



Published in final edited form as:

Int Q Community Health Educ. 2007 ; 28(3): 201–213. doi:10.2190/IQ.28.3.c.

“MY MOTHER TOLD ME I MUST NOT COOK ANYMORE”—FOOD, CULTURE, AND THE CONTEXT OF HIV- AND AIDS-RELATED STIGMA IN THREE COMMUNITIES IN SOUTH AFRICA*

T. A. OKOROR, Ph.D.,
Purdue University, Indiana

C. O. AIRHIHENUWA, Ph.D., M.P.H.,
Pennsylvania State University, University Park

M. ZUNGU, M.S.,
Human Sciences Research Council, Cape Town, South Africa

D. MAKOFANI, Ph.D.,
University of Limpopo, South Africa

D. C. BROWN, M.P.H., and
Pennsylvania State University, University Park

J. IWELUNMOR, B.S.
Pennsylvania State University, University Park

Abstract

The purpose of this study was to examine the role of food as an instrument in expressing and experiencing HIV/AIDS stigma by HIV-positive women and their families, with the goal of reducing discrimination. It goes beyond willingness to share utensils, which has been identified in HIV/AIDS research. As part of an ongoing capacity-building HIV/AIDS stigma project in South Africa, 25 focus groups and 15 key informant interviews were conducted among 195 women and 54 men in three Black communities. Participants were asked to discuss how they were treated in the family as women living with HIV and AIDS, and data was organized using the PEN-3 model. Findings highlight both the positive and negative experiences HIV-positive women encounter. Women would not disclose their HIV status to avoid being isolated from participating in the socio-cultural aspects of food preparation, while others that have disclosed their status have experienced alienation. The symbolic meanings of food should be a major consideration when addressing the elimination of HIV/AIDS stigma in South Africa.

INTRODUCTION

HIV/AIDS-related stigma and discrimination are significant barriers to prevention, care, and treatment and are as central to the global AIDS challenge as to the disease itself [1]. Stigma deals with attitudes and perceptions while discrimination is a differential treatment or action/behavior toward the stigmatized person based on those attitudes and perceptions [2]. HIV/AIDS-related stigma may be directed toward those infected with and affected by HIV/AIDS

*This research was supported by the U.S. National Institutes of Health, Grant # R24 MH068180.

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Direct reprint requests to: Titilayo A. Okoror, Ph.D., Dept. of Health & Kinesiology, Purdue University, 800 West Stadium Drive, West Lafayette, IN 47907.

in the form of externalized stigma [3–5], and/or experienced by those infected and affected by HIV/AIDS in the form of internalized stigma [6, 7]. Externalized stigma is described as the action or behavior toward the individual and internalized stigma is the internalization and acceptance of experienced stigma by the individual [2]. Although anti-discrimination laws have the potential to reduce HIV-related stigma, “manifestations of stigma are often too subtle to be immediately apparent” and are “rooted within individual psyches, families, and communities, and beyond the reach of the legal system” [5]. Stigma prevents people living with HIV/AIDS (PLWHA) from disclosing their sero-status, seeking care and treatment, and receiving support from families and communities [8–10]. PLWHAs experience social ostracism from families and communities, discrimination, or even violence [3–5, 11–13]. On a more social cultural level, stigma is an expression of the presence or absence of known patterns of relationship among family members. One form of cultural expressions through which stigma can be expressed is in the preparation and sharing of food.

Studies that have examined the role of food in HIV-related stigma have focused on sharing of food utensils, such as cups, spoons, and plates, or lack thereof with someone living with HIV/AIDS [14, 15]. While this may be true in some cases, it however, fails to provide insight into other functions of food within the African context. Food is generally regarded as a means of establishing a basis for friendship and community building in many African cultures. In a study to examine the role of culture in African-American eating practices, it was concluded that food has meanings related to survival, status, love, and respect [16]. Fajans described food as having “transformative value” because it serves as an agent in generating, enacting, and perpetuating social and cultural processes [17]. Food habits and behaviors are culturally defined and influenced and have symbolic meanings that may not be easily apparent to an outsider or someone not quite familiar with that culture. Boeck wrote that among the aLunud in Zaire, kinship relations are often expressed through metaphors of eating. There is a link between physical and social values expressed in the physical consumption of food and the metaphorical propagation of life, identity, and lineage across generations [18].

The meaning attached to HIV-related stigma, experienced by people living with HIV/AIDS within the African contexts, therefore, will be a reflection of the cultural values within that specific context and how they (i.e., PLWHA) defined and/or identified themselves. Hence, our focus is on the nature of the relationships that are represented within cultural values and meanings expressed in the sharing of food. A lot has been written about the impact of HIV/AIDS stigma on women, as many serve as caregivers and nurturers of the families [19–22]. A fundamental aspect of nurturing is in food sharing and cooking for the family even when HIV-positive. In their nurturing role, the cultural expectation for women to cook is commonly fused with cooking as a validation of women when family members accept the food prepared, and a form of rejection when the food is not accepted or it is criticized. Thus, women’s roles, in terms of family members accepting or rejecting what is prepared by them, provides another layer within which HIV-positive women experience HIV/AIDS stigma. The present study examines the role of food as an instrument in expressing and experiencing stigma by HIV-positive women and their families in three South African communities: Khayelitsha, Gugulethu, and Mitchell’s Plain.

THEORETICAL FRAMEWORK

The organizing framework for this study is the PEN-3 model [23–25]. It is a cultural model that addresses the role of culture and context in the adoption or non-adoption of health behaviors, and was originally developed as a framework for understanding the health behaviors of people of African descent [23]. PEN-3 model serves as a thinking tool by shifting the focus primarily from the individual to looking at the context and culture within

which the individual functions, in planning and implementing culturally appropriate programs. The model consists of three dynamically related domains: *relationships and expectations*, which examines how cultures define the roles of persons and their expectations in family and community relationships through perceptions, enablers, and nurturers; *cultural empowerment*, which affirms the possibilities within cultures ranging from positive to negative, and everything in-between (positive, existential, and negative); and *cultural identity*, which examines how identities influence decision-making through the person, extended family, and neighborhood. It should be noted that the first two domains are the assessment tools while the last domain determines the entry point for intervention. We used the first two domains to assess how perceptions of HIV-positive women impact their relationships within the family contexts, and how such, either positively or negatively, enable or nurture these women in performing their social expectation of food preparation and sharing.

METHODS

We conducted focus group discussions and interviews among women that are living with HIV/AIDS along with family members in three black South African communities: Khayelitsha, Gugulethu, and Mitchell's Plain. We used a purposive sampling method to identify and recruit participants. The study purpose and process was explained to participants in Xhosa and Afrikaans (local languages), and each participant gave their consent to participate. In collaboration with the University of the Western Cape and the University of Limpopo, the study is part of an ongoing NIH-funded project in South Africa designed to strengthen research capacity of South African Black post-graduate students by training these students under South African faculty mentors to conduct HIV- and AIDS-related stigma research, addressing underlying positive and negative social cultural issues in the family and at health care facilities. The Institutional Review Boards of The Pennsylvania State University, the University of Stellenbosch, and the Human Sciences Research Council reviewed and approved the study.

Population

The three communities (Khayelitsha, Gugulethu, and Mitchell's Plain) were selected for the study due to the populations in these areas. Khayelitsha has an HIV prevalence rate of 33%, while Gugulethu and Mitchell's Plain have prevalence rates of 29% and 5.1% respectively. Additionally, these communities were made up of mostly South African Blacks, in what is described as urban formal [26].

Sample

Fifteen interviews and 25 focus group discussions were conducted with 249 participants: 54 males and 195 females. As stated earlier, women living with HIV/AIDS along with family members were interviewed to assess the impact of HIV/AIDS stigma on food preparation among HIV-positive women. Women identifying as being HIV positive were selected to participate, while family members who reported having an HIV positive relative or family member were also selected.

Data Collection

South African post-graduate students conducted focus groups and interviews in Xhosa and Afrikaans, using an open-ended questions format. Six general questions/scenarios guided the discussions, lasting from 60 to 90 minutes. A primary strategy used in conducting interviews was NOT to include the word "stigma" in the questions, and probes were used when necessary. Audio-taped recordings of the interviews were first transcribed and then

translated into English. All data was loaded into Nvivo software for qualitative data management to facilitate data analysis.

Data Analysis

All transcripts were coded employing both inductive and deductive methods [27]. Each analyst kept an electronic memo and analytic logs concerning ideas, reflective thoughts, and salient themes during the coding process to facilitate the transition from coding to the analysis phase. At least two coders reviewed new codes generated. These procedures helped to ensure inter-coder reliability and standardization among analysts. A cross-tabulation of the Relationships/ Expectations (i.e., perceptions, enablers, nurturers) and Cultural Empowerment (i.e., positive, existential, and negative) domains of the PEN-3 model created a 3×3 table, which was used to arrange the themes that emerged. It should be noted, however, that we did not separate the themes surrounding food into the nine categories of the model because they were intertwined. Based on this fact, we present two primary themes: one representing food as a positive tool and an expression of support toward PLWHA; and the second is food as negative tool and an expression of rejection for PLWHA. Specific choices and food preparation methods provided evidence for the unique or existential aspects of food as a cultural expression in this population.

RESULTS AND DISCUSSION

The word “food” means different things to different people and varies from culture to culture. In many cultures of the world, food serves as an expression of different kinds of emotions, particularly love [28]. Among African Americans, for example, food is associated with one’s identity, the context in which it is consumed, and the healing and healthful value of what is consumed [16]. In many African societies, food-sharing goes beyond the physical consumption of food to defining relationships and cultural identity, based on how and when the food was offered and in what condition it was offered. Findings from this study reveal that women living with HIV/AIDS experience and perceive different reactions in relation to food preparation and sharing, ranging from positive to negative. Common words used to describe negative experiences include rejection, shaming, pain, and loss, while positive experiences included being supported and cared for by family and community members. The ideas that centered around food were food as a measure of acceptance:

My family treats a person who has HIV and AIDS very nice, we buy what ever he or she likes, like juice, and we talk to him or her not to feel bad because she has AIDS.

or rejection,

At home they don’t want me to cook for them.

These views were more pronounced within the family social contexts since it is in this context that care and support for people living with HIV/AIDS (PLWHA) is mostly provided.

Food as an Expression of Support and Acceptance

As a function of their nurturing role, cooking serves as a form of validation of women when family members accept what is prepared. The importance of food preparation and its nurturing role for the family made Smart-Grosvenor caution women: “protect your kitchen from outside intrusion” [29]. Food choice, time spent in food preparation, the manner in which the food is presented, and the person preparing the food all sent a message to the recipient. The recipient internally evaluates all of the above requirements to *hear* the intended message that may never be spoken. The unspoken message may be that of

hospitality, caring, belonging, or even hostility, indicating to the recipient that it's time to leave. When women talk about cooking, there was usually no separation made between the actual cooking and the utensils or tools used in the process, as it is perceived as being intrinsically intertwined, such that acceptance of one is invariably the acceptance of the other. Findings from our study indicated that participants perceived their family as being supportive when they were allowed to cook, eat with the family, or share food:

My family they don't reject me, they love me. I'm the only one in the family that has it. They'll never discriminate against me. They take their drink and they will always ask me, how are you, is it going well? How do you feel? Then I say it's going OK. So my family there's no one that pushed me away.

Eating in many traditional societies, like those found in Africa, is usually not an individual event in which just one person sits at a table and eats alone. In the Zulu culture, for example, a person does not eat alone, as he or she will be perceived as a witch since "witches are said to eat alone because they consume secret substances to acquire their evil power" [30]. Rather, the belief is that to enjoy a good meal you have to share, and this goes beyond dishing the food on a plate and giving it to someone. The sharing of a meal involves a group of people, usually those in the same age group, sitting around a bowl or plate of food and using their fingers to dip and take from the same bowl. Participants describing family members' actions of eating with them from the same plates and sharing cups and food as being supportive speaks to the underlying message they receive when family members continue to act toward them in the same manner before HIV/AIDS—you are *still* one of us, you *belong* with us:

We cook. My family is good to me and they share everything. And we eat and drink, still out of one cup and so and they understand me. Even I cook for them and they eat. If I got a sore I say, OK wait, I first cover the sore. And they will understand what I mean because they even like my food. They feel rejected if I don't [cook].

Although Westernization has normalized the use of a fork and spoon in many African societies, it is still not unusual to have people using their hands and fingers while sitting together around a bowl or plate of food [28, 31]. It is believed that those closest to you are those that *eat from the same bowl with you* and the act of dipping in the same bowl helps to strengthen ties and solidarity and further create a sense of belongingness among all. Household cooking can reflect social and symbolic meanings between mother and child, husband and wife, and "consanguineal and affinal relations," such that "the kinds of food and ways of cooking and eating are the building blocks from which symbolic meaning is constructed by the individual" [32]. Georges wrote that preparation and serving of Greek foods by his Greek relatives displays their sense of ethnic identity and pride that symbolically reinforces their bond to their heritage as distinct from others with a different ethnic identification [33]. In essence, food is a vehicle by which people define reciprocal relations for social control and social status [18]. PLWHAs continued that participation in food sharing reinforced their sense of belonging to the family, their closeness within the family, and this is equated to showing "love":

No, We cook. There is this cousin of ours who used to give a helping hand, as this one was sick she used to carry delicious food things like fruit when she comes from work she was supporting us in that way. The most important thing needed by a sick person is love.

Family members were described as sharing food and eating together with PLWHA despite their HIV status. Family provided them with what is needed, especially what PLWHA wants to eat and/or drink. There was also support in making sure PLWHA eats regularly, and change necessary behaviors that may jeopardize their health:

My sister was drinking beers a lot So after we heard that she is living with HIV and AIDS, we told her to stop drinking and take care of her health status, we were buying fruit for her, whatever she wanted we are giving her.

It's safe to say that such attention and love may lead to change in health behaviors for PLWHAs, promote emotional well-being, and buffer the stress of living with HIV/AIDS [22]:

I had no problem because my family was supportive ... before I knew a lot about my status they used to reprimand me with the way I was using alcohol but ... they talk differently now they talk right and nice and even if it's cold they will say do not go outside its cold, go and wear warm clothes, would also remind you to drink your pills, so I would say they are supportive.

Food as an Expression of Rejection

Traditional gender role of women in food preparation is one form of nurturing the family and community. Beoku-Betts wrote that food preparation can “provide a valued identity and a source of empowerment” especially for women, and provide “a means to perpetuate group survival” [34]. As the family nurturers, food preparation provides women with the opportunity to affirm their care-giving roles in the family while promoting cultural identity and social relationships. Participants in the study talked about experiencing discrimination and stigma from not been allowed to cook and family members and friends refusing to eat food prepared by them. Again, we noted that being denied the opportunity to cook for the family was seen as being denied one's nurturing role and all the positive values and stature accorded such a role. PLWHAs felt they were perceived as not being humans and some find it hard to disclose their HIV status out of fear of being prevented from cooking and/or isolated from participating in food preparation:

I found it difficult to disclose my status to my family and friends. When I prepare and dish out food, my family does not accept the food for fear that they might be infected. If there was education about how HIV/AIDS is transmitted, I am sure the situation would be different.

My mother actually told me that I must not cook anymore. We are used to kneading bread ourselves at home I must not knead bread anymore. If I did cook food then she would ask me if I had no cuts in my hands.

Discrimination and rejection from family members refusing to share food or let HIV-positive women cook clearly stems from fear of being infected:

They don't want to share anything. They don't want your food and other stuff Sometimes they separate your plates and your spoons. You notice that they don't even eat food prepared by HIV-positive person.

I think of not being accepted. For example, at home I don't cook because my family is scared that I will infect them.

Women, who live with family members that forbid them from preparing food, are likely to feel devalued. When family members are “aloof,” “dubious,” and “skeptical” when presented with food cooked by a PLWHA, it places additional stress or emotional burden on the woman who is already dealing with being HIV-positive:

We receive a different treatment based on the same example of food you prepare you will notice that they become dubious and skeptical to actually eat your food, and at times they don't even allow you to cook at all, hence they themselves are aloof on cooking.

You find out that the way we stayed in our families is not conducive to our health and it is to larger extent painful especially with the way her brothers or her sisters treat her you notice that they don't even eat food prepared by HIV-positive person.

Beyond the burden of their food being rejected, some family members separate utensils, like cups and plates, used by PLWHAs from the ones used by the rest of the family [14, 15]. A PLWHA's father is described as putting all the dishes, cups, and pots used by his daughter in the dog nest so as to make sure that it did not mix with the rest of the family's, while another mother washes her daughter's utensils with bleach to disinfect them. This is contrary to the cultural practice of dipping from the same plate or bowl as an affirmation of belonging to the family [28, 31]:

I could not share utensils with family fear of infection. The parents often think you are an embarrassment. Some people still don't want to share utensils with you for fear that you will infect them.

They took out the dog from its nest and put all her dishes, cups, and pots and said that her belongings should not mix with those of theirs. Her dishes, they did not put in the cupboard; they put them under the sink. This is very sinful and painful

Everything that I ate from was washed with Jik [*bleach*], steel wool cup, fork, knife, spoons, plates, everything. So I told her to buy paper plates then she can throw it away. It would be better for her than to buy Jik every time. She told my children that they must not play with my sister's children because they will get infected.

Some women have refused to disclose their HIV status to avoid being isolated because those who disclosed have experienced isolation and discrimination from family members who either prevent them from participating in food preparation and/or refusing to eat what they prepared. For women with children, this presents an even more challenging situation as they may also lose a valuable opportunity to (consolidate their) bond with their children. One participant, who is a mother and HIV-positive, discussed her fear and worry of disclosing to her children because she still wants to be able to cook for them, and not be repulsed by them just because she is HIV-positive:

I was not ready for disclosing to everybody and my children. I was scared and needed advice on ways I could disclose to people that is when they shared how to disclose to my children. I was worried. Will my children be repulsed by me? Like your first question about people with HIV I was concerned will they be repulsed? Will I be able to cook for these children? Will they eat my food as usual? These are the things I was thinking.

The fact that participants complained about being denied the opportunity to cook speaks, not so much as the physical act of cooking itself, rather to the isolation they experience from being denied their nurturing roles in the family and community. This form of acceptance or rejection especially affects many women and mothers. Women who previously were praised for their cooking and utilized their knowledge to endear their family members, no longer enjoy this form of acknowledgment and recognition from their families. This undermines their cultural identity within both their families and communities. Therefore, the prohibition of HIV-infected women from preparing food could be devastating and debilitating as it engenders feelings of powerlessness and unworthiness even when family members may do so out of fear of being infected, thinking that they are doing the HIV-infected woman a favor.

CONCLUSION AND RECOMMENDATIONS

Until recently [35, 36] HIV-related stigma research tended to be based on the assumption that stigma is the same universally. Thus, many studies that have documented discriminating and stigmatizing attitudes and behaviors against people living with HIV/AIDS in African contexts have measured these behaviors and attitudes using scales and indexes developed within Western contexts. Although findings from such studies have shown family and community members' unwillingness to share utensils with PLWHAs [14, 15], they do not provide insights into other functions of food within the cultural contexts where PLWHAs, especially women, may experience additional discrimination and stigma. In this study we examined the role of food as an instrument in expressing support or rejection of women living with HIV/AIDS. Use of qualitative methods enabled us to explore this topic, as little information is known on how HIV/AIDS stigma impacts food beyond sharing of food utensils. The PEN-3 cultural model allowed us to assess not just the negative aspects of food sharing (thereby focusing on just the problems as this tends to be the case in many studies), but also exploring positive ways in which food is used in expressing love, support, and acceptance.

Social relationships and expectations are determined and influenced by the cultural contexts within which such relationships operate and are defined. These contexts are "governed" by cultural values, an important aspect of accrued knowledge which is needed to interpret and respond to environmental experiences concerning one's own status within a family, community, or neighborhood and larger society [37]. The significance of food goes beyond the act of eating to include group sharing of food from the same bowl, a representation and preservation of socio-cultural processes, and a symbolic means of describing both familial and conjugal relationships. With this intricate, complex web of meanings and roles attached to food, understanding the impact of HIV- and AIDS-related stigma on these relationships is paramount to efforts in reducing it. Efforts to educate community and family members should include not just information on how HIV/AIDS is transmitted, but also address subtle forms of stigma and discrimination that, though borne out of concern for PLWHA, further isolates and discriminate against them.

Acknowledgments

The authors thank the following students for their participation in data collection: Regina Dlakulu, Vuyisile Mathiti, Heidi Wichman, Tshipinare Marumo, Shahieda Abrahams, Thandiwe Chihana, Nashrien Khan, Roro Makubalo, Xolani Nibe, Gail Roman, Matlakala Pule, Nadira Omarjee. We are also grateful to all the focus group and interview participants.

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