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Ethical Dimensions within Qualitative Research

Jennie Gunn, FNP, PhD
Assistant Professor
Delta State University
Cleveland Mississippi
jgunn@son.umsmed.edu

Abstract

In a qualitative study 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 who were born and resided in the Mississippi Delta, ethical issues were encountered beyond those expected. There is little consideration in medical journals of the ethical issues in qualitative research. Potential ethical issues were identified a priori by the researcher, but as the study progressed, additional ethical issues arose. While the researcher sought to elicit information about botanical use, the elders were more eager to share stories of the past. The ensuing struggle for the investigator was that of study purpose versus participants' purpose. The study became a catharsis of happy childhood stories and painful memories of poverty and oppression. The emergent themes of participants which had ethical implications included: Facing Memories, African American or Black, Being Modern, and Given Enough. Although analysis revealed findings concerning the use of botanicals, the study purpose, the ethical issues encountered demand further exploration. Hence, recommendations are provided for ethical considerations for conducting qualitative research.

Keywords: *Elderly, African American, Botanicals, Mississippi, Ethics*

Introduction

In a qualitative study of current and past healing ways with botanicals as recalled by African American female elders in the Mississippi Delta, this researcher considered and experienced ethical questions and issues. Eight key elder and sixteen general informants were asked what healing practices with botanicals were currently used, and what practices were remembered from the past. An ethnohistory (Leininger, 1991) was collected from each of the eight key participants to obtain a better understanding of the elder's worldview. Although forethought was given to ethical concerns, issues arose in narrative collection that deserved reflection for future studies. The importance of ethical treatment of participants was paramount, particularly because of past unethical research studies.

Two past studies specifically had tremendous ethical impact and were partially responsible for the formalization of some ethical rules when humans were involved in research (Trochim, 2006). The Nuremberg Trials Germans used humans for experimentation and The Tuskegee Syphilis Study that involved African American participants, set a precedent for studies that followed. The Tuskegee Study was recorded as "one of the most horrendous examples of research carried out in disregard of basic ethical principles of conduct" (Tuskegee University, 2003). 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 had been recognized as the treatment for syphilis (Freimuth et. al., 2000). 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).

To protect participants, universities now have institutional review boards that govern research. 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 and Morse, 2003). The participant’s interview gives way to the findings while guided by the research questions but new unexpected findings do occur since it is an open process of discovery. This botanical study also gave way to new findings that were not in direct response to any research questions.

As a white researcher with African American participants, specific consideration was exercised partially due to the established mistrust from the Tuskegee study. The principles of voluntary participation, informed consent, confidentiality (Trochim, 2006), respect for person, beneficence, and justice (Burns and Grove, 2002) were observed in the research preparation and execution. Participants in the study were asked if they would like to participate; there was no pressure to participate offered. An introductory letter and consent to audiotape were presented to the informants, and as much as is possible, participants were protected from identification. The researcher also aimed at doing good and avoiding harm, while respect for the participant was upheld.

To protect participants, universities now have institutional review boards that govern research. 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 and Morse, 2003). The participant’s interview gives way to the findings while guided by the research questions but new unexpected findings do occur since it is an open process of discovery. This botanical study also gave way to new findings that were not in direct response to any research questions.

Ethical Themes

According to Madeleine Leininger (2005), the founder of ethnonursing, an ethical issue is an issue that has moral consideration or evokes moral questions. Throughout data collection, moral issues came forth in spite of preparation. The researcher identified four qualitative ethical themes from the ethnohistories that did not answer any research question in the study: Facing Memories, African American or Black, Being Modern, and Given Enough. These themes provoked ethical and moral thought far beyond what was expected or planned.

Facing Memories

In ethnonursing, a qualitative method based on anthropology, the collection of an ethnohistory is recognized as an important tool in understanding participants (Leininger,

1991). Elders were asked to share their life history from earliest memories forward, while many memories were happy, many were unhappy. The researcher's dilemma was bringing up memories from 60 years ago that were unpleasant to the participant. The elders did so willingly without enticement, almost as a relief, but the researcher experienced pain from the stories recounting. The participant and researcher sat face to face, an African American and a white researcher, and shared happy as well as painful memories; it was a catharsis and freedom to tell the stories in a safe place to a white person who was truly interested.

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 pay, treatment as an inferior people, and other oppressive experiences. The accounts often began in the early 1900s. Many elders remembered stories of slave times from their grandparents. Consider this poetic analysis by the researcher concluded from the ethnohistory narratives entitled "*Yellow School Buses*," that demonstrated stirring memories:

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, was 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 meant 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 research stimulated some unpleasant memories. It was the desire of the researcher to uphold the principle of beneficence, to protect the participants from harm (Burns and Grove, 2002). 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. Anxiety and distress are potential risk concerns for participants according to Richards and Schwartz (2002), and the very questions used to elicit data, aroused potentially distressing memories for the elders.

Other researchers have experienced like ethical questions. 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; hurt did exist from past experiences. Corbin and Morse (2003) found in such interviews stress was similar to everyday stress and no worse, as long as a skillful researcher and ethical practices guide the interview. Hopefully, both researcher and participant benefited from the research because there was sensitivity and ethical consideration in the process.

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 of occurrences they remembered; they specifically wanted the stories 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, the request to be heard.

Many of the elders and general informants commented about the benefits of being white. For instance, one elder told how she did not have a car when she was a teenager, and when she discovered some whites did not either as a teenager, she was surprised and expressed amazement that a white person did not have more than she had. The participants revealed they had never talked openly to a white person about oppression until they were included in the interviews. Another elder talked about the benefits of being white when securing a loan from a bank; she made reference to whites having family and friends that worked at the bank, and therefore were more likely to get money.

African American or Black

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. Both researcher and participant experienced discomfort with the categorization. The participants did not agree over titles and explained why they liked or disliked being called African American. The topic also brought up older titles and the mention of those caused discomfort for the researcher and memories of oppression for the participant.

The act of referencing race, culture, or color for research purposes became an ethical question as well. It was a surprise finding that the title and domain of inquiry would elicit discussion. During the interviews, the researcher grew conscious of use of the term African American and asked the participants if they preferred to be called 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; she wasn't sure she came from Africa. Many shared how they had white ancestry and Native American but were always referred to as African American or Black. However, most key participants preferred to be called African American. 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 was the correct way to identify people in a specific group, race, or culture in this 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? Categorization into groups by color or race, further divides society (Airhihenbuwa and King, 2001). The title African American for many signifies a reunion with past culture or a geographic location, and allowed for “expression of identity, power, defiance, pride, and the struggle for human rights” (Airhihenbuwa and King, 2001). Prior to the use of the title, African American, names reflected skin tone, such as Colored, Negro, and Black, while African American referred to geographic origins. Does “scientific research about so-called racial group differences (e.g., eugenics)” have a tendency to “promote white supremacy” (Airhihenbuwa and King, 2001)?

This uneasiness or ethical dilemma may discourage researchers from including specific groups in research; minority participation might become limited in research studies creating further ethical issues. More importantly, if African Americans are not included in research, then the disparities that exist in health care may not be evaluated or remedied (Freimuth et. al., 2001).

Being Modern

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. The researcher recognized the old ways were associated with lack of professional medical care in previous times when the people were left to their own devices for healing. Through the literature review, the researcher also recognized that white doctors evaluated slaves for sale to make sure they would bring a good price for the slave holders. Many of the elders knew this also, but were satisfied that medical care or the modern way of healing exceeded the old ways.

Does this modern treatment indicate the elders specifically want to be treated as members of other races are treated? Are the elders concerned about “institutional racism” and “inferior treatment” from providers because they are African American (Airhihenbuwa and King, 2002)? 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. The researcher wondered if the very inclusion of the old ways of healing of African Americans was construed as negative to the participants setting the participants apart from the mainstream today.

The research concluded, the old ways of healing with plants and roots that were brought forward from slavery, were no longer used. Although the elders recalled the old salves, tonics, and medications, they indicated they did not work anymore. The elders and general informants expressed the desire for modern medicine and not the old ways, although they recalled them fondly.

Given Enough

The researcher recognized the elder women participants were 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. The researcher again realized the daughter was indicating that white people had taken everything from her and this white researcher may do the same. There was an immediate need on the part of the researcher

to back away from the participant and not to create anger or stir emotions that were unpleasant. Although the elder would have liked to tell her story, the daughter acted as a barrier between participant and researcher out of a need to protect her from harm. Had the planning and attempts to provide protection not been enough? Did old wounds enter into research?

Generally, however, any doubts the researcher had concerning participation during the preparatory research planning stages were unfounded; there was a tremendous willingness to participate. Historically, according to Freimuth et. al., African Americans “needed to be very cautious about when and how they interacted with the medical system or government agencies,” but most people asked to participate in this study were willing (2001). Of the twenty-six participants contacted, 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. Researchers are not assured trust from participants, and past experiences impact present feelings.

African American elders have given enough. “In this country, the lived social reality of African American individuals is experienced through the color of their skin,” and at times “their identity is bound with racial inequalities of our society” (Carlos and Chamberlain). 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”.

The researcher found through ethnohistory collection that many want to tell their stories if someone will simply listen. The one participant, who felt she had given enough and declined to participate, brought forth the reality that other African Americans probably share this feeling. The following poetic expression from the researcher’s journal analysis told the story of their willingness to help and of the researchers concerns.

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 to 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...

There is distrust of professionals, such as doctors and scientists (Corbin, Thomas, Williams and Moody-Ayers, 1999), especially when poor or minority participants are included. An 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 (Mokwunye, 2006). In this study, because of these concerns, attempts were made to form trusting relationships before the interviews were carried out. Gatekeepers introduced the researcher to the participants prior to data collection.

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. Participants also 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 ethnosing study was likely due to the relationship between the researcher and the participants or gatekeepers. The researcher spent time in the community; 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.

Other Concerns

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". Even though painful stories were recounted, elders did not appear anxious or distressed. The elders and general participants alike in this study requested their stories of oppression be told to the public.

Exploitation, or power imbalance between researcher and participant, was recognized as a possible occurrence. There were instances this perceived imbalance did exist. Some elders assumed that since the researcher was white, that financial problems or negative treatment by others did not exist. It was if being white meant no problems existed, an automatic success in everything seemed evident.

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 or that they may 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.

This risk, however, is far exceeding the botanical study. From the ethnohistory so much information poured forth. The stories were rich and sometimes shocking. While holding to the questions about botanicals and their use, the researcher realized the ethnohistory stories were more important than the ongoing research study. Even though the elders wanted the stories told and expressed that, the researcher wondered if misrepresentation would occur by publishing stories from the histories with the botanical

findings. A new venue had opened; the past had poured out into the research but did not answer a research question. The history was additional information.

The risk of identification, the fourth risk, of the participants was of ethical concern since many told embarrassing old ways of healing (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.

The elders delighted in selecting names for themselves. Many went back to great grandmothers or mothers to select a name. The names themselves were history and told a story. There was so much innocence and beauty and yet so much experience. The researcher was amazed at the openness the elders offered.

Conclusions and Recommendations

The need for ethical treatment required this researcher to ask how to best protect the participants, and planning began well before the study was initiated. Unfortunately, absolute rules do not exist in “governing ethics,” and “ethical rules are less clear and difficult” (Burkhardt and Nathaniel, 2002). In fact, “little consideration in medical journals of the ethical issues surrounding qualitative research” has been found (Richards and Schwartz, 2002). Past research experiences, such as the Tuskegee, have laid a broken foundation for future research, but ethical issues continue to arise today as they did in the past.

It was expected that ethnonursing 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). Although forehand thought was given to this research of botanical use practices in African American elders, unexpected ethical questions were discovered. The ethical issues identified included the themes: *Facing Memories, African American or Black, Being Modern, and Given Enough*.

The importance of having a member of the group, race, or culture on the committee is paramount to exploration, 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. 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 sought are much richer than those findings sought.

Recommendations for further research include maintaining an open attitude. The findings presented here were far different than the botanical research questions outlined. In ethnonursing, the research questions give way to the findings while the ethnonursing history serves as a backdrop; the participants view of the world. Data analysis of the ethnohistories may produce important findings as well as the research questions. Infusing ethnohistory themes with research question themes will enrich findings.

The job of the researcher in qualitative research is not to solve a problem or to remedy pain. The job is to listen and understand the data. It was difficult to listen to painful stories of oppression by one’s own race without inserting words or phrases

whether they are of apology or defense. It is the researcher's job to gather data; the richest data possible within the boundaries of the research. The researcher cannot prevent distress recalled that is unexpected and unplanned but should strive to do no harm and to show respect.

There was concern in the theme, Facing Memories, that once the research was complete, the elders would linger on the interview and the past stirrings. Many of the elders at a later time stated how much they enjoyed telling their stories and others said they had more to tell about the past. Although they understood the purpose of the research, the interviews became more than that. It also became evident in the research process that research and participant do not always understand each other. Through research such as this study, understanding will begin. Researchers see the participants through their cultural eyes and the participants see the researcher through their cultural eyes. Cultural views may never be the same but there can be understanding.

Before beginning research that identified people by a group, culture, or race, the researcher must ask and come to understand which reference is correct. Even then, not all people within a culture will agree on everything. Within a culture, people have different views; just because a race is one color does not mean the people share the same views. If the people cannot agree on cultural titles or identification, then the researcher must understand and give the participant the option of reference.

One might question if participants should be titled at all, but this research is an example of a reason reference to group should be made. A finding of this study was African American elders consider themselves well until they can no longer go about their daily routine. Once a person is down and cannot get up to do daily work, the person is ill. The very idea that elders feel sick but can still get around and do their work, indicated they are waiting to seek help until they are very ill. How does this impact prevention and health care? Could this be a reason outcomes of care are different for different groups? Therefore, there are times when grouping is necessary by race or culture.

In conclusion, this researcher realized that planning is not always all that is needed; an open accepting attitude is paramount. Other forms of data may exceed the data sought. Ethnohistories are important data sources and should be analyzed for themes and not just viewed as a backdrop. This researcher realized that even after the interview, the participant may linger over the information stirred within them and the researcher has little control over that. Researchers cannot always prevent distress even though they seek prevention. Worldviews occur on each side, the researcher and participant each have views and this should not become a hindrance to data collection; the researcher seeks the view of the participant. Finally, qualitative research is an open process and it must be viewed as ongoing even after the data collection has ceased. Perhaps the best recommendation is to do no harm.

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