“DAILY LIFE FUNCTIONING: ILLNESS EXPERIENCE OF HIV-INFECTED WOMEN IN CAMEROON, CENTRAL AFRICA”

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Background and Significance: Women, especially those in sub-Saharan African countries such as Cameroon continues to bear the disproportionate burden of HIV illness. For women in these settings, HIV/AIDS affects their core role as women. Because of their illness, many are unable to carry out daily chores including working on farms, raising their children and taking care of their families. These factors are reported to impact their quality of life. What are the stories of HIV-infected women in a developing country---Cameroon?

Purpose of the Study/Project: The purpose was to explore the day-to-day functioning of women living with HIV/AIDS in Cameroon, Central Africa.

Sample/Population: Thirty women (n=30) 18 years and older who self-reported as being HIV-infected were recruited from the urban and rural areas of the Northwest region of Cameroon.

Framework: The study is guided by a postcolonial feminist framework. This framework advocates for structural changes to create policies that addresses gender inequality and economic access for women.

Method/Approach: A qualitative, in-depth-narrative interview design was used. The analysis was driven by a framework developed from the Weissman, “Fast Fact Concept #17: Patient-Centered Interviewing: Understanding the Illness Experience outline for assessment of patient’s illness experience” (Weissman, 2000).

Results/Outcomes (preliminary findings OK if poster): Seven themes emerged from the analysis: a) Course of the illness (discovery and reaction), b) Daily experience of living with HIV/AIDS, c) Symptom experience, disease management and medication adherence, d) Lack of resources/social services and lack of social support, e) Economic impact: agricultural and environmental impacts, f) Disclosure, stigma and discrimination, and, g) Sexual decision making, reproductive health and role of women.

Conclusions/Implications: The study provides insight into the illness experiences of HIV-infected women in Cameroon. Women utilized both modern and traditional healthcare systems for their treatment. Symptoms and co-morbidities affected their daily functioning and their children’s future.
Learning Objectives

Background: HIV Prevalence (Global and Sub-Saharan African)
HIV/AIDS Prevalence (Among Women in sub-Saharan Africa)

Significance: What is Illness Experience/Illness Narratives?

Purpose of the Study: Explore the day-to-day functioning of women living with HIV/AIDS in Cameroon, Central Africa.

Research setting: North West Region, Cameroon (Central Africa)

Methods and Procedures: Qualitative cross-sectional in-depth narrative inquiry design

Sample, Recruitment and Data Collection:

Summary of Major Findings:

Strengths of the Study:

Limitations of study:

Implications education, practice and policy:

Implications for Future Research:

Conclusions:

Dr. Alomepe Building Bridges Conference May 2012
Presenter Name: Jacqueline Alomepe, PhD, RN-CNSRN

Presentation Title: Daily Life Functioning: Illness Experience of HIV-infected Women in Cameroon, Central Africa

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DAILY FUNCTIONING: ILLNESS EXPERIENCE OF HIV-INFECTED WOMEN IN CAMEROON, CENTRAL AFRICA

Jacqueline Alomepe, PhD, RN-CMSRN
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May 10, 2011

Learning Objectives
Background: HIV Prevalence (Global and Sub-Saharan African)
Significance: What is Illness Experience/Illness Narratives?
Purpose of the Study
Research setting
Methods and Procedures: Sample, Recruirments and Data collection
Findings
Strengths of the Study
Limitations of study
Implications education/ practice/policy/ Future Research
Conclusions
Discussions
Background: HIV Prevalence [Global and Sub-Saharan African Estimates]


Women’s Role in Africa/HIV/AIDS

- In most of Cameroon society, women are expected to bear and assume primary responsibility for raising their children.
- HIV/AIDS is an illness that impacts people’s day-to-day lives, affecting the women’s ability to farm, work, and carry out daily activities. How do women who are HIV-infected manage their HIV needs and the needs of their families? Self-care behaviors are essential to the management of HIV/AIDS.
- Increasingly, people who are HIV-infected are living longer, so efforts to assist those individuals to improve their quality of life is critical. With HIV, women’s health is strained, since women have always been the caretakers of their families and communities.

Background: HIV/AIDS Prevalence [Among Women in sub-Saharan Africa]

- Women are disproportionately impacted by HIV
- According to the United Nations AIDS Program (UNAIDS, 2010):
  - The vulnerability of women and girls to HIV remains particularly high in sub-Saharan Africa; about 76% of all HIV-positive women in the world live in this region.
  - In nearly all countries in sub-Saharan Africa, the majority of people living with HIV are women, especially girls and women aged 15-24.
  - The most recent prevalence data show that 13 women in sub-Saharan Africa become infected with HIV for every 10 men.
- Heterosexual sex remains the dominant mode of HIV transmission
  - The vast majority of people in sub-Saharan Africa continue to be infected with HIV through unprotected heterosexual intercourse and onward transmission of HIV to infants.
  - Research in 12 countries in eastern and southern Africa found a high HIV prevalence among discordant couples (where one partner is living with HIV), ranging from 36% to 85%.
- Women experience stigma, and complex socio-cultural issues impacts their health.
Significance: What is Illness Experience/Illness Narratives?

- Patient illness experiences/illness narratives capture their individual suffering and struggles (Kleinman, 1988)
- Illness is simply an individual experience; it is distinct, unique, and influenced by the socio-cultural environment of the patient (Kleinman, 1988; & Conrad, 2005)
- HIV is now a chronic disease and symptoms/ co-morbidities can be disruptive and impacts everyday activity.
- There is therefore a need to explore the subjective illness experiences of individuals living with HIV/AIDS if we expect individuals to engage in meaningful treatment and become proactive in their health care.
- There is limited understanding and documentation of HIV-infected Cameroonian women’s experiences of living with HIV/AIDS
Purpose of the Study

The purpose of this study was to explore the day-to-day functioning of women living with HIV/AIDS in Cameroon, Central Africa.

- The specific aims were to explore from the perspectives of HIV-infected Cameroonian women:
  - Impact of HIV/AIDS illness on daily lives

Research Setting - Northwest Region of Cameroon

- Data collected from Northwest section of Cameroon (Bemeda is the Capital and largest city in this region)
- Large population density in this area approximately 1.9 million inhabitants
- The Northwest is one of the two English-speaking regions in Cameroon; the other eight regions are predominantly Francophone
- Large government hospital in Bemenda and several Non-governmental organizations and church/philanthropic organizations playing role in delivery of health care in area
- Highest prevalence rate (8.7%) HIV sero-positive positive compared to other regions in Cameroon
- Investigator is from this part of the country
Bamenda Regional Hospital

The Regional Director of the Bemeda Hospital (Dr. Awasom) and Nurses

Researcher, HIV Support Centers, and Rural Topography
**Methods and Procedures:**  
**Sample, Recruitments and Data collection**

- Qualitative cross-sectional in-depth narrative inquiry design
- Convenience sampling using flyers and snowball techniques
- Participants include: (N=30) women who self report being HIV positive, (18 urban and 12 from the rural areas)
- IRB approval obtained from UWM and Cameroonian MOH Ethics Committee
- IRB permission obtained to waived written consent; Oral consent obtained from each participant before the interview began
- Interviews were conducted in ‘pidgin English’ in a private room or at participant’s home
- Completion of socio-demographic questions and in-depth interview lasted approximately 1hr to 2 hours
- Interviews were transcribed verbatim and field notes were used to augment missing information from the transcripts

**Analysis of Data:** Development of Analytical Coding Framework

**Domain 3: FUNCTIONING – Impact of HIV Illness on Daily Life**

- HIV/AIDS impacted the women’s functioning and were grouped under the following sub-themes:
  - Course of the illness (discovery and reaction)
  - Daily experiences of living with HIV/AIDS
  - Symptom experience, disease management and medical adherence
  - Lack of resources/social services and lack of social support
  - Economic impact: agricultural and environmental impacts
  - Disclosure, stigma, and discrimination
  - Sexual decision-making, reproductive health and role of women
Domain 3: FUNCTIONING – Impact of HIV Illness on Daily Life

Exemplars of Course of Illness (discovery and reaction)

“I lost my first baby. Then my second baby got seriously sick. In the hospital, he needed blood. I offered to give him blood. They tested my blood and found out I was HIV positive. I was surprised, shocked and disturbed...I refused to eat and I thought I was going to die. My husband was home sick and not long after the baby’s death my husband died...” (urban participant 13)

“After my husband’s death one of his friends told me that he died from AIDS. I went to the hospital and asked the doctor and he said yes. Hearing that, I fainted in doctor’s office. I was very angry, depressed and blamed my husband for infecting me” (rural participant 2).

Domain 3: FUNCTIONING – Impact of HIV Illness on Daily Life (Cont.)

• Exemplars of daily experiences of living with HIV/AIDS:
  
  For the women in this study, having HIV meant struggling with the challenges of carrying out daily activities.
  
  “Some days when I have strength I prepare food for the kids. When I am tired I allow the kids to cook, split wood, wash clothes and fetch water. With HIV I am sick all the time. I have pains, big belly, and running stomach, and fever. I have no way to get-up-and-go. I have no money to feed or pay my kids school fees. In the community, people do not like sitting with me because I lost so much weight.” (urban participant 25)

Domain 3: FUNCTIONING – Impact of HIV Illness on Daily Life (Cont.)

• Exemplars of Symptom experiences, disease management, and medication adherence:

  “The illness makes my body to itch, I have “craw-craw” (rashes) on body. The doctor gave me medication but my body continue to “scratch” (itch) for two years now.” (urban participant 26)

  “Look at my veins, you can see them now and that worries me. Sometimes I take bath and rub the veins so that they can look smaller. I use to have fat looking legs now I have bony legs and have also lost a lot of weight.” (rural participant 1, 2, & 3)

  “Since having HIV I am sick all the time I have. No feelings to my feet and my stomach is going big like I am pregnant.” (urban participant 25)
Domain 3: FUNCTIONING – Impact of HIV Illness on Daily Life (Cont.)

- Exemplars of Lack of resources and lack of social support:
  
  “I have no help in the community. If you tell the church members that you are positive, they will gossip your name in the community.” (rural participants 1, 3, & 4)

  HIV has affected my family. I have three sisters with HIV and both of their husbands died before they knew they were HIV positive.” (rural participant 10)

  After my husband died, his family treats me badly and we always quarreling. They do not help to care for the six children we had and they blamed me for poisoning my husband. Now I live in this small two bedroom mud house with no light or water. I cook on these three wood fire sides and as the newborn sleeps the bamboo bed. I pay rent by doing farming for the landlord.” (rural participant 4)

- Exemplars of Economic impact: agricultural and environmental impacts:

  “My life has changed since I have this illness. I have weakness in my hands and I cannot feel my hands, “my hands are dead like fish in the fridge.” Since I cannot feel my hands I cannot farm. Sometimes I cannot feel my legs so I cannot stand up for long as before. I need a job that I can sit down. I get tired easily.” (urban participants 23 & 26)

  “I am sick all the time my nose drips like water. I have no ‘power’ (energy). I can’t farm. I feel weak as if I am going to faint. The dust gets into my nose and I cannot breath and with rain I cannot farm because it gives me fever. (rural participants 1, 2, 3, 4, 5 &10; urban participants 15, 23, 26, 27 & 30)
Farming Activities and Pictures of Women Selling Produce in Open Market

Domain 3: FUNCTIONING – Impact of HIV Illness on Daily Life (Cont.)

- Exemplars of disclosure, stigma and discrimination:
  “When they told me I was positive, I thought I was going to die. Many people are afraid to tell others and would rather die than telling they are sick.” (rural participant 10)
  “When I found out that I was sick with the disease, I came home and told my husband to do HIV test and he refused. He packed my things and moved me and my son to my mother’s home. I went and told the chief who tried to contact him, but he ran away.” (rural participants 2 & 7, urban participant 30)
  “People me names. With this illness, it is hard for me to go anywhere. People gossip and stare at me. They refuse to sit with me, they refuse to share food or drink from the cup that I have used.” (rural participants 1 & 9, urban participants 24, 25 & 27)

Domain 3: FUNCTIONING – Impact of HIV Illness on Daily Life (Cont.)

- Exemplars of sexual decision making, reproductive health and role of women:
  “When I was pregnant, I felt seriously sick, my husband refused to take me to the hospital. My brother had to pay for me to go to the hospital. My husband had to give permission for me to take the HIV test...” (rural participant 11)
  “When I discovered that I had HIV I gave out marriage and sex. Later I saw one of my friends with HIV having two kids.....After seeing her having children and breastfeeding, I decided to become pregnant but without telling my partner about my HIV status. I know what I did was wrong but if I told my partner he would have ran away.” (rural participant 5)
Domain 3: FUNCTIONING – Impact of HIV Illness on Daily Life (Cont.)

Exemplars of sexual decision making, reproductive health and role of women:

- “... I pray to God to take the desire away. As you know men in Africa do not like to use condoms so I do not want to infect others. Men in Africa will say “I cannot be eating something that is in a covered dish.” (rural participant 11)
- HIV has affected my newborn baby because I cannot breastfeed her and buying formula is very expensive. I have to hide and feed her with formula in my bedroom because my friends are always questioning me why the baby is on formula.” (urban participant 13)
- “When my husband died some of the family members blamed me for infecting him and they sent me away from the home we owned. I have no money, I cannot support my kids.” (rural participant 11)
- “When my husband died my in-laws took all the property and sent me back to my parents. I now live with my mother and three other sisters and they are infected too.” (rural participant 10)

Summary of Major Findings

- Women in this study faced an array of challenges which impacted their day-to-day functioning
- Living with HIV/AIDS had varied meanings to the women and were influenced by social, cultural and community factors
- Overtime, the women in this study learned how to notice changes in their bodies such as extreme weight loss, extreme fatigue, pains, numbness, and weakness; they then took measures to manage these symptoms
- Women also experienced stigma and discrimination from family members and communities and in some instances were ostracized
- Living with HIV/AIDS as a woman in Cameroon can be cruel. Participants were resilient despite multiple health, social and economic challenges

Strengths of the Study

- This study provides an important first step to understanding the multiple challenges HIV infected women faced in Cameroon
- Interviewed the women in their socio-cultural environment
- In-depth interviews allowed the researcher to gain rich and clearer data on day-to-day experiences on complex health issues
- Interviews were conducted in “Pidgin English” which allowed the women to be at ease in telling their stories
- Weissman’s (2000) “Fast Fact Concept #17: Patient-Centered Interviewing” initially developed for in-patient settings was applied to exploring health beliefs and illness of individuals in a community-based setting
Limitations of the Study

- Qualitative in-depth interviews requires a lot of time effort. Specific skills are needed to plan, conduct and interpret an interview; inadequate skills of this nature will produce information of no value.
- In-depth interview as a method may suffer from subjectivity, and relies heavily on the integrity and intellectual honesty and interpretation of the researcher.
- Study was a cross-sectional, non-randomized study and limited to one geographic area in Cameroon.
- Objective clinical health indicators were not collected (e.g., CD4 cell counts, HIV viral load).
- HIV and sex are sensitive topics in African societies and thus some participants may have been guarded in sharing the details of the stories of their illness.
- Conducting research in another language presents challenges during transcription, some of the information can be missed and it is time consuming.
- Conducting research in rural areas with impassable roads requires long hours of trekking and planning for unforeseen circumstances.

Implications for Education/Practice

- Implications for Education: Incorporating humanism in care of patients, illness experience through training, reflective learning and through service learning. Re-evaluate Curricula: To include social science courses and more clinical hours to improve communication skills, African traditional practices and perceptions of health and illness in relation to HIV/AIDS. Use case studies and clinical rotations to familiarize themselves with the care of HIV.
- Implications for Practice: Healthcare professionals need to understand that both lay and scientific knowledge are important in the understanding of illness (Cultural sensitivity and competency). The subjective aspects is as important as the objective aspects of care. They combine to give a true and complete picture of the patient’s illness and allow the patient to have a voice. Health care systems can incorporate illness narratives in plan of care, admission and discharge templates, use of social network technologies through videos about health and culture.

Implications for Future Research/Policy

- Implication for Future Research: Future studies explore how narratives and meanings of illness can be used to help patients map their illness experiences to help healthcare providers understand the sometimes complex lives of their patients. A study that explores the doctor-patient relationship and patient-to-doctor relationships from the doctor and patient perspectives.
- Implication for Policy: Eliminate gender inequalities (e.g., micro lending loans).
- Collaborate with village elders to address family policies on widow inheritance and land ownerships.
- Developed policies to assist orphans and widows of HIV.
- Policies on subsidizing housing and food/nutrition for HIV-infected.
- Develop structural policies that address stigmas and discrimination issues.
Conclusions

• The study provides insight into the illness experiences of HIV-infected women in Cameroon.
• Their views of health and illness were influenced by both African societal values and modern healthcare systems and utilized both systems.
• Half of the women in the study were widows, being a widow had a negative implication for survival. HIV/AIDS, its symptoms and co-morbidities has caused functional impairments. Farming was central to the women’s livelihood; both as a source of food and for income for the children’s education.
• Today, the women can help neither themselves nor their children. What does the future hold and what can be done to better their lives? It is evident that women in this study need support and resources to help maintain their quality of life.

THANK YOU FOR LISTENING!!!

Questions and Discussion