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Ethical Responsibility in Healing and Protecting the Families of the U.S. Public Health Service Syphilis Study in African American Men at Tuskegee: An Intergenerational Storytelling Approach

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This essay is a reflection on how ethical violations continue to have an impact across generations within families of vulnerable populations that have experienced significant breaches in biomedical research. The focus is on the surviving family members of the United States Public Health Service Syphilis Study at Tuskegee (USPHS). Emphasis will be on responsible ethical practices in research and the use of an unique approach narrative storytelling to address the needs of family descendents who have been impacted by the USPHS Syphilis Study.

Keywords: Tuskegee, vulnerable populations, ethical practices, family descendents, public health, storytelling

There are three interrelated dimensions to be considered in thinking about ethical issues of surviving family members in the U.S. Public Health Service (USPHS) Syphilis Study at Tuskegee. First, ethical violations are the failure to carry out responsible ethical practices in public health care where participants, despite a cure for the diseases of syphilis, remained untreated with penicillin; where research was carried out on a “captive population; where the population, despite a cure being found during the study, were never informed about the treatment and actions were taken to prevent this group and not any other from receiving treatment and the information about a cure; where the true goal of the study was not shared, particularly when the end point became death; and where participants were given alternative treatments that were not really effective for syphilis (Northridge, 2011). The second dimension is the ethics that must be applied when working with vulnerable populations such as those persons and family involved in the USPHS Syphilis Study. The third is ethical dimensions of utilizing storytelling as a method of healing and the boundaries necessary for using storytelling as an intervention for addressing trauma and pain (De Haene, Grietens, & Verschueren, 2010; Denborough, 2008; White, 2000).

The major theme underlying this essay is that families like those survivors in the Syphilis Study should never become research subjects simply to further public health or biomedical research even when they are willing. We should develop ethical research policies and practices

that take into account the ways in which biomedical and public health research studies can serve to stigmatize as well as benefit the families and the descendants of participants. This article raises an issue that to date has rarely been addressed and that is the lingering impact of participation in egregious research by survivors of the original participants.

The ethical concerns just defined are important because family descendants of the men who were victims of the USPHS Syphilis Study have serious concerns that need addressing. We have come to understand these concerns as a result of work through the Tuskegee University National Center for Bioethics in Research and Health Care. Some of the concerns for these families include (a) discovering the process that enable some of the victims of the study to find peace and to forgive those who conducted the unethical study; (b) finding healing for the stigma and pain experienced by family members at the hands of an uninformed public; (c) ascertaining information about how money given by the government after President Clinton's Apology was spent by the Tuskegee Bioethics Center; (d) discovering ways to find financial support for the educational needs of grandchildren and great-grandchildren of those who participated in the study; (e) ensuring that family descendants of the study are not ethically mistreated by any further research; and (f) preventing the families of descendants as vulnerable populations from being exploited by unethical research, biological or otherwise. Given these concerns, the Tuskegee Bioethics Center has begun to try to address them by having discussions with key leaders of the families of the descendants of the study. This essay seeks to present ethical principles that address the six concerns named here. The first ethical concern is addressing the vulnerability of family members to further exploitive research.

VULNERABILITY TO RESEARCH EXPLOITATION

In talking to some of the current leaders of the families whose relatives participated in the study, it was mentioned that their relatives had come to grips with what happened to them and were willing to move on with what remained with their lives. Immediately I thought of the written comments made by Ralf Katz about civic mindedness and patriotic loyalty exhibited by those participating in the Syphilis Study as well as their descendants and how these factors might leave them vulnerable to further exploitation and manipulation in the present and future despite federal assurances about the protection of human subjects (Earl, 2011, p. 122; Katz, 2011, p. xxxvii). Katz (2011), in his study of the legacy of Tuskegee on African Americans, concluded that

the overall conclusion from the overwhelming evidence is that African Americans are as willing as any other racial or ethnic group to participate fully in biomedical research. This finding seems to echo how African Americans have participated in the wider arena of life in the United States throughout this country's history (p. xxxvii).

Such an apparent forgiving spirit and willingness to move on and be open to further bioethical research raises serious ethical issues for the Tuskegee Bioethics Center that sees as its mission to heal and protect the surviving families of the USPHS Syphilis Study. In other words, the center must devise ways to balance their desire to respond to the call for African American to participate in research for the good of the larger population to making sure that the survivor families do not yet again experience a trauma from exploitation and victimization for them or their children.

Another aspect of the vulnerability of the families or descendants of the Syphilis Study is related to the issue of stigma of being a relative of a participant, making the experience of further exploitative research doubly victimizing for them. The sense of victimization of families in the study across the several generations feeling victimized by the USPHS syphilis experiment is not known and has not been addressed. It is important to realize that the moral and ethical issues emerging out of the Syphilis Study is not just about the individual person, but it is about generations, just as it is about African Americans as a racial population. The harm that is talked about by family members includes how families were stigmatized and ridiculed. Children who are now adults in the family talk about being teased by their peers and how this teasing impacted their self-esteem. Moreover, stigmatizing also had to be treated similarly to family secrets, and family secrets always have deleterious impact on the self-esteem of family members for several generations. Stigma is toxic, and it must be discussed in order to foster the growth of all descendant family members.

In an effort to respond to the concerns raised by the families as well as the need to develop an ethical approach to deal with these concerns, the use of a narrative or storytelling approach was suggested to the Tuskegee Bioethics Advisory Board. A proposal of an intergenerational narrative or storytelling approach was presented as one solution for dealing with multigenerational pain that has been carried by family members. It was noted that this approach provides practical intervention strategies for family groupings who have been victimized by stigmatizing of their relative's participation in the study. Toward this end, the approach was presented as one vehicle to help surviving family members to (a) tell and retell their own stories related to the Syphilis Study; (b) identify themes that are at work in these stories; (c) give names to these stories that have been internalized; (d) assess whether the internalized stories have plotlines that are facilitating their positive human growth formation or undermining this developmental formation; and (e) help the families to decide whether these stories need to be updated, edited, or reauthored. In addition, the storytelling approach could also help to address other concerns, particularly how the men in the original study learned to forgive and how some family members found ways to cope with the stigma and pains they experienced.

THE SIGNIFICANCE OF STORYTELLING

The storytelling approach is intended for intergenerational groupings. Each family member, no matter the age, will be given the opportunity to tell and retell his or her own story. This model of storytelling and soliciting stories builds on talking and listening approaches legitimized by the marriage and family therapy movement as well as religious groups for healing. Moreover, new scientific research efforts, particularly in the psychology of religion, have begun to establish the validity and reliability of storytelling as practices of meaning making for helping people cope with socioeconomic stress, crises, negative life events, illness, and death (Hood, Spilka, & Gorsuch, 1996; Wimberly, 2011). The family leaders who represented their families to the Tuskegee Bioethics Center Advisory Board were clear that a spiritual or religious approach to storytelling was desired and viewed to be helpful.

There are a number of functional benefits that the storytelling approach offers to intergenerational families dealing with family pain related to the USPHS syphilis experiment.. These essential functions include promoting "1) a sense of safety; 2) calming; 3) a sense of self- and collective

efficacy; 4) connectedness; and 5) hope” (Hobfoll et al., 2007). Ethnographic research further shows that storytelling following trauma not only performs the aforementioned functions, but it helps people to confront trauma (Wimberly, 2011). What storytelling does is to help family members recall and revise internalized unhealthy stories that can have negative intergenerational consequences if not addressed. In short, the value of storytelling for families who have been impacted by the infamous USPHS Syphilis Study is that it gives these family members agency and control over the internalized stories. Moreover, storytelling will enable them to edit, reauthor, update, and modify or leave such stories alone.

Of critical significance is the potential contribution of this storytelling approach to making vulnerable poor and underserved populations less vulnerable to unethical recruitment into future risky bio-medical experiments. In the next section the ethical practices related to the use of storytelling with vulnerable populations are examined.

AN ETHICAL APPROACH TO STORYTELLING WITH VULNERABLE POPULATIONS

There are many positive benefits in storytelling and working with vulnerable populations, but there can be negative consequences as well. Therefore, it is important particularly for vulnerable populations to engage ethical principles when using storytelling. Fortunately, there is research summarizing the extensive use of storytelling related to refugee trauma, which has significant implications for using this approach with family descendants of the USPHS Syphilis Study. The research is entitled *Holding Harm: Narrative Methods in Mental Health Research on Refugee Trauma* (De Haene et al., 2010). This study emphasizes ethical requirements to ensure that the use of storytelling is of benefit for vulnerable populations. The major danger pointed out in the research is that revisiting painful memories brings with it the reawakening of the original pain and suffering of the initial trauma. Therefore, support for families may need to extend beyond the initial storytelling event to ensure benefit. In short, the ethical principles, which are outlined next, help those who propose to employ storytelling ensure that the storytelling benefits rather than harms the participants.

The following are ethical practices to ensure that storytelling benefits the descendants of the USPHS Syphilis Study at Tuskegee:

- The basic objective should be to foster family participation in the storytelling. This is done by making sure that family participants know they have the choice to participate or not participate in the storytelling.
- Keep the following goals of the storytelling experience as the focus: (a) healing cross-generational pain and stigma, (b) learning how to help family members to get beyond hurt to forgiveness, and (c) help family members to avoid being victimized again.
- Make sure that the original concerns and questions of the family are the content of the storytelling; for example, what was the process that enabled their victimized parents or grandparents to forgive?
- It is important to ensure that the leaders of the families are on the ground floor in planning for the storytelling sessions. They need to be involved in the design of the cross-generational sessions.
- It became very clear during one of the meetings with the family leaders that defining the meaning of family needs to be the primary work of the family descendants. This concerns

children from parents who were married and well as children that came from nonmarried relationships.

- Leaders of the storytelling events must get the permission of family participants in order to explore themes that have the potential for making family participants uncomfortable, and the leaders need to respect family participants' decisions not to explore particular topics.
- Avoid at all costs stigmatizing and stereotyping comments that would bring shame on family participants.
- Help family participants as far as is possible to retell what they experienced as the result of the study so that the reliving or reexperiencing the memories is less traumatic. Often this involves appropriate timing of the storytelling leaders' intervention.
- Ensure that, if and when the storytelling is overwhelming for the family participants, they get additional healing sessions if needed or requested.
- Through empathic listening and intervening practices to storytellers, ensure that the personal emancipation and liberation from stigmatizing personal and internalized stories get tended to even if it must be done privately outside the group storytelling sessions.
- Emphasize and support family members' right not to participate.

IDENTIFYING STORIES AT WORK IN THE USPHS SYPHILIS EXPERIMENT AT TUSKEGEE

For the storytelling approach to be effective, it must enable family members to tell the stories. Grandchildren and great-grandchildren who participate in the storytelling activity must be introduced to the stories of the syphilis experiment so they can understand what talk took place in the past. Once all know the stories, including the grandchildren and great-grandchildren, there is the need to help those participating in the storytelling event to identify particularly the negative internalized stories, their themes, and plotlines. Such identification will enable family members to externalize or observe from a distance how the negative internalized stories have impacted their lives. This is a critical step in order to move forward for forgiveness and freedom. For example, some of the family members of those who participated in the syphilis experiment still remember being stigmatized and avoided by their childhood peers. Consequently, such hurtful treatment and the resulting impact on their identity and their self-esteem need to be identified. This type of negative interaction with others often shapes the stories, convictions, and beliefs that victims have about themselves and their relationships with others. Therefore, naming these stories, assessing them, and revising or editing them becomes a critical step in the forgiveness and freedom to move on with their lives. In these ways, storytelling promotes healing and establishes an ethics of self-care.

Precaution should be taken to ensure that grade-school-aged children should not be present for certain sessions, but high school youth should be able to participate in the story listening process.

THE META-NARRATIVE APOLOGY

Storytelling methods must also enable family members to identify, name, assess, and evaluate how public narratives, conversations, or discourses impact their lives. Prior to the apology of President William Clinton in May of 1997 to the nation and to the families victimized by

the USPHS Syphilis Study at Tuskegee, the men in the Syphilis Study and their families were subjected to very negative stories and ridicule, especially by those not knowing the essence of the study. However, when the study was revealed for its malevolent nature, a completely new awareness emerged. Riggins Earl indicates that the Clinton Apology introduced a new and more healing public conversation. Such an apology has the potential to help the family members of those victimized by the Syphilis Study to revise their internalized negative stories and self-evaluations.

Earl called the Clinton Apology a metanarrative or an overarching story that offers healing significance for the families of those studied. For him the apology provided an ethical voice of beneficence or right actions (Earl, 2011). The Clinton Apology serves as hopeful promise for renewal and possibilities for updating identities and the self-images of those who were victims in the Syphilis Study. For Earl (2011), “the apology itself provides a powerful symbolic white alternative narrative voice to white America’s degrading narrative of blacks” (p. 120).

I agree with Earl about the significance of the apology being a metanarrative that can help the descendants of the USPHS Syphilis Study to edit their own stories, especially the negative internalized stories where families and relatives of the original study in which stigmatized and belittled.

Earl identified another narrative, and this narrative was held by the family descendants and related to civil duty and patriotic alliance. This narrative was a religious and moral narrative. Its themes were resilience and showed faith, love, and forgiveness for those who initiated and sustained the study for 30 years (Earl, 2011). The name I give to this narrative is “courageous resilience.” Over time, some of those participating in the study found ways to reauthor the story about victimization so that they could live purposefully and meaningfully despite what had happened to them.

Despite the identification of this patriotic and forgiving narrative at work among those who have been victims of this infamous USPHS Syphilis Study, this kind of civic and beneficent willingness to contribute to the common good can be exploited and manipulated to the participants’ detriment and the detriment of their descendants. Therefore, continued efforts to establish and enforce ethical strategies and policies for protecting vulnerable populations from being exploited need to be the focus of the Tuskegee University Bioethics Center.

In conclusion, there remains the need for storytelling and for healing. The apology made by President Clinton must be used to help those families and communities impacted by the Syphilis Study and similar poor and underserved communities to edit internalized negative themes caused by unethical recruiting into medical experimentation. Vigilant efforts by the government to implement ethical policies to assure appropriate ethical recruiting strategies in medical experimentation need to be doubled along with sufficient monitoring.

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