

# **Northside Seed Grant Program**

## **Post-Traumatic Stress Disorder (PTSD) and HIV/AIDS among African American Women: Research Design Phase**

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## **Post-Traumatic Stress Disorder (PTSD) and HIV/AIDS Among African American Women Research Design Phase**

The primary purpose of this study is to gather expert knowledge on how best to address mental health disorders among HIV-positive African American women in North Minneapolis. Mental health disorders, particularly Post-Traumatic Stress Disorder (PTSD) and depression frequently precede behaviors that lead to HIV infection. Additionally, people without previous histories of mental illness are at increased risk of developing a mood disorder as a consequence of an HIV diagnosis.

African American women constitute the largest group of HIV-infected patients and continue to experience the fastest increase in infection rates. Endemic poverty, psychological stress and violence in North Minneapolis place all of its residents at an increased risk of infection. We hypothesized, however, that African American women, due to their experience of trauma combined with a cultural legacy that favors self-dissociation from one's body, are at even greater risk. A common psychological result of physical and sexual trauma, dissociation allows a person to continue functioning mentally through "separating" one's sense of identity with one's body. Eventually we plan to explore whether dissociation, and other mental health factors, result in the person having a decreased interest in maintaining good health and using safe sex practices.

We further hypothesized that while community clinics strive to provide adequate health care for HIV patients, there remains a gap between understanding the behaviors that put people at risk for HIV and treating the mental issues that, if alleviated, could prevent infection in the first place.

With those questions in mind, we held a variety of focus groups over the course of August and September, 2009. We asked participants to provide their expert advice on ways to approach African American women in a full-length study, as well as opinions on the types of questions they feel must be asked.

Over the course of collecting information from the focus groups, several common themes developed, and have provided a valuable methodological foundation for future research. These themes are outlined below, and include some direct quotes from participants that particularly emphasize the concept in question.

### **Locating Potential Participants**

By far and large, focus group members emphasized the importance of looking beyond major thoroughfares to find potential participants. While Broadway Avenue on the North Side would be a good starting point, recruiters would most likely have more success going to less crowded areas, more hidden streets to locate African American women.

Also, specific corners, neighborhoods and businesses offer the potential to encounter women:

- Chicago Deli
- Un Bank
- Mc Donalds
- Merwins
- Salvation Army
- Boys and Girls Club
- Cub
- Lowry (Sex traffic)

## Strategies for Approaching / Talking to Potential Participants

Among the most common themes on this topic, focus group members reiterated the following:

- Researchers who approach women would ideally be African American – if this is not possible, then it is crucial for researchers to possess a strong level of cultural awareness and competency. A historic lack of trust between African Americans and European-Caucasians mandates that building trust must be the first step in discussing the project with women of the North Side.
- Researchers must be aware that some of the women they approach will most likely be functioning under the influence of alcohol and/or illicit drugs. This may make communication difficult, but researchers must also bear in mind that the women will fear being arrested, and should assuage these fears.
- An incentive of some sort, most likely monetary, would be a powerful, yet non-coercive tool for promoting participation in the research
- In talking to an African American woman, researchers must confirm that she feels safe talking to them, that she is no danger of any legal or personal retribution, and that she will obtain information and guidance for any health assistance she desires.

Quotes:

- Pain stops when we start telling our story
- Need to create - Non-judgmental, safe space
- People think that someone is going to report back to child protection, or someone else – this is about a process of healing
- Confidentiality is crucial
- Have compassion and be non-judgmental.
- Communication and approach that is sincere and genuine.
- Build relationship by being transparent.

## Discussing PTSD

While our experts presented a wide variety of specific questions to ask participants in the long-range study, most agreed that the first step should not be “Have you ever experienced trauma?”, but rather start by getting a feel for the participant’s views on and definitions of trauma. A researcher’s definition of PTSD, based on clinical and scientific research, may not necessarily be related to a lay-person’s notion of trauma. Events that occurred in a person’s childhood, in adulthood, a year ago, a week ago, etc. are viewed differently through memory’s lens, and can have different emotional impacts. Researchers were advised to start by asking women how *they* feel about trauma, how they define it in *their own* words, etc. By allowing participants to voice their definitions first, focus group members advised the researchers would be able to introduce topics of personal stressors and traumatic experiences with greater ease.

Quotes:

- Define trauma to the researcher, could be a different definition of it than what the researchers think
- What's "post"? it's a fluid timeline, so what is "post-traumatic" for you – is this yesterday or 20 years ago – people will have different reactions depending on when something happened
- In the African American mind, time is not linear, there is no beginning and no end, things pop up and down over time
- Need to define PTSD from an Afro centric point of view
- Culturally, how you look at things impacts how you define it
- People with obvious PTSD will often deny it, and define their stress in different ways

### **Obstacles to Care for Mental Health**

Lack of access to mental health care is often cited as the primary reason why most African Americans with PTSD do not seek out treatment, however, our experts offered other explanations. First and foremost, they stated that African Americans have an inherent mistrust for psychiatrists and mental health professionals – not only due to racial differences, but also due to differing cultural viewpoints. Standard psychiatric care operates on a Western model that approaches PTSD as a clinical illness, best treated with psychotherapy and medication. While this is a valid and frequently effective approach, many African Americans cannot relate to such a model.

A further issue which came up in our focus groups was the issue of stigma. African American women are under heavy pressure from their own community to put their emotional needs last. Strength and stoicism is highly valued, and a woman who expresses she cannot function in her current situation will often be viewed as weak-willed and disloyal to her culture. As a result, researchers are advised to bear this stigma in mind when discussing psychiatric care.

Quotes:

- We are taught, 'keep going, keep doing it, keep struggling', and we've internalized that
- When we say 'stop', I need a break, we have been taught that we are weak
- Service providers have been trained to criminalize it when an African American woman says 'no more'
- There needs to be a community intervention for when women say 'I do not have the energy, physically, psychologically to keep pulling this wagon'
- Afraid of medication
- People want an African American doctor

### **Gender-Specific Obstacles**

A crucial component of understanding the positions African American women fill in society is the family dynamic of gender-based socialization. Our focus group members overwhelmingly agreed that black women are taught by their mothers to be caretakers, breadwinners, and the emotional backbones of their families. Furthermore, they are taught to view their self-worth through a sexual lens – men choose their women, and a woman must be

physically appealing to have any male attention. This creates a highly-sexualized atmosphere based on competition – women compete among themselves for men, and men achieve status via sexual conquest. The advice we received reiterated the importance of addressing sexual self-worth when talking to research participants.

Quotes:

- We raise our daughters and sons differently – we raise our sons and train our daughters
- We expect a girl to do different things than boys
- Men aren't taught responsibility because women do all the heavy lifting
- Men who father kids aren't really daddies, instead it's about conquest, and 'I got her' – they don't associate it with Russian roulette
- It's about 'I got her and let me tell everybody'
- It's a competitive environment, when it shouldn't be
- Girls dress that way to get attention – if they dress less sexually, they think boys won't like them, that that's the only way to get a man to talk to her
- Women pass down the belief that men are a scarce resource, so that, plus peer pressure, form a unique adolescent form of stress

### **Causes for Engaging in Risky Sexual Behavior**

There is an infinite number of reasons why African American women have a trend of engaging in risky sexual behavior, but four main themes emerged from our focus groups:

1. Black women have devalued themselves to the point of not caring what happens to their bodies. Endless cycles of trauma, violence and poverty erode the instinct for self-preservation, and many women are simply no longer interested in their own survival.
2. Sex education, as it is passed down to children by their parents and grandparents, focuses primarily on avoiding pregnancy, not sexually-transmitted diseases. As a result, many women believe that as long as they use birth control medication, they have fully protected themselves.
3. African American women are hesitant to ask their partners to use condoms because they believe bringing up such an issue would indicate they either do not trust their boyfriends, or they themselves are being unfaithful. Rather than risk losing a relationship, many women will avoid even discussing condom use.
4. Trading sex is, for many women on the North Side, the way they provide for their families and/or support their drug habits.

Quotes:

- In public policy and public health, no one ever asked why women who come in for HIV testing come after the fact, after sex, and not for prevention or to get protection
- The right question is, how did women devalue themselves?
- If we look at the lessons we teach our girls, we see they affect young boys – boys see how men treat their mothers, and think, 'that's how men behave'
- We've ingrained the question of pregnancy – don't get pregnant, don't have a baby, so you think 'well, as long as I'm on birth control, I'm okay' – no one talks about STDs

- We sexualize how young girls look and advertise their sexuality, and that's a stressor, that's competition, that's risk

### **HIV/AIDS & PTSD**

When asked if they believe PTSD is in any way correlated to risk of HIV infection, focus group participants unanimously said 'yes'. Psychological trauma, particularly if it is of the sexual variety experienced in childhood, teaches people to view themselves as worthless and deserving of suffering.

The quotes explain this concept best:

- HIV/AIDS is the presenting problem – issue, not knowledge, Body bears witness to trauma – never recovered from the realities of slavery
- People with trauma treat their sexuality [in different ways] - childhood stuff, generational, taught nothing, know nothing, people didn't know they were doing wrong, suppression of trauma through drugs and alcohol...
- When women go through abuse they feel that they are the blame.
- For example women who are abused young continue the behavior with men or by being a sex worker.
- At risk behavior is the most fatalistic and punishing of all the behaviors a victim participates in.
- We have the new generation being brought up in foster care who are seen after but not loved. They become emotionally detached. They become desensitized and succumb to peer pressure.
- Sometimes you can be deceived by someone that you trust and have known for a long time so familiarity can place you at risk.
- Provocative dress can sometimes be related to acceptance with young women.

### **Plans & Ideas for the Community**

When given the opportunity to share what they would like to see done in the community with research findings, the focus groups offered a wide variety of ideas. Overall, they centered on a few common themes:

1. Sex education must start from early childhood, not once a child reaches adolescence and may already be sexually active.
2. Mental health screening should also take place from early childhood, and should be focused on helping a family as a whole alleviate its stresses – when the whole family is helped, children will grow into adults who will not put themselves at risk for HIV/AIDS.
3. A clinic should be organized and staffed by African Americans who can relate to patients and provide them with free care, both physical and psychological.
4. No progress can be made until the community accepts and supports its gay and lesbian members.
5. Spirituality and the Black Church is central to African American life, even among the non-religious. Members of the clergy are in a unique position to help their parishioners educate themselves about mental health and sex education.

## Quotes:

- Participant really liked the idea of a drop-in center and strongly suggested that it be a place that would allow space for personal hygiene. She also said it would be beneficial because it would give the women a sense of belonging and would help them get their lives back on track. She also said it would be a good idea if the drop-in center had bus schedules available. She said closer to West Broadway would be better than the 3700 location.
- Participant handed out a flyer about HIV/AIDS among GLBT women. She reiterated that prevention still needs to be discussed and that women need to be reminded that even though both she and her partner are infected, that they may have different strains of the virus—they could reinfect and kill one another, unintentionally.
- trauma is visible in children – tension, stress, being on guard, sometimes stubbornness – they can't relax into a hug, you see this early on, in kindergarten
- Need to work on trauma in early years
- HIV/AIDS prevention should start at birth, not when you become sexual
- Need to pay attention to the grandparents who are raising the children – the grandparents are not educated about STDs and prevention and don't know what to teach their grandchildren
- Need to tackle peer pressure
- Need a clinic that puts all of these pieces together – a free clinic, not a community center – health care, condoms, people who will talk to the kids, talk to the grandparents, etc., we need all these different programs
- Have dances, event etc. to attract people to the clinic, because many won't come, even if it's free
- The way to a family is through their children
- We have to de-stress these families
- Have to address gay/lesbian/bisexual men and women
- Money for self-esteem programs.
- Community events for the north side residents or a scared straight program
- The Hebrew text was referenced ...start teaching sex education in churches regarding intercourse as a sharing of energy? Rather than immorality...
- Black Church needs to speak up.
- Intervention that would involve HIV screening and treatment.
- Some stress can come from smaller problems or by being involved with a traumatic incident.
- Needs to be inclusive of African American gay males.
- Look at reasons our brothers feel they cannot disclose their sexuality.
- Have somebody with experience to do outreach into the gay community.
- Create a safe anonymous venue for men on the down-low to receive prevention information such as a hotline or computer access.