lack of informed consent procedures was problematic; and distrust of researchers posed a substantial barrier to recruitment" (p. 797). In spite of mistrust, they found African Americans did recognize research was necessary but were not willing to participate in just any research study. African Americans do distrust professions such as doctors and scientists according to a study by Corbie-Smith, Thomas, Williams and Moody Ayers (1999). "Many participants described concerns about the ethical conduct of clinicians and investigators when poor or minority patients are involved and cited examples of exploitation as supporting evidence for their mistrust of the medical establishment" (p. 537). Mokwunye (2006) said a trustworthy environment must be developed between researcher and participant because of health care disparities noted in the literature and the need to improve health care delivery.

Because of these concerns, attempts were made to form a trusting relationship before the interviews were carried out. Gatekeepers introduced the researcher to the participants and the researcher attempted to form relationships prior to data collection.

The elders in this study read with interest the information letter and consent forms but most left the copy on the table after signing and voiced they did not want a copy. Recruitment was not a problem and participants generally said the interview was a pleasurable experience.

Fouad et. al., (2002) created a community coalition to study minority participation in research. They found participants were more skeptical when procedures such as a blood draw were carried out than when it was not and that participants desired information about the research prior to participation. A positive coalition between the informants, the community, and the research institution was necessary for trust building. The success of the participation in this ethnonursing study was likely due to the relationship between the researcher and the participants or gatekeepers. The researcher spent time in the community and all key informants were gathered through gatekeepers who could vouch for the researcher's trustworthiness. The researcher's position as a faculty member at the local university also improved trust in the relationship. Most participants knew of the university or knew someone who attended the university and could relate to the researcher.

Richards and Schwartz (2002) described possible ethical risks to those participating in qualitative research. The risks included: "anxiety and distress; exploitation; misrepresentation; and identification of the participant in published papers by themselves or others" (p. 135). Even though painful stories were recounted, elders did not appear anxious or distressed.

Exploitation, or power imbalances that exist between researcher and participant, was recognized as a possible occurrence. The researcher was a nurse, but the elders did not know until they read the consent form. Did this create a degree of trustworthiness even though the researcher was not involved in the care of any of the participants? How much value is put into the term nurse or the associations that go along with it?

The third risk according to Richards and Schwartz (2002) was misrepresentation of intentions. This risk involved the chance that the participant's conclusion would not be the same as the researcher's conclusion from data analysis. The participants lose control over their narratives. In this research, reflection throughout data collection was ongoing and the researcher asked for confirmation or comments on findings throughout the interview process. The elders confirmed and expounded on the findings. There were no disagreements on findings but there were clarifications.

The risk of identification, the fourth risk, of the participants was of ethical concern since many told of sometimes embarrassing old ways of (Richards &Schwartz, 2002). The elders shared personal accounts of occurrences, and the stories from the past were at times painful and revealing. In order to prevent identification, the elders were asked to select a fictitious name so they might recognize their narratives. This allowed participants to recognize their own words in the research results when published.

Lastly, scientific soundness was identified as "a fundamental ethical concern of all research" (Richards & Schwartz, 2002, p. 137). The research should be worthy and the researcher trained and competent. The ethnonursing method is based on the premise that understanding those in our care, their culture, and worldview, will enhance the delivery of nursing care (Leininger, 2002). Leininger designed specific enablers to aid the researcher in the process, and courses are taught around the United States on the ethnonursing research method. The researcher attended classes to learn the method in order to protect the participants before data collection ever began.

Conclusion

Ethical treatment requires the researcher ask how to best protect the public; planning begins before the study. Unfortunately "there are no absolute rules for governing ethics" and "ethical rules are less clear and difficult" (Burkhardt & Nathaniel, 2002, p. 25). In fact, "little consideration in medical journals of the ethical issues surrounding qualitative research" has been found (Richards & Schwartz, 2002, p. 135). Past research experiences, such as the Tuskegee, laid a foundation for future research, but ethical issues continue to arise today as they did in the past.

The researcher ideally is forthcoming and honest, and the research process involves the entire research team and other peers in discovery (Clarke, 2006). The ethical issue itself may be a new finding and with its discovery, new insight occurs. It is expected that ethno nursing research might bring forth new ethical issues since qualitative research was created to examine "dimensions of the social world, including the perceptions, experiences and complexities of the research participants" (Matthews, 2006, p. 47).

Although forehand thought was given to this research of botanical use practices in African American elders, unexpected ethical questions were discovered. The issues identified include: the issue of title; the desire to share the stories of pain and happiness as a releasing experience; the desire to be treated like others; and the feeling of having given enough. These findings were important; perhaps more important than the botanical list discovered.

The importance of having a member of the group, race, or culture on the committee is paramount to understanding and discussion. We do not necessarily understand each other even with the desire to do so. Each person in any society is an individual with beliefs and experiences of their own, and so practices that are acceptable to most may be questionable to others within the same group. Lastly, research on a particular topic often uncovers other issues of importance that are far more important than those intended. In fact, perhaps findings that are not planned are much richer than those findings sought.

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