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University of Alberta

HIV Illness in Ghanaian Women

by

Judith Ellen Mill ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Doctor of Philosophy

Faculty of Nursing

Edmonton, Alberta

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Abstract

HIV disease is a serious, and growing, public health concern in Ghana. The recent epidemiology of HIV disease in Ghana indicates that more new cases are occurring in women and that women are infected at a younger age than their male counterparts. In response to this concern, a research project was undertaken in Ghana in early 1999. The purpose of the study was to develop an understanding of the broad context of HIV disease transmission in Ghana. Participatory action research was the methodology that guided the research and in-depth interviews and focus groups were used to collect the data. Thirty-one HIV sero-positive women were interviewed to explore their explanatory model of HIV illness and their thoughts about effective strategies for HIV prevention in Ghana. In addition, eight nurses, two traditional healers, ten professionals and five HIV sero-positive men were interviewed, individually and in focus groups, to reflect on the women's comments and the themes emerging from the data.

The dissertation has been prepared using a paper format and includes an introduction, four publishable papers and a conclusion. The first paper describes the process of ethical decision-making that was used during the research, from the identification of the problem to the dissemination of the findings. In the second paper, the women's narratives provide a moving description of the risk environment that influenced their vulnerability to HIV infection and their ability to protect themselves from infection. The women's explanatory model of their HIV illness, including their beliefs about HIV disease, is described in the third paper. In the final paper, the secrecy surrounding 'breaking the news' of HIV infection is examined as one manifestation of AIDS stigma in Ghana. In the conclusion, the author argues that the women's life experiences, and their ultimate infection with the HIV virus, provides compelling evidence that in Ghana HIV illness is a disease of development. The dissertation concludes with a discussion of the implications of the findings for nursing, including recommendations for future research.

University of Alberta

Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled HIV Illness in Ghanaian Women by Judith Ellen Mill in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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31 May 2000
Date

Dedication

This dissertation is dedicated to the courageous Ghanaian women who shared the stories that are documented in the following papers.

Acknowledgement

There are many individuals, in Canada and Ghana, who contributed to the successful completion of my doctoral studies. As my supervisor, Dr. Linda Ogilvie provided exceptional mentorship. Linda taught me scholarship, and at the same time respected and valued the expertise that I brought to our relationship. I am grateful. Dr. Janet Ross Kerr was a motivating influence on my decision to pursue graduate education in 1994 and to continue with PhD studies in 1996. I appreciated her belief in my abilities and her ongoing wisdom that she shared in a gentle manner. Dr. Stan Houston and Dr. Toh Swee-Hin provided valuable insights concerning the issues surrounding HIV illness and encouraged me to consider the illness from new perspectives. There were many colleagues in the PhD program, in particular Karen Benzies, Susan Duncan, Patricia Marck and Jenny Medves, who provided ongoing support and intellectual stimulation.

I am grateful to my Ghanaian colleague, Miss Mary Opare, who initially invited me to Ghana to carry out my dissertation research. Miss Joanna Laryea, the Head of the Department of Nursing at the University of Ghana, made the necessary arrangements with the Ministry of Health and the University of Ghana for my research project. I am also indebted to Dr. John Anarfi, Senior Research Fellow with the Institute of Statistical. Social and Economic Research at the University of Ghana. Dr. Anarfi acted as an external consultant to my dissertation committee during my field research. My research assistants, Mr. Tawiah and Mr. Afedoe, provided outstanding support during the collection of the data and translation of the interviews. Based on their in-depth understanding of Ghanaian culture, they offered insightful comments about the interpretation of the data. Without the assistance of these research partners in Ghana, this project would not have been possible.

Finally, I must acknowledge the support received from my family during my doctoral studies. My parents provided ongoing support for my pursuit of higher education. The encouragement of my two sons, Steve and Geoff, made a significant contribution to my ability to carry on when the end seemed so distant. The most enduring and positive influence throughout my doctoral studies came from my husband, Tom. His ability to intellectually challenge, while providing love and encouragement, is a unique gift. I am truly indebted to his contributions to my scholarly development.

Table of Contents

Introduction

Setting the context

This research project is part of a broader research program that I have undertaken since beginning graduate school in 1994. There were several experiences that have influenced my quest to understand the broad factors that influence the transmission of disease, and in particular human immunodeficiency virus (HIV) disease. Prior to pursuing graduate education, my clinical practice as a public health nurse was firmly grounded in a biomedical approach to disease prevention. Traditional HIV prevention programs conceptualized 'risk' as behaviour within the control of the individual and focused on the identification of 'risk groups'. Public health interventions were designed to reduce 'high-risk' behaviours within these groups. The use of condoms and the practice of monogamy are examples of interventions that were advocated to reduce the transmission of sexually transmitted diseases such as HIV disease. During work with women's groups in Zimbabwe in the early 1990's, I was confronted with the realization that condoms and monogamy might not be appropriate HIV prevention strategies for all individuals, in all cultures. My grounding in the biomedical approach to illness prevention was severely challenged.

This awareness led me to explore the experience of HIV sero-positive Aboriginal women for my master's thesis at the University of Alberta (Mill, 1996). During this qualitative study, I began to question the concept of 'high-risk' behaviour because it implied choice. I conceptualized the 'high-risk' behaviours of the Aboriginal women in my study as survival techniques used to cope with extremely difficult situations (Mill, 1997). In the area of HIV prevention, theories of risk behaviour must be broadened to conceptualize risk as a socially organized phenomenon rather than an individual one (Rhodes, 1997; Standing, 1992). Through this re-framing of risk, the dialogue shifts from victim blaming and health education to an underlying assessment of determinants of health and root causes of disease and from individual to population health promotion strategies. There is a need to move beyond the epidemiological concept of 'risk-group' to explore the complex question of why risk situations are produced. My research with Aboriginal women in Alberta raised questions and provided the impetus for the current dissertation project "HIV Illness in Ghanaian Women".

Why Ghana? Why Women?

Several factors influenced my decision to carry out my dissertation research in Ghana. The first reason relates to the collaborative relationship that has developed between the Department of Nursing, University of Ghana and the Faculty of Nursing, University of Alberta. I was invited to Ghana to carry out the field research for my dissertation by Mary Opare, formerly a classmate at the University of Alberta, and currently a lecturer in the Department of Nursing, University of Ghana. The Head of the Department of Nursing in Ghana subsequently extended this invitation to me. After beginning work on my research proposal, the Department of Nursing, University of Ghana and the Faculty of Nursing, University of Alberta entered into a partnership to design and implement a Master of Philosophy (Nursing) program at the University of Ghana. The second reason relates to my philosophical belief that health is a global issue. I am deeply concerned about HIV infection in sub-Saharan Africa, where HIV disease continues to cause immense suffering as it spreads through homes and communities. A third, less altruistic reason, relates to a personal goal to develop international research expertise.

Although Ghana has not experienced the high HIV sero-prevalence rates seen in many countries of sub-Saharan Africa, several epidemiological indicators suggest that HIV disease is a serious public health concern. There has been a steady increase in the number of individuals with HIV disease since 1986 and currently it is estimated that 4% of the population or 600,000 individuals are HIV sero-positive (Disease Control Unit, 1999). The recent epidemiology of HIV disease in Ghana indicates that more new cases are occurring in women and that women are infected at a younger age than their male counterparts (Disease Control Unit, 1999). A variety of complex and frequently interrelated factors, including gender, unequal power relationships with men and poverty, influence women's vulnerability to HIV infection and their ability to adopt behaviours that will reduce their risk of infection (Jackson, 1998; Kitts & Roberts, 1996; World Health Organization, 1994). Ghanaian women constitute one population with increased vulnerability to HIV infection due to limited educational opportunities, poverty and unequal power relationships with men (Mill, 2000).

Theoretical Perspectives on HIV Prevention

HIV prevention efforts have gradually evolved to reflect our increased understanding of the factors that influence transmission. Following the discovery of the modes of transmission for the virus, individual behaviour change was promoted as the primary strategy to decrease its spread. The behavioural approach advocated the prevention of HIV infection through the use of condoms and fewer partners, and was quite successful in reducing the spread of HIV infection in certain segments of the population such as gay men in North America. The Health Belief Model (HBM) (Rosenstock et al., 1994) and Bandura's social cognitive theory (Bandura, 1994) are examples of theoretical perspectives that have utilized a behavioural approach for HIV prevention. Behavioral models are predicated on the belief that sexual behaviour is "a reasoned and intended behaviour and that individuals have control over it" (Campbell, 1997, p. 189). A major weakness of the Health Belief Model and the social cognitive theory is the over-emphasis on individual control over behaviour.

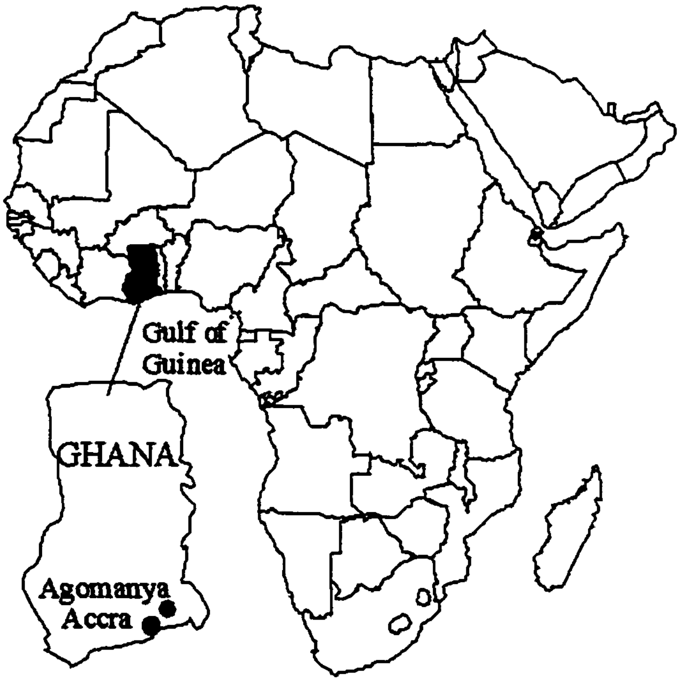
Although important, a focus on individual behaviour may be limited in its effectiveness because it does not acknowledge the broader context of disease transmission (Aggleton, 1996; Freudenberg, 1990; McKinlay, 1996). Knowledge about the transmission and prevention of HIV infection is only one factor that influences behaviours, such as condom use, to reduce viral transmission (Asamoah-Adu et al., 1994; Campbell, 1997). For example, research findings in Ghana indicate that although 96% of men and 65% of women know about condoms, only 20% of individuals have ever used a condom (UNAIDS, 1999). Motivation and the necessary behavioural skills, in addition to accurate knowledge about HIV transmission, have also been identified as important variables in behaviour change (Campbell, 1997). Researchers have increasingly documented the need to understand the broad structural and cultural factors that influence vulnerability to HIV infection, particularly for women (Jackson, 1998; Long & Messersmith, 1998; Standing, 1992).

The Dissertation Project

The current study entitled "HIV Illness in Ghanaian Women" was carried out between January and May 1999 as part of the requirements for my PhD in Nursing at the

University of Alberta. Ghana is situated on the Gulf of Guinea in West Africa (Figure 1). The purpose of the study was to develop an understanding of the broad context of HIV disease transmission in Ghana and to explore the cultural, social and economic factors that interacted to influence Ghanaian women's vulnerability to HIV infection and to mediate their ability to protect themselves from infection.

Figure 1. Map of Africa Showing Ghana and Study Sites



The following research questions were explored with thirty-one HIV sero-positive women, five HIV sero-positive men, eight nurses, two traditional healers and ten professionals:

1. What is the life experience of Ghanaian women who are HIV positive?

2. What are the lay and professional explanatory models of HIV illness in Ghana?
3. What methods do Ghanaian women use to cope with their illness?
4. What strategies do Ghanaian men and women feel would be effective for HIV prevention in Ghana?

Participatory action research (PAR) was the methodology chosen for the study for several reasons. PAR is appropriate to explore and challenge the power imbalances in gender and economic status that, in turn, impact health (Schoepf, 1994; Seng, 1998). As a methodology, PAR provided a flexible, socially and culturally adaptable framework to guide the research process. The ability to adapt methods for use in a range of settings, to explore local knowledge and to enhance the quality of the research by including the insights of local individuals (Cornwall & Jewkes, 1995) made PAR an suitable methodology to answer the research questions. Finally, PAR facilitates critical thinking, encourages individuals to explore the root causes of their situations (Schoepf, 1994) and helps to ensure that the research is relevant (Lindsey & Stajduhar, 1998).

The nurses, traditional healers, professionals and HIV sero-positive men were interviewed, individually and in focus groups, to reflect on the women's comments and the themes emerging from the data. Their inclusion in the research is important for several reasons. The additional perspectives of these participants provided context to the narratives shared by the women. In addition, it is anticipated that consciousness-raising occurred during the interviews with the traditional healers, nurses and other professionals and with the HIV sero-positive men. Finally, it was strategic to request key individuals working in HIV prevention, treatment, policy development, education and research to reflect on the findings and their implications for policy development in Ghana. Their reflections provide insights that were integral to the interpretation of the data and the dissemination of the findings.

The dissertation project has been organized into four publishable papers and a concluding chapter. The first paper focuses on the process of ethical decision-making that was used during the project, while the three remaining papers highlight the major areas of the findings.

Ethical Decision-Making in International Nursing Research

In the first paper, "Ethical Decision-Making in International Nursing Research". I examine the process of ethical decision-making that was used, from the identification of the problem to the dissemination of the findings. I advocate the adoption of universal ethical principles in international research that, at the same time, acknowledge the ethical standards related to the institutional setting and cultural environment where the research takes place. Researchers in international settings are obligated to exercise ethically sound decision-making that ensures that both sets of standards are met. I discuss the rationale for using participatory action research (PAR) and demonstrate that this methodology provided a flexible, socially and culturally adaptable framework for the study. Based on my experience in Ghana, I argue that the parameters of 'action', implicit to participatory action research (PAR), must be broadly defined within the context of international research. Strategies that were used to foster collaboration with research partners and the participation of HIV sero-positive individuals and professionals are reviewed. I suggest that two different types of consciousness-raising were evident during the research: an indirect, internal process that occurred in individuals as a result of their participation, and, a more deliberative process to actively facilitate consciousness-raising among Ghanaians.

Criteria to assess rigor are described and applied to the current study. The use of translators for data collection, the association of HIV illness with prostitution and the influence of Christianity are discussed in relation to their impact on the rigor of the study.

HIV Risk Environment for Ghanaian Women: Challenges to Prevention

The second paper is entitled "HIV Risk Environment for Ghanaian Women: Challenges to Prevention". In this paper the women's life experiences document some of the broad structural, cultural and social factors that influence HIV transmission in Ghana. Poverty was a pervasive theme during the women's formative years and restricted their access to education and vocational training. For these women, limited education in turn constrained their ability to support themselves as adults. As a result many women became involved in sexual relationships in exchange for money. I argue that these relationships represented a strategy for survival. For most women, the use of condoms with sexual partners was restricted by the high value placed on fertility, the negative association of condoms with prostitution and disease, and the women's limited ability to influence decision-making in this area. Participants' reflections on HIV prevention strategies appropriate and feasible in Ghana included condom use, taking care of oneself, mandatory HIV testing and education programs. A discussion of several strategies to expand and intensify prevention efforts concludes this paper.

I'm not a Basabasa Woman: An Explanatory Model of HIV Infection in Ghanaian Women

"I'm not a Basabasa Woman: An Explanatory Model of HIV Infection in Ghanaian Women" is the third paper in the dissertation. Prevailing views of health and illness, including indigenous knowledge and traditional beliefs, are important components of the broad context of disease transmission. In this paper, the findings related to women's beliefs about their illness are documented and their explanatory model of illness is described. Beliefs and attitudes described by the women revealed a misconception that HIV infection is confined to particular groups. Although the association of HIV illness with travel and with 'basabasa' women, or prostitutes, can be traced to the early epidemiology of the epidemic, the prevalence of these beliefs may result in individuals being unaware of their vulnerability to infection. These beliefs highlight the need to refocus prevention efforts. The explanatory model described by the women includes their views about the etiology, pathophysiology, symptomology, course of illness and methods of treatment for their illness. I will demonstrate areas of divergence and convergence between traditional and professional explanations of, and treatment for, HIV disease. Most of the women believed that their sexual partner was a possible source of their infection, however, almost half mentioned supernatural forces as a possible reason for their illness. Similarly, the women's choice of treatment was not restricted to one domain. The women sought treatment from traditional, biomedical, or spiritual healers, or from a combination of healers. The findings raise challenging questions in relation to the integration of biomedical and traditional health belief systems and have important implications for HIV prevention.

Shrouded in Secrecy: Breaking the News of HIV Infection to Ghanaian Women

The final paper is entitled "Shrouded in Secrecy: Breaking the News of HIV Infection to Ghanaian women". The phenomenon of stigma is one component of the broad context of HIV transmission. Knowledge of AIDS stigma is important because of the impact that it may have on the disclosure process and the subsequent care and treatment of infected individuals. In addition, AIDS stigma may negatively affect the lives of HIV positive individuals and their families and has the potential to interfere with the efficacy of HIV prevention efforts. In this paper, the research findings are used to document the presence and impact of AIDS stigma. I will argue that the secrecy surrounding 'breaking the news' of HIV infection is one manifestation of AIDS stigma in Ghana. Narratives described in the paper document many negative outcomes experienced, or anticipated, by the women in relation to HIV disclosure. Women were shunned on the basis of physical characteristics, such as weight loss, associated with their illness. Others were isolated by community members or forced out of their home when their diagnosis became known. Their stories provide an impassioned description of the stress and suffering that many of the women endured and the necessity to shroud their illness in secrecy. The possibility that this secrecy actually maintains and amplifies AIDS stigma is examined. Recommendations in relation to education and research to address the complex issue of AIDS stigma are discussed.

In the conclusion of the dissertation I critically review the findings in their entirety. One of the major implications of the research is that HIV disease in Ghana is a 'disease of development'. In the past, the concept 'disease of development' has been used, primarily, to refer to changes in the epidemiology of parasitic diseases as a result of the failure to forecast or consider the ecological impact of development. I argue that HIV disease provides a contemporary example of a 'disease of development' because of the social, political and economic factors that influence its spread. Poverty, limited access to education and gender inequity are development indicators that implicate HIV disease as a 'disease of development' because of their influence on the transmission of the virus.

These factors permeated the lives of the women in the current study and increased their vulnerability to HIV infection. The implications of the research for nursing are considered and recommendations for future research initiatives are summarized in the conclusion.

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Ethical Decision Making in International Nursing Research

Introduction

The conduct of nursing research in international settings presents challenges and rewards that may differ from those arising from research projects closer to home. This is especially true for research involving human subjects because cross-cultural ethical issues compel researchers to engage in continuing decision-making to ensure that the work is ethically sound. Ethical principles must be applied in a manner that is responsive to differences in language, culture and economic status between the researcher and the participants. Research methods may require adaptation to overcome barriers in language. Approaches to data collection must be adjusted to ensure that local beliefs and practices are considered and respected. Additional steps are required during data analysis to ensure that interpretation and meaning have not been altered during translation. In order to overcome these challenges, patience, flexibility and sensitivity are required of the researcher. Concomitant with the challenges, however, are several rewards and benefits that enhance the appeal of international nursing research. Research in international settings enables the nurse to consider health and nursing research from a global viewpoint. International collaboration facilitates the development of nursing knowledge about universal health issues, such as the health of marginalized populations (Meleis & Gray, 1998). At the same time, there is the opportunity for nurse researchers to establish international research partnerships and to bring new perspectives to health issues within our own borders.

In this paper, I will draw on my dissertation research in Ghana between January and May 1999 to document the process of ethical decision-making used in an international nursing research project. Ethical decision-making is defined as "ethical reasoning and behaviour about best action, based on the conviction that some actions are better than others" (Alberta Association of Registered Nurses, 1996, p. 3). Applied to research, ethical decision-making means that decisions are made during the research process to achieve the best possible outcome. For example, the methodology and methods are chosen to ensure that they are appropriate to answer the question under investigation. I will review the concepts of ethical universalism versus ethical relativism and discuss the application of ethical principles to international research. Several issues that surfaced during the investigation will be highlighted. I will examine the decision-making that took place during the study, with reference to aligning the methodology with the problem and choosing appropriate methods for data collection. Finally, criteria to assess rigor will be described and applied to the current study.

Contemplating Ethical Universalism

An issue that is central to the conduct of research in international settings, and on which researchers hold differing opinions, is the notion of ethical universalism. This issue focuses on the question of whether ethical principles are universal across settings and cultural groups or are relative to the setting or culture. Brink (1989) assumes a position of ethical relativism in her argument that human rights are a "product of culture...and... each society specifies how those rights will be protected" (p. 518). Similarly, Lützén (1997) suggests that the concept of ethical universalism requires debate and advocates the adoption of a context-specific approach to nursing ethics. Ijsselmuiden and Faden (1992), on the other hand, examine the concept of individual informed consent and provide a convincing argument to support the requirement for universal ethical principles. The authors suggest that the need for individual informed consent in developing countries has been challenged from three perspectives: that individual consent is culturally inappropriate in cultures that are group-oriented; that informed consent is difficult in situations where the subjects' mental competence is questionable or language barriers inhibit clear communication; and that the urgent need for health research findings in African countries supersedes the increased time and resources that may be required to obtain individual informed consent. Ijsselmuiden and Faden refute the assumptions that each of these positions is based upon and conclude that a culturally relativistic approach to individual informed consent cannot, and should not, be supported.

The World Health Organization (WHO) and the Council for International Organizations of Medical Sciences (CIOMS) have jointly established international guidelines recommending ethical universalism for research on human subjects (Council for the International Organizations of Medical Science (CIOMS), 1993). Many researchers have demonstrated support for this position (Angell, 1988; Angell, 1997; Barry, 1988; Lurie & Wolfe, 1997). Barry (1988) maintains that proposals for the conduct of research in developing countries require an independent ethical review using ethical standards as rigorous as those applied to research in a developed country. A more emphatic argument is made for ethical universalism by Angell (1988) in an editorial for the New England Journal of Medicine: "human subjects in any part of the world should be protected by an irreducible set of ethical standards...just as there can be no compromise in scientific standards based on local traditions, there can be none in ethical standards" (p. 1083).

Kleinman (1995) offers a critique of both ethical relativism and ethical universalism in his discussion of differing ethical perspectives[1]. He challenges the position of cultural relativism based on a concern that cultural practices may be considered acceptable solely on the basis of the opinion of the dominant group. Kleinman, however, also cautions against an uncritical position of cultural universalism. He reminds us that, "before we apply an ethical category that we hold to be universal, we had first better understand the context of practice and experience" (Kleinman, 1995, p.64). Kleinman adopts a mediating position of deliberative relativism that places greater emphasis on the discussion of the ethical issue, than on its resolution. Other authors, while not adopting a position of cultural relativism, have argued that ethics must be informed by culture and that researchers must reflect on conflicting ethical standards (Christakis, 1988; Lipson, 1994).

The adherence to universal ethical principles is necessary, but not sufficient, for research involving humans (Bauman, 1993; Carson, 1996; Kleinman, 1995). The application of universal ethical standards does not acknowledge the ethical implications arising from both the unique nature of the relationships and the unique context of each research setting. Carson (Carson, 1996) agues that ethical discourse must be opened up to acknowledge the obligations to one another that are intrinsic to collaborative research work. Research and researchers must be informed and guided by an understanding of the institutional context of ethical decision-making that may differ cross-culturally (Kleinman, 1995).

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[1] Although Kleinman (Kleinman, 1995) uses the terms 'cultural relativism' and 'cultural universalism' in his analysis of ethical perspectives, their meanings are similar to the terms 'ethical relativism' and 'ethical universalism' used by other authors.

International research involving human beings must meet two related, but culturally distinct, ethical tests. The research must meet international ethical standards for the protection of human subjects. Secondly, international research must meet ethical standards relevant in the institutional setting and cultural environment where the research takes place. Researchers in international settings are obligated to exercise ethically sound decision-making to ensure that both tests are met. I advocate a position of ethical universalism as recommended by WHO and CIOMS (Council for the International Organizations of Medical Science (CIOMS), 1993) that, at the same time, acknowledges the importance of being knowledgeable about local cultural traditions and discussing contentious ethical issues. The ethical principles raised in this discussion have guided the decision-making process in the current study, from the identification of the problem to the dissemination of the findings.

Designing the Methodological Framework

Defining the Problem

The research project was carried out in Ghana, a West African county on the Gulf of Guinea. Although Ghana has not experienced the high HIV sero-prevalence rates seen in East and Central Africa, there has been a steady increase in the number of individuals with HIV disease in the past 12 years (Disease Control Unit, 1999). The recent epidemiology of HIV disease in Ghana indicates that more new cases are occurring in women and that women are infected at a younger age than their male counterparts (Disease Control Unit, 1999). A variety of complex and frequently interrelated factors influence women's vulnerability to HIV infection and their ability to adopt behaviours that will reduce their risk of infection. Ghanaian women constitute a population with increased vulnerability to infection with the virus due to structural factors including limited educational opportunities, poverty and unequal power relationships with men (Jackson, 1998; Kitts & Roberts, 1996; Mill, 2000; World Health Organization, 1994).

The current study was designed to explore the cultural, social, economic and political factors that influenced Ghanaian women's vulnerability to HIV disease and mediated their ability to protect themselves from infection. In addition, the explanatory model[2] of HIV illness from the perspective of HIV sero-positive women and men was examined. The following research questions were addressed in the study:

1. What is the life experience of Ghanaian women who are HIV positive?
2. What are the lay and professional explanatory models of HIV illness in Ghana?
3. What methods do Ghanaian women use to cope with their illness?
4. What strategies do Ghanaian men, women and nurses feel would be effective for HIV prevention in Ghana?

Participatory action research (PAR) was the methodology selected for the study Although the ideal in PAR is for the impetus and leadership for the research to come from a group or community experiencing oppression or injustice, the reality more commonly is that the impetus comes from an agency or academia (Dickson, 1995). Similarly, Reason (1994) discusses the different positions taken toward leadership in PAR and suggests that there is a "...tension between the ideal – and the rhetoric – of participation and the practical demands for effective leadership". (p. 335). The profound stigma that accompanies HIV disease in Ghana, and the secrecy that surrounds the

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[2] An explanatory model of illness includes information about the etiology, pathophysiology, symptomology, course of illness and methods of treatment for an illness (Kleinman, 1978; Kleinman, 1980).

diagnosis (Mill, 2000), makes it extremely difficult for HIV sero-positive women to come together to articulate their common concerns. During a feasibility trip to Ghana in May 1998, I observed several examples of individuals and support groups publicly tackling the issues surrounding HIV disease. These initiatives were limited and were undertaken very cautiously. Within this social milieu, I elected to take a leadership role in the design and implementation of the research project.

Aligning the Methodology with the Problem

Participatory action research was selected as the methodological framework for the study for several reasons. As a methodology, PAR provides a flexible, socially and culturally adaptable framework to guide the research process. PAR is appropriate to explore and challenge power imbalances in gender and economic status that, in turn, impact health (Schoepf, 1994; Seng, 1998). The ability to adapt methods for use in a range of settings, to explore local knowledge and to enhance the quality of the research by including the insights of local individuals are particular strengths of participatory methodologies such as PAR (Cornwall & Jewkes, 1995). Another advantage of PAR in the area of HIV prevention relates to its potential to support and sustain behaviour change at the individual level and attitudinal change at the community level (Stevens & Hall, 1998). Finally, PAR facilitates critical thinking, encourages individuals and communities to explore the root causes of their situations (Schoepf, 1994) and helps to ensure research relevance (Lindsey & Stajduhar, 1998).

The methodology of PAR is informed by the ontology and epistemology of critical theory (Morrow & Brown, 1994). One of the fundamental starting points of PAR is a concern with power and powerlessness. Based on this concern, adherents to this methodology advocate the need to expose and challenge those individuals and institutions within society who maintain positions of power through the control of knowledge (Rahman, 1991). A second pre-supposition of PAR is the valuing of the experience and popular knowledge of people (Fals-Borda, 1991). Related to this principle of PAR is a goal of knowledge production that is useful to a particular group and, at the same time, results in their empowerment (Reason, 1994). Collaboration is a third key element of PAR that is fostered through dialogue and occurs when "...the academic knowledge of formally educated people works in a dialectical tension with the popular knowledge of the people to produce a more profound understanding of the situation" (Reason, 1994, p. 328).

Fostering Collaboration

Participatory action research emphasizes the process of collaboration and the formation of partnerships with the participants in the research. The relationship between the researcher and participants is predicated on respect (Connors, 1988; Cornwall & Jewkes, 1995) and moves away from a position of objectivity in traditional science to assume a more subjective stance (Fals-Borda, 1991). This shift in relationship leads to findings that are value-mediated rather than value-neutral (Connors, 1988; Wilson, 1992). Our own values and beliefs influence "...what we choose to observe, what we consider to be data and what we write about..."(Wilson, 1992, p.181). Although, theoretically, participatory methodologies seek to achieve a collegial relationship between the researcher and the local people, in practice, this level of collaboration is seldom achieved (Cornwall & Jewkes, 1995). The concept of collaborative relationships within PAR also extends to the production and ownership of the knowledge that is generated. Researchers using this methodology are obligated to ensure that knowledge is owned by the community specifically, and the public ultimately, rather than academia (Fals-Borda, 1991).

The collaborative process was initiated during the one-month feasibility trip to Ghana. The purpose of this trip was to develop an understanding of the context of HIV illness in Ghana, and to ensure that the research was relevant and feasible and that the methods and methodology were appropriate to answer the research questions. During the feasibility trip I met with key people in the National AIDS Control Program, the Ministry of Health and the University of Ghana, as well as with HIV sero- positive individuals. Dr. John Anarfi, a senior research fellow with the Institute for Statistical, Social, and Economic Research (ISSER) at the University of Ghana, and an experienced researcher in HIV epidemiology and illness, agreed to act as an external consultant to my dissertation committee for the duration of the field research. Although a feasibility trip may not always be possible, I believe that it was a key factor in the successful implementation of the study. The research proposal was completed based on the information gathered during the feasibility trip and ethical approval for the study was obtained from the University of Alberta. Data collection, from January to May 1999, marked the second phase of the research project. The meetings that had taken place, and the collaborative relationships that had developed during the feasibility trip, were instrumental to the completion of the data collection and analysis in 1999 and 2000.

Community participation is linked with collaboration and is a cornerstone of research methodologies that are ‘participatory’. Several models of participation have been described in the literature. Although the degree of participation is variable in the different models, Kirkpatrick (1990) argues that true participation implies that people are involved throughout the process of decision-making. The benefits of the participation of the 'researched' in the research process are well documented (Fals-Borda, 1991; Lindsey & Stajduhar, 1998; Reason, 1994); however, several authors raise issues in relation to the concept of participation and the likelihood of it occurring. Stone (1992) cautions that the concept of participation "...is an external idea rooted in particular values" (p. 415) and that it may be of greater importance for the outsider than the local person. Participation in research may be a low priority for individuals caught in a daily struggle to meet their basic needs (Cornwall & Jewkes, 1995). Woelk (1992) argues that "community participation is in grave jeopardy" (p. 423) due to the financial crisis that exists in many developing countries and the decreased spending on programs that foster participation.

Participation of HIV sero-positive individuals and professionals working with these individuals was encouraged whenever possible during the research. The following scenario provides an example of participation and highlights the researcher's efforts to take advantage of opportunities to establish networks with the community. During my first trip to Ghana in May 1998, I was invited to participate in the inaugural meeting of a National Support group for HIV sero-positive individuals. Kwame is a pseudonym for one of the participants whom I met at the meeting and is one of two HIV sero-positive individuals from the meeting who participated in the research. Kwame gave me his name and address in order to contact him when I returned in 1999 to collect data. I did not need to contact him, however, as our paths crossed again by chance. During my second trip to Ghana in January 1999, I met Kwame in the HIV outpatient clinic of the hospital where we were interviewing women. He was very interested in participating in the research. I told him that I wanted to interview several HIV sero-positive men in a focus group and he offered to organize this for me. Kwame said that he knew several HIV sero-positive men through his work with AIDS support groups. He followed through with his commitment. After several conversations on subsequent visits to the outpatient clinic, Kwame had arranged for five HIV sero-positive men to meet with me and a research assistant at a mutually agreed upon time to discuss their HIV illness.

Choosing Methods

Participatory action research provides a methodological framework and philosophy to guide the research process, but does not prescribe the methods that must be used (Seng, 1998). Qualitative approaches, including open-ended interviews and focus groups, were the data collection methods chosen for the study. Thirty-one HIV sero-positive women were interviewed to explore their experience with HIV illness. Dr. Anarfi suggested interviewing men to reflect on the women's comments and to elicit their perspectives on HIV prevention in Ghana. Five HIV sero-positive men were interviewed: one was interviewed individually and four participated in a focus group. Focus groups were carried out with eight nurses and individual interviews were conducted with 10 professionals, including physicians, traditional healers, HIV counsellors and nurses who worked in HIV prevention, treatment, policy development, education and research. The inclusion of the broad range of participants, in addition to the HIV sero-positive women, added context to the stories shared by the women. Wilson (1992) maintains that ethical research allows the reader to hear as many voices of those who participate as possible. The reflections of the key professionals provided insights that were important to the interpretation of the data and the dissemination of the findings. The findings related to the study are described elsewhere in several papers (Mill, 2000).

Two male research assistants, with extensive experience in the conduct of HIV research in Ghana, were hired to assist with recruitment and interviewing. It was recommended that male interviewers be used because Ghanaian women were perceived to be more ‘gossipy’ and less likely to maintain confidentiality (personal communication, Dr. Anarfi, May, 1998). Dr. Anarfi, himself male, made this recommendation based on extensive research experience in Ghana with sensitive topics, including sexuality and HIV illness, and with men and women. One of the research assistants spoke English, Twi, and Krobo, while the second assistant spoke English, Twi and Ga. All of the interviews with the HIV sero-positive women, with one exception, and the focus group with HIV sero-positive men were carried out in one of the local languages. The remaining interview and the nurses’ focus group were conducted in English. The recruitment of HIV sero-positive participants took place in the outpatient clinics of a large teaching hospital in the capital city Accra and two smaller hospitals in Agomanya, a town 100 km northeast of Accra. The HIV counsellor at each study site provided initial information to potential participants. A research assistant then spoke with the participant to determine the language that in which she preferred to be interviewed and to obtain oral, taped consent. The interviews took place in a private room in the hospital and ranged in length from 30 minutes to one hour and 15 minutes. Guiding questions were prepared (see Appendix 1) to assist each interviewer to explore the area of HIV illness with the women and to ensure that there was some consistency in the questions asked. I was present for all of the interviews. This allowed me to observe the non-verbal communication of the participants and to provide input about the interview when requested by the research assistant.

The research assistants conducted practice interviews with each other before conducting our first interviews with HIV sero-positive women. These practice interviews were followed by self-critique and suggestions from me about strategies to elicit the women's stories. In the initial two or three interviews, the research assistants focused primarily on asking each of the guiding questions. As a result, their first few interviews were superficial and followed a 'question and answer' format. We met with Dr. Anarfi, who had reviewed the transcripts of the interviews, and discussed approaches to encourage the women to 'tell their story'. Although the research assistants were experienced in qualitative research methodology, they required gentle coaching and practice before they felt comfortable conducting open-ended, unstructured interviews. The strategy that seemed to work best was to have the research assistant conduct the interview, without referring to the guiding questions. When the assistant felt that he had explored all of the relevant areas with the participant, he would stop the tape-recorder and provide the researcher with a brief summary of the women's story. This dialogue often resulted in me suggesting areas to probe in greater depth and triggered the research assistant to think of additional topics to explore with the participant. This type of interaction also took place after each interview had been transcribed and provides an example of my effort to encourage collaboration with the research assistants and Dr. Anarfi, while at the same time assuming a leadership role in the research.

Focus groups were chosen to complement the interviews because of their potential to provide a deeper understanding of the social context of HIV illness and the likelihood that the comments made by some group members would stimulate the thoughts of others (Robinson, 1999). The nurses' focus group was drawn from nurses working in all of the nursing units in the teaching hospital where the interviews with HIV sero-positive women took place. Permission to recruit nurses for the focus group was obtained from the principal nursing officer of the hospital. She participated by informing the senior nursing officer of each nursing unit about the study and asking her to suggest one nurse as a participant in the focus group. The principal nursing officer worked with me to organize the date, place and participants for the two focus group meetings. I had planned to use both sessions for the nurses to comment on the emerging themes and to offer their perspective on HIV prevention. Early in the first focus group meeting, however, I realized that the nurses had many issues that they needed to discuss in relation to the care of HIV sero-positive patients. For example, they were very concerned about the lack of protective garments, such as gloves, gowns and masks, available for use when caring for their patients. I made the decision during the first focus group to allow the nurses to continue to express their concerns about their work environment, and to delay my agenda for our second meeting. The guiding questions (see Appendix 2) that had been prepared for the first focus group were revised based on this decision. My ability to be flexible and responsive to the needs of the nurses helped to establish their trust and rapport that, in turn, increased the nurses' openness during the second focus group.

Collaboration continued throughout the research project. I met regularly with Dr. Anarfi to review the data collection process and discuss the emerging themes from the interviews. He suggested culturally appropriate ways to explore sensitive topics, such as the women's history of prostitution. Similarly, meetings were held once or twice weekly with the two research assistants to review the transcribed interviews and discuss strategies for recruitment. These meetings were sometimes held formally at the University of Ghana, but more often, informally, in the back seat of a taxi on route to the study site. After interviewing 17 women, the research assistants commented that they were beginning to hear repetition in the women's stories and observed that most of the participants had known of their diagnosis for a fairly short period of time. As a result of this awareness, we recruited several women who had known of their diagnosis for longer periods of time. The knowledge and expertise of the research assistants was valued and their contributions went far beyond that of traditional research 'assistants'. The broadening of the role of research assistants to assume a more collaborative relationship with the researcher has been described in participatory research projects in other settings (Mill & Morris, In press; Stevens & Hall, 1998). The valuing of the research assistants as co-researchers was a principal factor in the successful recruitment of participants to the study.

At the completion of data collection, I interviewed each of the research assistants to obtain their comments about the research process. One of the areas that we reflected on was the potential impact of having me present during the interviews. They admitted that, in their experience, having a third person present during an interview could be a negative influence. They did not feel, however, that this posed a problem in the current study. Both of the research assistants observed that the participants felt very 'free' to discuss their life history because the researcher was an 'obruni' (person with white skin) and, therefore, would not understand their language. One of the assistants believed that the researcher's skin colour might have actually enhanced the interview process. He stated, "So your [researcher] presence to me was rather helpful. It made them [the women] open up. They looked at a white lady who had travelled all the way from Canada to conduct this research".

Analyzing the Data

The process of data analysis occurred simultaneously with data collection, using techniques described by Miles and Huberman (1994). The first level of analysis included coding of the transcribed interview data by assigning a label to a portion of the data to give it meaning (Miles & Huberman, 1994). An initial list of codes was prepared to detail the themes emerging from the data. The codes in the list were revised and renamed as necessary during analysis and grouped together into larger thematic areas. The NUD*IST qualitative software program was used to label, revise and retrieve codes during analysis. Memos were prepared within NUD*IST to record methodological decisions and analytical insights. During the process of data collection and analysis, several individuals and groups, including nurses, HIV sero-positive men, and professionals were asked to reflect on the data from the women's interviews and to comment on their meaning.

Facilitating Consciousness-raising

Consciousness-raising and change are two goals that are central to the purpose of PAR. Henderson (1995) suggests that consciousness-raising is the method through which change is achieved. Based on my experience in the current study, I would argue that the parameters of 'action' that are implicit to PAR must be broadly defined. Consciousness-raising is change and provides an example of 'action' that resulted from the study. Fals-Borda (1991) suggests that there are two types of "agents of change" that contribute different types of knowledge to the process of transformation that is sought: external and internal agents of change. I assumed the role of an external change agent by contributing academic knowledge to the process, whereas the HIV sero-positive participants assumed the role of internal change agents by contributing experiential, practical knowledge about the problem.

In the current study, two different types of consciousness-raising were evident. The first was an indirect, internal process that occurred as a result of participation in the research. I documented consciousness-raising in the research assistants, the nurses, the professionals and the HIV sero-positive participants who participated in the study. The researcher assistants felt that their participation in the study had increased their awareness of HIV disease in Ghana. Specifically they learned that the disease was not confined to particular risk groups. Similarly, the research assistants and the nurses increased their knowledge about the degree of risk associated with the vertical transmission of the virus from mother to child. I believe that during the focus group the nurses developed a deeper understanding of the experience of their patients with HIV disease and it is expected that this understanding will result in changes to the way HIV sero-positive patients receive care. Several of the professionals commented that they had become much more aware of the attitudes and beliefs toward HIV illness in Ghana as a result of their participation. The HIV sero-positive men and women felt that they had benefited emotionally from sharing their stories with the researchers. Further, and of equal importance, my participation as a researcher has had a profound impact on my own awareness of HIV illness in Ghana and has helped me to appreciate the challenges and opportunities inherent to international research.

A second, more deliberative type of consciousness-raising was also evident in the study and consisted of active efforts to facilitate awareness among Ghanaians. One example of this second approach occurred during a presentation to 40 health workers at the teaching hospital. I presented the key findings from the research and asked the audience to consider strategies to address the issues that had been raised in relation to HIV infection. One of the nurses commented that the findings indicated that poverty and the inability of parents to pay school fees seemed to be a major factor contributing to women's HIV infection. She suggested that, "parents should take family planning seriously and only have the number of children that they could afford". Her comment led to a discussion of the economic factors influencing HIV infection and the need, therefore, to influence politicians and policy makers to address poverty. One participant suggested that nurses become more involved in HIV prevention. This was followed by an in-depth discussion of strategies that nurses could use to become involved in activities in their communities. It was evident from the energy and enthusiasm that permeated this discussion that the presentation had raised consciousness and contributed to the sharing of ideas about HIV prevention in Ghana. Wilson (1992) stresses the importance of organizing meetings with individuals and communities at the completion of the field research to share findings and elicit comments. A summary report of the preliminary findings was provided to the officials in the Ministry of Health, the National AIDS Control Program and the study sites prior to leaving Ghana.

Promoting Ethical Research

The conduct of research in an international setting demands that the researcher consider how ethical principles, including autonomy, beneficence, non-maleficence, and social justice (Beauchamp & Childress, 1994; Brink & Wood, 1994) will be applied to the research. Several features of the current study demanded that its ethical implications receive particular scrutiny. The conduct of research in a setting where language, customs, beliefs and values may differ from those of the researcher has the potential to violate these ethical principles. Participants recruited to research projects in developing countries may be more vulnerable to coercion (Christakis, 1988), necessitating additional care to ensure that freedom of choice is maintained. Coercion may occur as a result of a power imbalance between the researcher and the participants. Research on the topic of HIV infection, and its prevention, requires the exploration of highly sensitive topics, including sexual behaviour, sexuality and traditional belief systems (Ringheim, 1995). Individuals with HIV disease in Ghana are highly vulnerable to stigmatization by their families and communities (Mill, 2000) and, therefore, are more likely to experience harm as a result of participating in research (Lipson, 1994). Informed consent may require special effort in communities with limited levels of formal education, high illiteracy rates, and cultural and language barriers (Gostin & Lazzarini, 1997). These features required that the utmost care be taken during the implementation of the study, including adequate measures to ensure the confidentiality of the participants.

Ensuring Informed Consent

The issues of particular relevance in relation to the principle of autonomy in the current study include informed consent, coercion and confidentiality. Obtaining informed consent was a particularly challenging aspect of the current study due to the differing perspectives about informed consent between researchers in Ghana and Canada. During the feasibility trip to Ghana, the researcher was informed by the Director of Health

Research for the Ministry of Health that written consent was not required from research participants recruited from health facilities in Ghana. It was assumed that any individuals who were patients in a health care institution could be recruited to the study provided that permission for the study was obtained from officials at the health institution, the University of Ghana, and the Ministry of Health. The implication was that the officials would decide who would participate in a research study, based on their approval of it.

Permission for the project was obtained from all of the necessary officials in Ghana. Although individual consent was not needed according to Ghanaian research protocol, the importance of individual informed consent for research relating to sexual behaviour (Ringheim, 1995) and for research in developing countries (Wilson, 1992) has been advocated. I decided, therefore, that it should be sought. Dr. Anarfi and the two research assistants were consulted regarding the best strategy to obtain consent. We agreed that the low literacy levels of many participants might preclude the possibility of obtaining written consent and, therefore, elected to proceed with oral tape-recorded consent from each participant. Following consultation with the research assistants, we decided to orally translate the consent form from English to the appropriate language at the time of the interview. Prior to commencing each interview, the research assistant read the consent (see Appendices 3 & 4) in the participant's language and answered questions about the study. The participants often asked for reassurance that they could not be identified as a result of their participation and that we were not filming the interview. The consent process was recorded on a tape that was separate from the interview in order to ensure that participants' names did not occur on the interview tape. Written informed consent was obtained from each of the nurses in the focus group and each of the professionals interviewed (see Appendices 5 & 6).

Avoiding Coercion

While observing the research assistants obtain consent from each participant, I felt a growing uneasiness that women may have felt obligated to participate based on their 'out-patient' status in the facilities where recruitment took place. Each week there was a steady flow of HIV sero-positive women 'willing' to be interviewed in the outpatient clinic and very few women (two) declined to participate. I had not anticipated that recruitment would proceed so smoothly! During the interviews at the conclusion of the study, in addition to soliciting feedback about the research process, I reviewed my uneasiness with each research assistant. We discussed the question of women's freedom to decline participation. One of the assistants thought that women felt free to participate in the study. The other research assistant, however, stated that he felt that the women were compelled to participate when asked by the HIV counsellor, who was also their nurse. He commented:

> ...We wouldn't have succeeded with this study without the nurses and then we are lucky, those nurses are the people they consult, for drugs or whatever. So anything that the nurses will tell them, they can never refuse. They feel it is part of their treatment...Yes, I feel they [the women] have no choice but to allow us to interview them because we are not even having the interviews outside the clinic block, but within the clinic block and I feel that they thought it was part of their treatment.

The research assistant did not see this scenario as a problem. He felt that it was the women's responsibility to participate in the study because their participation might provide insights that could help in the search for a cure for HIV disease.

The comments of the research assistant raise the possibility that coercion may have influenced some of the women's participation. Patients may feel pressured to participate in research when approached by their caregiver (Frisch et al., 1990). This situation poses a very difficult ethical dilemma in relation to the potential coercion of vulnerable research participants. As the researcher, I am concerned that women may have felt compelled to participate. The perspective offered by the research assistant, however, problematizes the issue of coercion and merits further dialogue. Questions that require further debate include who decides what constitutes coercion and when it has occurred?

The payment of participants for their participation (with the exception of expenses) represents another potential form of coercion (Cox, 1995; Ringheim, 1995). I discussed paying participants with several researchers at the University of Ghana and learned that, in Ghana, it was customary to offer research participants money. Despite this advice, and based on a Western sensitivity to coercion, each participant was offered a gift to thank them for participating. They were also given a small sum of money (equivalent to one Canadian dollar) to compensate them for their transportation expenses and to buy food after the interview. The women were very grateful for the gift but, upon reflection, I question the rationale for this decision. Most of the women struggled with debilitating poverty and may have realized greater benefit from additional money. Would the payment of participants in the current study have represented coercion or compassion? The context of the research must be carefully considered when making a decision regarding the payment of participants.

Maintaining Confidentiality

Maintaining the confidentiality of the participants was extremely important due to the sensitive nature of the topic. The research assistants were trained in the handling of sensitive data, the transcripts were coded to ensure that the participant's name did not appear on them and the audiotapes and the interview data were stored in a secure location to ensure that confidentiality was maintained. The research assistant's comment, related to the conduct of the interviews "within the clinic block", emphasized a tension between maintaining confidentiality and avoiding coercion. I discussed the optimal location for the interviews with Dr. Anarfi. The two possibilities were the outpatient departments of the hospitals participating in the research and the participants' homes. Dr. Anarfi believed that visits to a home by an 'obruni' would not go unnoticed and would arouse suspicion in the community. He suggested, and I concurred, that the interviews be carried out in a private room in the hospital. This strategy optimized the ability of each participant to keep their interview confidential from family members and their community. A negative repercussion of the decision, however, may have been that some women felt coerced to participate. Ethical principles, such as maintaining confidentiality and avoiding coercion, cannot be viewed as independent because their outcomes may overlap. Achieving a balance of ethical correctness in the application of ethical principles requires decision-making and ongoing reflection on the impact of these decisions.

Promoting Beneficence and Avoiding Non-maleficence

The decision to locate the interviews within the hospital setting also demonstrates consideration of the ethical principle of non-maleficence. This principle refers to the obligation of the researcher to do no harm or to cause no harm intentionally (Beauchamp

& Childress, 1994). By avoiding interviewing in the home, the researcher hoped to avoid exposing participants to social isolation if their participation in the study became publicly known. Researchers must ensure that their participants do not experience physical or emotional harm and are not subjected to adverse affects, such as social ostracism, from family members or their community as a result of their participation (Ringheim, 1995).

Beneficence refers to the principle of "doing good" and is used to assess the potential for the research to benefit individuals, communities or the public at large (Beauchamp & Childress, 1994). Although direct benefit was unlikely for each participant, it is possible that some participants found the opportunity to "tell their story" to be therapeutic. One of the research assistants commented that, "...psychologically I think they [the women] feel they have gained something out of the interview". Similarly, one of the HIV counsellors stated that although many individuals were reluctant to share their HIV sero-positive status with family members to avoid being stigmatized, they found it beneficial to talk to outsiders: "...they like to share their HIV positive status with people outside, like researchers...." The research 'process', including the human contact and the intellectual stimulation as a result of participation, is often the most beneficial aspect of field research (Wilson, 1992). Another potential benefit of the current research is that the findings will add to the knowledge concerning the issue of HIV illness in Ghanaian women and will be beneficial to communities for the planning of future HIV prevention programs.

Advancing Social Justice

The principle of justice refers to "...fair, equitable, and appropriate treatment in light of what is due or owed to persons" (Beauchamp & Childress, 1994, p. 327). Several of the factors integral to the HIV risk environment of Ghanaian women were embedded in the fabric of social justice. The interviews with the women revealed that many had experienced inequitable access to economic resources, marginalized educational opportunities and limited power in decision-making in relation to sexuality (Mill, 2000). Clearly, strategies designed to prevent HIV infection in this population must acknowledge this reality and attempt to challenge the inequities that dominate many aspects of women's lives. Participatory action research, with a focus on exposing and challenging oppressive structures (Rahman, 1991), offered the participants the opportunity to explore these inequities. The use of PAR has the potential to challenge the status quo and investigate effective strategies for the prevention of the HIV transmission in Ghanaian women, thereby advancing social justice.

In addition to fairness, the principle of social justice requires that knowledge generated from the study will be readily accessible in the public domain (Brink & Wood, 1994). This principle is congruent with the goal of PAR to ensure community and public ownership of knowledge. Following data collection, preliminary findings from the study were shared with two community groups in Ghana. I gave a presentation to GHANET, a network of individuals and organizations working on HIV prevention in Ghana. More than 30 members of GHANET participated in the presentation, including representatives from government, the research community, persons living with AIDS, and non-governmental organizations. A second presentation was given to approximately 40 health care workers from several departments in the teaching hospital. Copies of the final dissertation, or published articles based on it, will be forwarded to individuals and government departments in Ghana that were involved with the research project.

Achieving Rigor

Meleis (1996) identifies eight criteria to assess the rigor and credibility of culturally competent scholarship, including research with marginalized populations. These criteria are relevant to the assessment of rigor in the current research and include: contextuality, relevance, awareness of identity and power differentials, empowerment, time, disclosure, communication styles and reciprocation. The feasibility trip prior to beginning the study helped to ensure that the criteria of contextuality and relevance were met. During this trip, I developed an understanding of the broad context of HIV illness in Ghana and ensured that the proposed research was relevant to the population. The collaborative relationships that were established with the research assistants are one example of the researcher's attempt to acknowledge and mitigate the power differentials that existed in the research process. A power imbalance between the researcher and the participants was also recognized, but was more difficult to eliminate. The process of consciousness-raising, as a strategy for the empowerment of the research participants, has already been documented. A flexible approach to time (Meleis, 1996) was necessary throughout the research to enable the development of collaborative relationships based on trust and respect.

Disclosure

Disclosure of the authentic experiences of the participants is another criterion for the assessment of rigor (Meleis, 1996). The validity of the informants' comments may have, at times, been compromised by their inability or unwillingness to tell the truth. The research assistants believed that a few of the women did not completely "open up" during the interview and may not have accurately reported some of their history, such as the number of previous sexual partners. One research assistant recalled: "I think the majority I interviewed opened up and they told me everything but...there are some I suspect that they felt shy to tell me that they have sex with many men". Knowledge of the number of sexual partners of each woman, however, was not a critical aspect of the data.

Anthropologists have commented on the significance of 'lying informants' and stressed the importance of understanding the underlying reasons for lying (Bleek, 1987; Salamone, 1977). The reticence of some women to discuss their sexual history may be based on the negative association of HIV illness with prostitution in Ghana (Anarfi & Awusabo-Asare, 1993; Ankomah, 1998) or the reluctance of Ghanaians to discuss sexuality (Mill, 2000). Bleek (1987), during field research in Ghana, reported that some informants lied when asked intimate questions by a stranger or when they wanted to give socially desirable responses. The strong influence of Christianity in Ghana (Anane, 1999) may have resulted in women being more likely to report membership in a Christian faith and less likely to discuss the possibility of supernatural explanations and traditional treatments for their illness. Despite these potential limitations on the validity of the data, the richness of the women's narratives provide evidence of their trust in the researchers and their willingness to disclose many aspects of their life histories.

Understanding communication styles

The researcher's understanding of the communication styles of the participants also provides evidence of rigor in culturally competent scholarship (Meleis, 1996). Several challenges in relation to language were evident and may have impacted the quality of the interviews and the rigor of the current study. The ability to conduct effective interviews is predicated on the interviewer having an adequate understanding of the normative patterns of communication in the society where the research takes place (Briggs, 1986). Conduct of research in a country where the first language of most people, including the participants, was not English limited my understanding of communication patterns in Ghana. The use of research assistants to conduct and translate each interview, from a local language into English, decreased the auditability of the research. Although there is a paucity of information in the literature about the translation of data, one recent study reported that translation did not affect the themes that emerged during analysis (Twinn, 1997).

Language patterns in Ghana during informal discourse are commonly 'indirect' and 'obscure' and meanings are often expressed "...in proverbs, circumlocution, innuendoes, metaphors and euphemisms" (Obeng, 1994, p. 37). The tendency to use indirect language required me to ask the research assistants, and other Ghanaians, to explain the meaning of certain words or phrases. In addition, the use of metaphors in the local languages made the translation of the interviews from the local language to English challenging for the research assistants. I frequently queried portions of the interview transcripts to ensure that I understood their meaning. On two occasions I had one of each research assistant's transcribed interviews translated a second time to validate the accuracy of the translation. On the first occasion, early in the interview process, each research assistant acted as the second translator for the other assistant. An independent translator completed a second translation audit later in the interview process.

Encouraging Reciprocity

Reciprocity between the researcher and the participants is the final criterion for the assessment of culturally competent scholarship (Meleis, 1996). Reciprocity is implicit in PAR and both influences, and defines, the relationship between the researcher and participants. This relationship is based on respect and understanding and may, at times, involve the researcher sharing information with the participants. For example, when local knowledge has the potential to result in harmful consequences, "...there is an ethical obligation not only to share outsiders' knowledge, but to attempt to change local beliefs as in the case of local understandings of communicable diseases such as HIV" (Cornwall & Jewkes, 1995, p. 1674). In the current study, during the nurses' focus group, I was obligated to share current biomedical knowledge, and to correct professional misconceptions, about the risks of vertical transmission of HIV from mother to child. Reciprocity also includes the researcher's responsibility of self-disclosure in order to enhance collective understanding (Soltis-Jarrett, 1997). I agreed to share my perspective on gender relations in North America when asked by the nurses in the focus group.

The experience of doing fieldwork in a 'developing' country can be particularly unsettling because "...the researcher is obliged to come to terms with the realities of the relationship between scholarship and human experience" (Wilson, 1992, p. 179). This relationship is particularly challenging when there is a significant gap between the privileged position of the researcher and the economically disadvantaged position of the participants (Bleek, 1979). The following case study presents one such experience in reciprocity. Kwame was the organizer of the focus group with HIV sero-positive men mentioned earlier in the paper. At the time of the focus group, he was an in-patient at the teaching hospital where the focus group was held, but insisted on participating in the focus group. One week after the group, during a subsequent visit to the hospital, the research team was informed that Kwame's condition had deteriorated and was very grave. The following comments are excerpts from my field notes, following a hospital visit with Kwame:

> Accompanied by my two research assistants, I entered Kwame's hospital room. I experienced an overwhelming feeling of sadness when I saw Kwame lying on a mat on the floor. He was restless, confused and appeared to be in pain. I knelt down, took his hand to let him know I was there, and told him that we were thinking about him. I left his room, unsure of how to help Kwame, but knowing that I needed to find a way. During the visit I felt that I had come face to face with the grim reality of HIV disease in Ghana. I felt myself slipping from my safe position at the intellectual level of HIV illness, to the emotional, and less secure, level. HIV disease took on a very real and ugly face for me in those few minutes in Kwame's room. A few days later, I attended a meeting of professionals working in the area of HIV prevention. I was relieved when one of the participants initiated a collection to help provide for Kwame's continued care and treatment.

This experience brought into sharp focus the devastating reality of HIV disease and had a strong emotional impact on my personal consciousness of the enormity of HIV illness in Ghana.

In addition to presenting the voices of the participants as accurately as possible, an 'ethical' researcher is obligated to become engaged in political debate and critique of the society studied (Wilson, 1992). The position of the researcher in PAR is inherently political because of the focus on disrupting the status quo (Smith et al., 1993) and empowering marginalized groups to overcome inequities in their lives (Cornwall & Jewkes, 1995). Bond (1997), based on her HIV prevention work in Zambia, argues that politics permeates the research process from data collection to the write up of findings. The researcher must consider the risks and benefits of becoming involved in political debate, however, because there may be considerable risk involved in challenging the dominant way of thinking (Smith et al., 1993). Prior to leaving Canada, I had planned to assume an active role in exposing the structural factors influencing HIV infection in

Ghanaian women. Once engaged in the research in Ghana, however, I made a conscious decision to maintain a low profile in regard to the politics of HIV infection in Ghana. I had a very strong sense that voicing my observations about the issues could be harmful because of my inadequate cultural knowledge. Taking a position that was inaccurate would compromise the relationships that I had developed and jeopardize my role in 'consciousness-raising'.

The reflective aspect of PAR helped to enhance the rigor of the study by allowing participants to comment on the data, thereby confirming the researcher's interpretation (Seng, 1998; Wilson, 1992). For example, in the current study, both the nurses' and the male focus groups confirmed many of the themes that emerged during the women's interviews. They confirmed that HIV illness was highly stigmatized in Ghana; that HIV disease was associated with travel and with prostitution; that condoms were unacceptable within marriage; and that women had very little control over measures to reduce their risk of HIV infection. The presentations that were made to the community groups at the completion of the study also enhanced the rigor of the research, by validating the experiences described by the study participants. I regularly discussed the findings with Dr. Anarfi and the research assistants, to ensure that the translated interviews had been accurately interpreted.

Evaluating the Process

In this paper, I have argued that a fundamental requirement for international research is the application of universal ethical principles. The adherence to universal principles, however, neither acknowledges nor negates the unique context of each research locale. Therefore, international research must also meet the ethical standards related to the institutional setting and the cultural environment where the research takes place. Researchers in international settings are obligated to exercise ethically sound decision-making that ensures that both sets of ethical standards are met. I have traced the decision-making that took place in my dissertation research in Ghana, from the definition of the problem to the dissemination of the data. At the same time, I have attempted to demonstrate that decisions were made in a manner that upheld universal ethical principles, while being sensitive to local ethical practices.

Participatory action research provided a flexible, socially and culturally adaptable methodological framework to enable me to apply the two related, but distinct, sets of ethical standards during the study and to guide the research process. Although I took a leadership role in the design and implementation of the project, I encouraged collaboration and the formation of partnerships with HIV sero-positive individuals and with professionals whenever feasible. The collaborative relationship that developed with the research assistants and with Dr. Anarfi was a key factor in the successful implementation of the study. In terms of the goal of consciousness-raising, two different types were evident during the research; an indirect, internal process that occurred in individuals as a result of their participation, and a more deliberative process to actively facilitate consciousness-raising among Ghanaians.

There were many times sitting at my computer, with sweat trickling down my back and ink dripping down the pages of my work, that I asked myself "Why"? There were other times during interviews with women, my head pounding with the heat and light headed from hunger, that I asked myself "Why?" Why had I travelled thousands of miles from my home to carry out sensitive research, under such challenging circumstances? As I pondered the answer, at times even considering giving up and returning home, I was always be pulled back by the stories of the women. I was dedicated and obligated to make their stories public.

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HIV Risk Environment for Ghanaian Women: Challenges to Prevention

Introduction

Prevention of infection with the human immunodeficiency virus (HIV) is a complex and challenging problem for health professionals worldwide. Despite progress in limiting the spread of HIV infection in certain regions of the world and in some sub-groups of the population, the epidemic continues its unrelenting spread in most parts of sub-Saharan Africa (World Health Organization, 1997) and is of increasing concern for women (World Health Organization, 1994; World Bank, 1997). HIV transmission in sub-Saharan Africa is primarily heterosexual and women represent more than half of the newly infected adults (Decosas & Pedneault, 1992; Kitts & Roberts, 1996). Several authors have argued that society must integrate a gender perspective into the analysis of HIV/AIDS because of the impact that gender inequality has on vulnerability to HIV infection (Kitts & Roberts, 1996; Schoepf, 1992; Wilton, 1997a). In addition, it is essential to consider the broad structural and cultural factors that influence women's vulnerability to illness (Long & Messersmith, 1998; Walters et al., 1999).

Ghana is experiencing high rates of HIV infection, with more new cases of HIV disease occurring in women than in men (Disease Control Unit, 1999). The first cases of HIV disease were reported in Ghana in 1986 and during the early years of the epidemic approximately 88% of the cases were female (Neequaye et al., 1986). Many of these women had been working as prostitutes in the neighbouring country of Ivory Coast and returned home after becoming ill. As of December 1998 there were 29,546 cases of HIV disease, representing a female/male ratio of 1.5/1, reported to the Disease Control Unit, Ghanaian Ministry of Health (Disease Control Unit, 1999). In Ghana it is estimated that

80% of the cases of HIV disease are transmitted heterosexually, 15% through vertical transmission and 5% through blood (UNAIDS, 1999). Ghanaian women have been identified as a group with increased vulnerability to infection with the HIV virus (Disease Control Unit, 1996).

Women's vulnerability may be influenced by factors such as gender, unequal power relationships and poverty. A study was undertaken in Ghana from January to May 1999 to examine the experience of HIV sero-positive women. The purpose of the research was to explore the broad context of disease transmission and to identify factors that mediated women's ability to protect themselves from infection. Two questions that guided the study were "What is the life experience of Ghanaian women who are HIV sero-positive?" and "What strategies do Ghanaian women feel would be effective for HIV prevention in Ghana?" This paper will describe and analyze the findings of the study relating to these questions.

Background

Political and Economic Environment

In order to understand HIV illness in Ghana, it is important to consider several political, economic and cultural factors that may influence health generally, and HIV infection specifically. The country, formerly known as the Gold Coast, was a colony of Great Britain for more than one hundred years, achieving independence to become Ghana in 1957 (Kisseih, 1968). Colonialism, through the depletion and exploitation of resources and the appropriation of land, has been identified as one of the root causes of increased poverty and poverty-related illnesses in the sub-Saharan countries such as Ghana (Aidoo, 1982; Kibirige, 1997). The prolonged period of colonial rule continued to impact the development and provision of health services in Ghana after independence. Anyinam (1989) argues that the colonial government built a weak foundation for the development of the health care system that resulted in regional disparities and medically focussed health services that persisted for three decades after independence.

A comprehensive health care system, providing access to medical, psychological and social care for patients with HIV illness, is the foundation for effective HIV prevention programs (Chièze, 1997). In 1985, the Ghanaian government shifted the primary responsibility for health care costs from the state to the individual. The introduction of user fees and charges for drugs has had a negative impact on the ability of poorer Ghanaians to access the health care system and has resulted in delays in seeking treatment and an increased reliance on alternative health care facilities (United Nations Development Programme, 1997). This major policy shift, coupled with a decrease in government health spending from 10% of total expenditure in 1989 to less than 5% in 1994 (United Nations Development Programme, 1997), has resulted in fewer Ghanaians having access to a health system barely able to maintain services.

External influences such as the debt crisis, and the structural adjustment programs imposed by the International Monetary Fund (IMF) to mitigate this crisis, have also impacted the health care system and the subsequent health status of Ghanaians in the post-independence period. In Ghana, external debt more than tripled between 1984 and 1994, to 4.6 billion dollars US (Kibirige, 1997) and is currently estimated to be 5.9 billion dollars US (World Bank, 1999). This has resulted in a rapid increase in the percentage of the GNP required for debt servicing, from 6% in 1970 to 23% in 1994 (Kibirige, 1997). Anyinam (1989) argues that although structural adjustment programs have resulted in improvements in several areas of the Ghanaian economy, these gains are not reflected in improved socioeconomic conditions and health status of individuals, especially among the most vulnerable. Continued high rates of maternal and infant mortality and communicable diseases as well as a low life expectancy reflect the compromised health status of Ghanaians (Anyinam, 1989).

The Human Poverty Index (HPI-1)[1] in Ghana is 36.1 % indicating that more than one-third of Ghanaians live in poverty (United Nations Development Programme, 1999). The correlation between poverty and the spread of the HIV virus is well documented (Archibald, 1997; Kitts & Roberts, 1996; Wilton, 1997; World Bank, 1997) and has been identified as a factor increasing Ghanaian women's vulnerability to HIV infection (Awusabo-Asare & Anarfi, 1997a; Awusabo-Asare et al., 1993). The World Health Organization maintains "poverty is at once the line of least resistance, and one of the most powerful driving forces behind the spread of AIDS" (World Health Organization, 1994, p. 49). Although reasons for the relationship between poverty and HIV infection are complex, it has been suggested that poverty may decrease women's exposure to health education opportunities, lead to inadequate nutrition, and increase their susceptibility to disease (Kitts & Roberts, 1996). Poverty, with its accompanying inadequate resources for survival, has been cited as a predisposing factor to prostitution (DeCock et al., 1994; World Health Organization, 1994), that is itself a strong risk factor for HIV infection in African women (DeCock et al., 1994).

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[1] The HPI-1 is a poverty index for developing countries and is determined by three indicators: longevity, adult literacy rates, and standard of living (United Nations Development Programme, 1999).

Patterns of labour migration in many countries in sub-Saharan Africa may also contribute to increased HIV infection. Migration involves men, and to a lesser extent women, moving away from their usual place of residence for employment and results in long periods of separation within the family unit. The economic crisis in Ghana, in combination with the differential economic development among West African countries, is a fundamental force driving migration (Anarfi, 1993). The social disruption and changing rules for extramarital sexual relationships that occur in conjunction with migration result in increased vulnerability to HIV infection, particularly for women (Anarfi, 1993; Anarfi et al., 1997; Decosas et al., 1995; Mbizo & Bassett, 1996). Labour migration is often accompanied by an increase in the use of commercial sex partners by men separated from their wives and may contribute to increased prevalence of HIV infection in women (Decosas & Pedneault, 1992; Ulin, 1992). Itinerant women traders, due to their mobility, have been identified as highly vulnerable to HIV infection in Ghana (Anarfi et al., 1997).

Cultural Traditions

Cultural beliefs and practices relating to fertility, sexuality and the 'female' role may present significant barriers to the adoption of HIV prevention strategies by women. In most sub-Saharan countries, a woman's social status is directly linked to her ability to produce children (Ankomah, 1998; Caldwell et al., 1992; DeBruyn, 1992; World Health Organization, 1994). The Akan tribe of southern Ghana believes that "...children constitute the meaning of a woman's life. In the Akan view, a woman without children is incomplete, useless..." (Bleek, 1987, p. 143). In married couples, the responsibility for infertility is viewed as the female partner's problem and barren women are frequently subjected to ridicule by the community (Amoah, 1991). The high value placed on fertility may also impact decision-making by HIV sero-positive women during pregnancy. An HIV infected woman may decide to proceed with her pregnancy, knowing the risk of transmission to her baby, in order to fulfill a societal expectation to bear children. The promotion of condoms to prevent the spread of sexually transmitted diseases such as HIV and, coincidentally, pregnancy may be perceived as being in direct opposition to a powerful social norm.

Attitudes and practices relating to sexuality in sub-Saharan Africa may also influence women's vulnerability to HIV infection. Polygyny is a common feature of many African societies, particularly in West Africa, that may impact women's ability to protect themselves from HIV infection (Caldwell et al., 1992; Caldwell et al., 1989). In Ghana, pre-marital sexual relationships are acceptable for men and in some instances for women, and extra-marital relationships are socially sanctioned and common for men (Anarfi, 1990; Anarfi & Awusabo-Asare, 1993). Neequaye et al (1991) found that 55% of married men, in comparison to 9% of married women, had extramarital relationships. Postpartum sexual abstinence is a custom in many areas of Africa that may predispose women to HIV infection. Awusabo-Asare and Anarfi (1997b) reported that the average period of post-partum sexual abstinence was 13.8 months and varied depending on the respondent's tribal affiliation and place of residence. Although there is limited research to explore the causal link between postpartum sexual abstinence and increased extra-marital relationships, there is evidence that men often seek partners outside the marriage when their wives are not available (Anarfi, 1990; Awusabo-Asare & Anarfi, 1997b; Bleek, 1987). These cultural practices, in combination, may render monogamy unrealistic as an HIV prevention strategy for many Ghanaian women.

Gender is an important variable in determining the health and well being of women because of the unequal relations of power and the increased rates of poverty that often accompany the 'female' role (Long & Messersmith, 1998; Wilton, 1997). In a position of lower status and power than their male partners, women may be unable to negotiate safer sexual practices, such as the use of condoms (Aggleton, 1997; Campbell, 1997; Mbizo & Bassett, 1996; Ulin, 1992). The World Health Organization has suggested that women's powerlessness provides one of "the most intractable barriers to the control of AIDS" (World Health Organization, 1994, p. 56). One researcher in Ghana concluded that "men's influence over their wives' contraceptive attitude seems to operate both through comparative advantage in mate selection and through cultural norms that subjugate women to men" (Ezeh, 1993, p.173). Ghanaian women's increasing economic dependence on men in the post-colonial period has decreased their ability to influence decisions about sexuality (Awusabo-Asare et al., 1993).

Women's unequal status in many countries in sub-Saharan Africa may also result in decreased access to education. Lack of educational opportunities, in combination with a marginalized economic position, increase women's vulnerability to HIV infection via several mechanisms (Aggleton, 1996; Campbell, 1997; DeBruyn, 1992). Some women feel pressured into partnerships at an early age in exchange for school fees (Decosas & Pedneault, 1992; Dinan, 1983; Ulin, 1992) or feel totally dependent on their partners for economic survival (Campbell, 1997). In Ghana, girls are less likely than boys to attend school and more likely to be withdrawn by parents facing financial difficulties (United

Nations Development Programme, 1997). Educational opportunities for girls are influenced by several factors including cultural bias, economic stress, pregnancy and the scarcity of labour (United Nations Development Programme, 1997). Ghanaian researchers demonstrated that education was positively correlated with the delayed onset of child bearing and that adolescents with no education were more likely to begin child bearing early (Nabila & Fayorsey, 1996).

The formation of sexual partnerships between older men and younger women is a feature of the demography of HIV disease in Africa that has profound implications for women's vulnerability to infection. This age differential is viewed favourably by men who hope that younger women will be less likely to be infected with the AIDS virus (Campbell & Kelly, 1995; Jackson, 1998; Obbo, 1993; Ulin, 1992). Therefore, in exercising their disproportionate power to choose partners, men's attempts to minimize risk of infection for themselves results in a concomitant increase in women's risk of infection. In Ghana, women’s low socioeconomic status also increases their likelihood of marrying early and to an older man (Anarfi & Awusabo-Asare, 1993). The formation of sexual partnerships between older men and younger women has shifted the epidemiology of HIV illness. This phenomenon has resulted in a peak in HIV prevalence at an earlier age for women and a differential morbidity rate for women (Decosas & Pedneault, 1992). The peak prevalence for HIV disease in Ghana is 25-29 years for women, as compared to 35-39 years for men (Disease Control Unit, 1999), indicating that females become infected with the virus earlier than their male counterparts.

The preceding review highlights the complexity of the issues surrounding HIV infection in Ghanaian women and the broad factors that must be considered in the design of prevention programs. The legacy of colonial rule in Ghana, in combination with the current debt crisis, has impacted the development of health services in the country and the health status of Ghanaians. Cultural beliefs, including the high value placed on fertility and the social sanctioning of extra-marital relationships for males, present significant barriers to the adoption of HIV prevention strategies by women. Gender issues, such as unequal relations of power and access to educational opportunities, may also influence women's vulnerability to HIV infection. This paper explores the life experiences of HIV sero-positive Ghanaian women and documents the participants' reflections on HIV prevention in Ghana.

Design and Methods

Participatory action research (PAR), based on the philosophical presuppositions of critical theory, was the methodology used for this study. This methodology emphasizes collaboration with the partners in the research and 'consciousness raising' of all participants involved in the research process (Rahman, 1991). The research was conducted in two stages. In May 1998 the researcher made a month long exploratory trip to Ghana to consult with key people involved in HIV prevention and care in order to ensure that the research was relevant and feasible. Data collection, using in-depth interviews and focus groups, took place from January to May 1999 and was facilitated by the partnerships that had been developed during the exploratory trip.

The HIV sero-positive women were recruited from among all patients seen in the HIV out-patient clinics of the Fever's Unit of a large, urban teaching hospital in Accra and two smaller hospitals in Agomanya. Agomanya is a town approximately100 km northeast of Accra that serves a primarily rural population. Inclusion criteria for the study included: agreement to participate; over the age of 18 years; HIV sero-positive; and, willing to be interviewed through an interpreter. Twenty-seven women from the Fever's Unit and 4 women from Agomanya were recruited using non-probability convenience sampling. The demographic information about the sample is summarized in Table 1. It is interesting that only 20% of the sample were married. The most recent demographic survey indicated that 70% of Ghanaian women between 19 and 49 were married (Ghana Statistical Service, 1995). In addition, the average number of children of the participants was 1.4 and 13 of the women had never had a child. Although some women may not have completed their childbearing at the time of the interview, this average is very low in comparison to the total fertility rate in Ghana of 5.5 children per woman (Ghana Statistical Service, 1995). In Ghana it is desirable and acceptable for a woman to prove her fertility before marriage negotiation is concluded (Ankomah, 1998) and, therefore, childless women are less likely to be married.

Nurses, traditional healers, other professionals and HIV sero-positive men were interviewed to reflect on the women's comments and the themes emerging from the data. Their comments have been included with those of the women. Five HIV positive men participated in the study: one was interviewed individually and four participated in a focus group. A focus group of eight nurses, working on a variety of units in the teaching hospital, met twice. Two traditional healers and 10 professionals, including HIV counsellors, physicians, research assistants and nurse educators, were also interviewed. HIV counsellors are professionals, such as social workers and nurses, who have received additional training in counselling HIV-infected clients.

The inclusion of a range of participants in the research, in addition to the HIV sero-positive women, was important for several reasons. The additional perspectives of these participants provided context to the narratives shared by the women. In addition, it is anticipated that consciousness-raising occurred during the interviews with traditional healers, professionals and HIV sero-positive women and the focus groups with nurses and HIV sero-positive men. Finally, it was strategic to request key professionals working in HIV prevention, treatment, policy development, education and research to reflect on the research findings and their implications for policy development in Ghana. Their reflections provided insights that were integral to the interpretation of data and to the dissemination of findings.

Two experienced, male research assistants were hired to assist with the recruitment and interviewing of participants, and with the translation and transcribing of interviews. Thirty of the interviews with the HIV sero-positive women, the interviews with traditional healers, and the male focus group were conducted in a local language (Twi, Ga, Ewe or Krobo). All other interviews were conducted in English. At each study site, the HIV counsellor described the study to potential female participants and asked if they would be willing to talk to the researcher. In a private room, the research assistant explained the study to the women and provided an opportunity for questions. Oral, informed consent was obtained from each HIV sero-positive participant and tape recorded on a separate tape. The interviews ranged in length from 30 minutes to one hour and 15 minutes. Following each interview, participants were given a gift and a small sum of money to compensate them for their time and inconvenience. Written informed consent was obtained from the nurses and each professional.

Analysis of the data was initiated early in the interview process and continued throughout data collection. Following translation, each interview was entered into the qualitative software program NUD.IST (Non-numerical Unstructured Data Indexing, Searching and Theorizing) to assist with the handling of data during analysis. The interviews were read and re-read to identify themes and sub-themes that emerged from the data. The names of the participants whose stories and opinions are shared in the following sections have been changed to provide anonymity.

Life Experiences

Often poor, sometimes destitute

Poverty was a pervasive theme during the formative years of most of the women and was influenced by a variety of complex, and often interrelated, factors. Many of the women in the study were from large families. The number of children in the participants' families of origin ranged from 2 to 13 with the average number of children being 5.6. Although this was not problematic for all of the women, some of the participants expressed the belief that the number of siblings in their family had impacted their family's financial status and subsequent ability to provide for them. Several of Anne's eight siblings attended school, however, she did not have the opportunity to pursue any formal education:

> My mother brought forth many of us. Those who were attending school among us were many. They were seven so my mother and father said they could not afford to send all of us to school.

Kelly had also experienced the consequences of too few resources for too many children. While being cared for by her aunt, Kelly had dropped out of school at middle form three because her aunt could not care for all of the children living with her.

Many of the women lived in families where one or both of the parents were absent due to divorce or death. Almost half of the participants (14 women) stated that their father was deceased and 3 women had lost both parents. Many of these women had lost their parent(s) when they were still very young. A consistent theme emerged that demonstrated the tenuous economic status of Ghanaian families and the devastating effects of losing a parent on the already limited family resources. Parents' divorce or death, alone or in combination, seemed to reduce the women's likelihood of attending school and pursuing vocational education. In the following passage, Hope shares her feelings about the impact of her mother's death:

> Without your mother, everything of yours spoils...My grandmother was finding it difficult to support us in school and we ourselves had to fight for our food. There were my younger brothers and sisters to think of and I had to trade and give some money to my grandmother and that's why I had to stop school.

Brenda's father died when she was a young child and, without financial support from extended family, she did not have the opportunity to attend school. Brenda recalled:

> When my father died, we were very young and as such, my mother couldn't send any of us to school...Those days are not like now. People were only caring for their own children. And so they did not look after my father's children.

Ten of the women's parents divorced during their childhood years. Several of the women expressed the belief that their inability to continue school was influenced by their parents' divorce and subsequent financial problems. Cynthia left school in form three after her parents divorced and her father refused to continue supporting her.

Child fostering is practiced in Ghana when families who are unable to cope with their child care responsibilities send their children to be cared for by extended family members or, occasionally, friends (Ardayfio-Schandorf & Amissah, 1996). More than half of the women in the study were fostered during their childhood. Several of the women had negative memories of fostering and recalled quarreling with, or being maltreated by, their foster families. Participants were sent to live with extended family members for several reasons. Relatives who did not have a daughter often needed help with household chores, caring for younger children or generating income. Many of the women who were fostered were not sent to school. Martha recalled, "...because I was helping my uncle's wife to sell, I couldn't continue school". Amanda's father, finding it increasingly difficult to care for his daughter, sent her to work as a house girl for a friend in Lagos, Nigeria. After arriving in Lagos, Amanda was shocked to learn the real reason for being sent to live with the family friend:

> Over there, as a matter of fact, before God, it wasn't a house girl that she wanted me to be. It turned out that I was to be a "tena edan ano" (prostitute)[2].

The women in the study attended school for 6.3 years, on average. Eight of the women had never been to school and only one woman completed high school. After leaving school, five of the women received vocational training to learn trades such as hairdressing and sewing. Although a few of the women stated that they chose not to continue their education, many of the participants cited economic reasons for leaving school. Faith was forced to drop out of middle school because neither of her parents could pay her school fees. In the following passage, she recalls her family's situation:

> My father had a heart problem and because he was sick he could not work to enable him to pay my fees and my mother also was not in any gainful employment.

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[2] Prostitution takes different forms in West Africa, including Ghana. One of the most common forms in Ghana involves women acquiring rooms with doors opening to the outside. They sit in front of these rooms to receive clients. The meaning of "tena edan ano" is to "sit in front of a room".

Several of the women stated that they left school in order to help support their family with activities such as trading. Gender was the primary reason that Catherine was never sent to school by her parents: "In the north our parents sent the boys to school and asked us girls to help our mothers in household chores". Other women also recalled not being able to continue school for financial reasons, although resources were found for their brothers' school fees.

With limited education and few vocational skills, more than two thirds of the participants worked as traders prior to becoming ill. In Ghana, trading is an occupation that is particularly common among women who do not have professional or vocational skills. Trading involves buying food or household items at wholesale prices and selling these goods at a profit. The women working as traders sold, at the roadside or in the market, various items including iced water, cooked rice, second hand clothes, casava dough, yams and groundnuts. The remaining women worked in a variety of other activities; three women were seamstresses, two each were farmers and hairdressers, one woman worked as a fish smoker and one woman worked as a commercial sex worker.

Boyfriends for Money

Twenty of the women felt that their families had not been able to adequately provide for them during their childhood. They talked openly about the struggles that their families had endured to provide them with sufficient food, clothing and money for school uniforms. Although the women were able to generate some income prior to becoming ill, many stated that their income was insufficient to purchase food, clothing and shelter. They expressed the need, therefore, to take boyfriends to supplement their incomes to enable them to take care of themselves. Rene gives a very clear description of her reasons for taking a boyfriend:

> My father's relatives were not helping us. My mother too had no money...But my boyfriend was able to provide all that I needed. Anytime I bought food, I didn't buy fish but he always bought fish for me and he gave me money so that I was always free... That's why I took a boyfriend.

Some women stated that their boyfriends provided financial support to learn a vocation or trade, thereby helping them to become more financially stable. Faith, on the other hand, said that her boyfriend would not allow her to work as this might jeopardize her respect for him:

> My boyfriend told me that if I got work to do, that I would not respect him. And that we women, that is our character - when we get money, we don't respect men.

The male participants provided a different perspective on the need to take boyfriends. They suggested that women could be quite materialistic in their relationships with men and stated that a woman might leave for another man if he was not able to give her sufficient money for clothes!

Most women described their sexual relationships as monogamous, although the duration of the relationships described ranged from several weeks to many years. Despite many women taking boyfriends for financial reasons, they did not view themselves as prostitutes or 'basabasa' women. In Ghana, 'basabasa' refers to inappropriate or improper behaviour and when used in reference to sexual behaviour it means prostitution (Mill, 2000). Only one woman in the study had worked as a prostitute prior to her infection with the HIV virus. Faith's account of her struggle to support herself underlines the influence of economic realities on sexual relationships:

> When I sold ice water and deducted my transport from the profit, I realized I was left with nothing. So I realized selling ice water was not profitable. And so I was forced to pick another boyfriend.

The majority of the women recalled having two or three boyfriends during their lifetimes; however, several participants stated their first and only sexual partner was their husband.

We explored with the women whether their boyfriends or husbands had relationships or flirted with women other than themselves. Some of the women said that they could not tell if their partners had other girlfriends because they lived apart and were not aware of all of the man's activities. Amanda's partner kept his marriage a secret from her: "While we were together as friends, I did not know that he had a wife as he failed to disclose that to me". When she learned of this, they quarreled and she stopped seeing him. Some women, on the other hand, were aware that their husbands or boyfriends had a reputation for flirting and knew that they had another girlfriend, or wife, in addition to themselves. Gladys was asked what she could do if she knew her husband had girlfriends: "If he is a womanizer there is nothing one can do, unless he has the will to stop". Regardless of their level of awareness, the women appeared resigned to, although not supportive of, the infidelity of their husbands and boyfriends.

Pay Cash or Carry Death

Poverty was evident not only during the women's childhood, but also after they had acquired HIV infection. Twenty-eight of the women were experiencing symptoms such as coughing, weight loss and diarrhea at the time of their diagnosis. The symptoms ranged from mild to profound and forced many of the women to stop working because of gradually diminishing strength. All of the women expressed the desire to maintain their health by 'taking care of themselves' and eating sufficient food. Faced with debilitating poverty and a progressive illness, however, this was a formidable challenge for many of the women. After living with the virus for several years, Sarah's physical health was compromised and her survival involved the continuous balancing of scarce resources:

> Now when I walk I get tired and I don't get enough to eat. I have no money so if I eat in the morning I don't get food in the afternoon. In the evenings it [eating] is possible only when somebody gives me something small. It is for this reason that my body is not in good condition.

The nurses also spoke of the difficult economic circumstances that many patients with HIV illness faced. One nurse, who worked with HIV infected patients regularly, believed that dealing with the profound poverty of her patients was the most challenging aspect of her job:

> Yes with the patients we have problems with most of them, economic wise, social problems. Most of them complain about money - even money to come down to the clinic and to buy drugs. Even those on admission, sometimes we use our own money to buy them food or drugs if there is a need. Some of the relatives come and dump them and they never visit them.

A Ghanaian columnist (K.B. Asante, Daily Graphic, March 22, 1999) coined the phrase 'pay cash or carry death' in early 1999 to depict the rapidly escalating crisis in the health care system. In an era of user fees and rising charges for drugs, Ghanaians were often denied health services that they could not pay for in advance. Many of the HIV sero-positive women found it very difficult to acquire treatment, especially drugs, to control the symptoms of their illness. Money for drugs was a barrier to the women's treatment, regardless of whether they were outpatients or inpatients. Catherine was asked if she received drugs as an outpatient:

> No, they don't give you medicine, they only give you a prescription to go and buy it from town. Even when you are sick in bed, they can't get any medicine for you. You will be given a prescription to go and buy the medicine.

Karen recalled "at one stage I could manage only the lorry fare [to come to hospital], but I couldn't get money to buy drugs if they were prescribed for me". Her comments regarding the impact of poverty on health are extremely insightful:

> That's why we say HIV is a disease for the rich. If you don't have money you can't keep long [live long]...If you have the disease and you are rich, you can live longer than the ten years people talk of...It is a disease for the rich. It is not for the poor.

Karen's comments may reflect an awareness of the availability of anti-retroviral drugs for the treatment of HIV infection in some countries of the world. Anti-retrovirals were unavailable in Ghana, except to the very wealthy, due to prohibitive costs

Reflections on Prevention

Against the backdrop of their own life experiences, the women were asked to reflect on their ability to adopt strategies to protect themselves from infections such as HIV. This aspect of data collection was challenging because some of the women were reluctant to speculate on prevention strategies for which they did not have direct experience or were reticent to give advice to other Ghanaians. The women believed that condoms were an important HIV prevention strategy, despite the reality that there were many barriers to using condoms with their partners. Determining one's HIV status, taking care of oneself and participating in education programs were additional strategies mentioned by the women to prevent HIV transmission in Ghana. The HIV sero-positive men, nurses, traditional healers and professionals were also asked to comment on possible strategies for HIV prevention in Ghana.

Condom Use

Although most of the women had heard of condoms, only five had ever used one with a partner. Brenda stated "I've heard of it [condom], but I haven't used it before...I have always been with my husband". Several of the women commented that condom use was associated with immoral behaviour and promiscuity, but not with marital relationships. Charity seemed defensive when asked if she had ever used a condom:

> No, if you contact my parents, sisters and brother, they will tell you what sort of person I am. I did not have sex with many men. No man used condoms to have sex with me.

Although a few of the women had no knowledge of why condoms were used, most knew they prevented sexually transmitted diseases. Many of the women were also aware that condoms could prevent pregnancy. Only a few women knew that they could be used for both purposes.

The high value placed on fertility influenced the women's relationships with their partners and the vulnerability of the women and their partners to HIV infection. Twelve of the women did not have any children. Some of these women stated that they had prevented pregnancy using various methods of birth control, but most of the childless women had been unable to become pregnant. Several of the women explained that their inability to become pregnant had resulted in their boyfriend or husband terminating their relationship. Faith, for example, recalled her partner's reaction when she could not become pregnant:

> So he said I should go away because he needed a child and I couldn't give him one. So he sacked me from his place and hired a room for me.

Most Ghanaian men change partners if their wives do not become pregnant, because they do not accept that they could be the cause of infertility in their marriage. To prove their fertility, women divorced on these grounds become desperate and try to become pregnant with different men with the hope that they would be exonerated as the cause of infertility. Rene knowingly risked the exposure of her partner and her unborn child to the HIV virus in order to fulfill her need to have a child. She became pregnant after learning that she was HIV sero-positive, without consulting her boyfriend and without the knowledge of the physicians and nurses at the Fever's Unit. Rene was relieved that her two year-old son was HIV sero-negative, but she did not know the status of her former boyfriend.

The emphasis on childbearing in the Ghanaian culture influenced the acceptability and use of condoms by the partners of many of the women. They explained that men and women married in order to bear children and therefore it would be almost impossible to ask a husband to use a condom. Karen explains the difficulty with condoms in marriage:

> As for him he is my husband with whom I live, so I can't tell him to use condoms when he wants to sleep with me...If a man and woman are married, it is because of children that they have come together.

Most of the participants believed that condoms were more acceptable in a non-marital relationship. Martha stated, "if he was a mere lover I can tell him [to use condoms], but not a husband". The nurses reiterated the difficulty that Ghanaian women have in asking their husbands to use condoms. One nurse stated that if a woman suggested that her husband use a condom she could be accused of interfering with his decision about family size and risk being beaten, sent home and in some instances divorced. Another nurse remarked:

> Yes, a condom alone can bring big problems...Yes, that was why family planning - involving men in family planning is so difficult. Because there are just a few of them who understand and then they comply. But normally if you talk about family planning, then the man gets annoyed. So getting to the issue of condoms - trouble.

A few of the women and men believed that the increasing HIV prevalence in Ghana had resulted in an increased acceptability of condoms within marriage.

The men's responses regarding the acceptability of condoms were generally consistent with those given by the women and nurses. The men conceded that they would interpret a request from their wife or girlfriend to use a condom as an indication that she had a sexually transmitted disease and that they would be very upset about this situation. None of the men considered the possibility that the woman might be asking him to use a condom to protect herself from a disease. Peter stated that if his girlfriend asked him to use a condom,

> I would think that maybe she has contracted some disease. I would think instantly that she has HIV and that's why she's asking me to use condoms...Otherwise she cannot ask me to use condoms.

John speculated on his reaction if his wife asked him to use a condom:

> I would have thought that that was now the way of life. They say it is 'family planning'. If you wear a condom it will help you. It can help to space children and so it will make me think that she wanted us to practice family planning.

In addition to cultural factors that influenced the use of condoms among the participants, there are several other factors that inhibited their use. Many of the women reported that neither they nor their partners liked using condoms during sex, equating it to "eating toffee with the wrapper on". Several of the participants had heard stories that condoms could burst during use, negating their value in protecting against the HIV virus. The nurses, but not the HIV sero-positive women, raised the issue of cost and availability as factors that limited the accessibility of condoms for some people. Christianity was another factor that may have mediated the acceptability of condom use among the participants. The overwhelming majority of the women were Christian and several mentioned the teachings of the bible, "to go forth and bear children".

Mandatory HIV Testing

About half of the women and all of the men suggested HIV testing as a strategy to reduce transmission of the virus. Some participants suggested testing prior to becoming sexually active, whereas others believed that it should be done pre-maritally. Hope stated "these days women are asking their suitors to go for an HIV test before marrying the man". Some churches in Ghana required an HIV test from each member of the couple before a marriage ceremony could be carried out. In general, the nurses placed less importance on HIV testing to decrease the spread of the virus and more emphasis on the need for communication between partners. One nurse believed that at the time of marriage an HIV test might act as a deterrent to pre-marital sex, but "after marriage it doesn't hold". Although participants believed that the HIV test would reduce the spread of the virus, a few women pointed out its limitations. Gladys recommended HIV testing before marriage, but pointed out, "even with this test I'm not quite sure because the test is not fool proof - since men are not trustworthy, after this test one can still become positive". One of the professionals expressed concerns about the financial implications of mandatory or widespread HIV testing[3].

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[3] At the time of the study the cost of HIV screening initiated by an individual was 20,000 cedis which is equivalent to approximately US$6.00. This fee was waived if a physician requested the HIV test.

Taking Care of Oneself

When asked what Ghanaians should do to prevent HIV infection, many of the participants stated that men and women must "take care of themselves" and be "very careful in sexual matters". A few women emphasized that by "giving oneself to God" they would have the strength to take care of themselves. The meaning of taking care ranged from abstinence in sexual relationships before marriage to having fewer partners and "not roaming from man to man". Although the men concurred with the notion of abstinence before marriage, they admitted that, for some men, it was not possible. Peter admitted, "there are some men who can't bear staying without a woman". For some women, taking care of themselves also included using condoms and determining their HIV sero-status. Several participants mentioned that fidelity after marriage was an important aspect of taking care. A related theme that emerged during discussions with the women, and that was reiterated by the professionals, was that parents must take greater responsibility for their children. Pamela's advice for parents provides a very moving description of the hardships faced by many of these women and highlights the need for parents to provide financial support for their children:

> If I have any advice, I'd give it to parents. Since I came from the village, if she [my mother] had helped me, I wouldn't have gone to men and got this problem. I have struggled to sell ice water and learn sewing. I am planning to open a kiosk. If I am to die shortly, all of my efforts will be in vain.

Education Programs

Some of the HIV infected women and all of the men, nurses and professionals stressed the need for increased public education about HIV prevention in families and communities. Members of the nurses' and the male focus groups mentioned the importance of promoting more open communication between couples. One nurse believed that the current large-scale education programs being conducted in Ghana, using television and radio, were not very effective. She felt that there was an urgent need for more individual and small group education that provided opportunity for discussion and enabled more personal interaction. Moses, an HIV sero-positive male, believed that the negative comments about AIDS victims made by members of his church reflected their desperate need for education. Although there had been efforts to integrate HIV prevention education into school curriculums, it was not mandatory in Ghana at the time of the research. One strategy that was beginning to be used in Ghana was to have people with HIV illness give testimonies of their experience. This was felt to be an effective way to personalize the problem and "give a human face to the disease". Daniel, the only participant who had publicly acknowledged his HIV status, had become actively involved in education sessions in schools and churches.

Beliefs and attitudes about sexuality in Ghana were identified as barriers to the implementation of HIV education programs. Several participants mentioned that Ghanaian parents were not comfortable discussing issues relating to sexuality with their children. Health professionals also pointed out that sexuality was a sensitive subject. They did not always feel free, therefore, to discuss sexuality with young people because parents might interpret this as encouraging promiscuity. One nurse, in describing the challenges of working in AIDS prevention, stated:

> With our culture sexuality is an unwritten taboo...so we don't talk about sex openly. So it becomes very difficult for people to talk to people about sex.

Some of the participants mentioned that openly discussing sexuality in schools and other public settings would be viewed as a violation of traditional values and culture.

Discussion

These findings document social, cultural, economic and political factors that influenced Ghanaian women's vulnerability to HIV infection. The poverty experienced by many of the women during their childhood years, coupled with a societal belief that favours the education of males, restricted the participants' educational and vocational opportunities. Educational institutions in Ghana, particularly at the primary and secondary level, have historically charged school fees. Despite a government policy in 1992 to provide free, universal, basic education throughout Ghana (United Nations Development Programme, 1997), parents are still required to pay for school uniforms, books and registration fees for their children in primary and secondary schools. When choices of which children to send to school must be made, parents tend to send boys. Consequently, basic education is frequently inaccessible to children, particularly girl children, of parents unable to pay the required fees. There is an urgent need to ensure that women's opportunities within the education system are equal to those of men and that access to education, for both male and female children, is truly 'universal'.

The findings related to fostering raise an interesting question. Caldwell and Caldwell (1987), based on their research in West Africa, suggest that the concept of fostering may be a foreign distinction that reflects an ethnocentric perspective. Although cognizant of this possibility, I have chosen to comment on fostering because it is a practice that is referred to by Ghanaian researchers. A study of fostering in Ghana found that 28% of junior secondary school children had been fostered (Ardayfio-Schandorf &

Amissah, 1996). The finding that 55% of the women in the current study had been fostered is quite high and may be indicative of the level of poverty in the women's families. Ardayfio-Schandorf and Amissah (1996) found that fostering was more prevalent among female children and among families with low incomes, high fertility or experiencing marital disruption through death or divorce. Many of the women in this study came from families that faced several of these challenges. Being fostered may be a significant predictor of increased vulnerability to HIV infection in Ghana. Additional research on the outcomes associated with fostering is warranted.

For the women in this study, limited education influenced their ability to support themselves as adults. As a strategy for survival, women often felt compelled to take a boyfriend. Although many of these relationships included an exchange of goods or money, the women did not view themselves as 'basabasa' women. The practice of taking a boyfriend for financial reasons has been documented previously (Anarfi, 1999; Ankomah, 1998; Buor, 1996; Foreman, 1999; Schoepf, 1994; Standing, 1992) and has been differentiated from prostitution (Ankomah, 1998; Standing, 1992). As well, Ankomah (1998), during recent research on pre-marital sexual relationships in Ghana, found that the provision of sexual services by women in exchange for financial support from men was common. In addition, parents, especially mothers, often directly or indirectly sanctioned these relationships. Ankomah argues that premarital sexual exchange is a recent phenomenon that represents an economic survival strategy. In a study to identify factors that influence the reproductive behaviour of Ghanaian adolescents, Nabila and Fayorsey (1996) found that unemployment contributed to promiscuity and sexual relationships for economic gain. They also found that marital disruption through separation, divorce and widowhood resulted in more single, female-headed households. Children in these households were subject to economic pressure to become sexually active before marriage (Nabila & Fayorsey, 1996).

Women's lower social and economic status in relation to men influenced their vulnerability to HIV infection, particularly within marriage. This vulnerability was partially related to women's limited control over condom use with their sexual partners. Monogamous women who realize that their husbands have multiple sexual contacts are often powerless to protect themselves from HIV infection. The association of condoms with prostitution (Caldwell et al., 1989; Cleland & Ferry, 1995), filth, disease and mistrust (Varga, 1997) in many sub-Saharan African countries, significantly diminishes their acceptability with regular partners and husbands. In the current study, a wife's suggestion that her husband use condoms was sometimes interpreted as an indication that she (the wife) had a disease. Married women face additional barriers to condom use because they interfere with conception. The discussion of condoms, therefore, is a complex and difficult issue for married women and carries with it the danger of being abandoned socially and economically. Despite these very real barriers to condom use, the female participants frequently recommended condoms as an important HIV prevention strategy in Ghana. This dissonance may represent a growing awareness among the women that, despite their limited ability to influence condom use, there was an urgent need for Ghanaian women to exercise control over condom use in their relationships. Researchers in Uganda have recently documented a declining HIV-1 prevalence in young pregnant women and demonstrated that increased condom use was the most likely explanation for the decline (Kilian et al., 1999).

Expanding the Response to HIV Prevention

Traditional HIV prevention programs have conceptualized risk as a phenomenon within the control of the individual and have focused on the identification of 'risk groups'. It was evident that the women in the current study did not belong to a previously identified risk group and that their risk environment was largely mediated by forces outside of their control. Although important, a focus on individual behaviour may be limited in its effectiveness because it does not acknowledge the broader context of the risk environment (McKinlay, 1996; Swart-Kruger & Richter, 1997; Wallman, 1996). Risk behaviour, when examined in context, may represent interrelated survival techniques (Kane & Mason, 1992; Mill, 1997; Schoepf, 1994). In the area of HIV prevention, theories of risk behaviour must conceptualize risk as a socially organized phenomenon rather than an individual one (Rhodes, 1997; Standing, 1992). The efficacy of prevention programs will be enhanced if they acknowledge the societal factors that influence individual risk.

Increasingly, the availability of voluntary counselling and testing (VCT), although controversial, is a prevention strategy that merits consideration. Studies in Rwanda (Keogh et al., 1994) and Zaire (Heyward et al., 1993) found that VCT resulted in increased rates of condom use. Researchers and health professionals, however, have raised several limitations related to the provision of VCT. A recent study in Tanzania (Maman et al., 1999) found that only 22% of HIV-infected women disclosed their HIV status to their partner, whereas 69% of non-infected women disclosed their status. In addition, negative social outcomes following disclosure of HIV status, including marital conflict (Maman et al., 1999), blame and fear (Keogh et al., 1994; Mill, 2000) and violence (Gielen et al., 1997), have been reported. One of the health professionals in the current study expressed concern about using Ghana's limited health care resources to provide universal VCT services. He also argued that increasing access and availability to testing, without a concurrent increase in anti-retroviral drug treatment for those individuals found to be HIV sero-positive, raised serious ethical concerns. The advantages and disadvantages relating to VCT in Ghana must be carefully considered before providing the program as a complement to current HIV prevention strategies.

The guidance and support of traditional leaders, such as chiefs and elders, to assist in the development of HIV prevention programs in Ghana have been largely unsolicited. A senior planner in the National AIDS Control Program was asked about the involvement of traditional leaders in HIV prevention and their potential to promote changes in attitudes in areas such as fertility:

> It is true that we haven't done much with these categories of people that you just mentioned. It is a good suggestion and we may have to probably step up our activities with the traditional rulers, the chiefs and then the community elders - who in a way are the custodians of culture and tradition - ...if we really want to make headway.

This group has tremendous potential to contribute to the development of HIV prevention strategies that impact on cultural beliefs and attitudes. Traditional healers are another group in Ghana that could be utilized more extensively in HIV prevention. The healers interviewed in this study were primarily involved in the treatment of patients with HIV illness. The involvement of traditional healers in the planning and implementation of HIV prevention programs would enhance their cultural appropriateness (Good, 1988; Green, 1999; Somsé et al., 1998).

A recent government initiative that recognizes HIV infection not only as a health issue, but as a broad issue impacting all aspects of life, provides an example of a project with the potential to extend HIV prevention activities in Ghana. A guiding principle of the initiative is that HIV prevention must be considered as part of the mandate of all government departments, in addition to the Ministry of Health. This initiative represents a partnership between the government and UNAIDS to promote political commitment and to encourage multi-sectoral involvement in issues relating to HIV disease in Ghana (UNAIDS, 1999). A pilot project is being implemented in 10 districts, in cooperation with the district assemblies, to encourage all government departments, such as agriculture, education and finance, to consider HIV prevention in all aspects of their work. This project, recognizing the broad context of HIV infection and highlighting the far-reaching implications of HIV disease, is an excellent example of an approach that must be supported, expanded and investigated systematically.

The importance of understanding the broad factors that influence HIV infection is well entrenched in the literature. There is still a paucity of research, however, about how to transform this knowledge into action. The women's stories provide a compelling description of the context of HIV transmission in Ghana and support the need for multi-dimensional intervention strategies. Ghanaian women's inequality in relationships with partners and families is documented throughout the findings. Prevention programs must be designed that raise awareness of gender inequities and that include strategies that are culturally feasible for women. Collaboration with traditional leaders and healers has tremendous potential to contribute to the development of HIV prevention strategies that impact on cultural beliefs and attitudes. Women and men in Ghana confront issues relating to poverty and access to health services on a daily basis. Solutions to these issues require political and economic commitment at all levels of government and must be addressed through social policy changes. The complexity and interrelatedness of the issues surrounding HIV infection in Ghanaian women demand that prevention efforts be expanded, intensified and targeted to address the social, economic and cultural factors that influence the transmission of the virus.

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Table 1: Sample Demographics
N = 31

	Frequency
Age	
≤ 29 years	9
30-49 years	18
≥ 50 years	4
Marital Status	
Single	13
Widowed	6
Married/Living together by mutual consent	6
Divorce/Separated	6
Travel	
No	23
Yes	8
Number of Children	
None	13
One	9
Two	4
Four or more	5
Occupation	
Trader	22
Seamstress	3
Farmer	2
Hairdresser	2
Fish smoker	1
Commercial sex worker	1
Tribal Group	
Akan	13
Ga	8
Ewe	5
Krobo	3
Kassina-nankani	1
Dagomba	1
Religion	
Christian – Mainstream (eg Roman Catholic)	15
Christian – spiritual (eg Church of Christ)	15
Muslim	1
Years of Education	
None	8
3-6 years	3
7-10 years	19
12 years	1

I'm not a 'Basabasa' Woman: An Explanatory Model of HIV Infection in Ghanaian Women

Introduction

Ghana is a sub-Saharan African country that continues to experience an increase in the rate of infection with HIV (Disease Control Unit, 1999). Ghanaian women represent a particularly vulnerable part of the population for whom HIV prevention is urgent, as recent epidemiological data on AIDS indicate that there are more new cases in women than men and that women are infected at a younger age than men (Disease Control Unit, 1999). Approximately 80% of new HIV infections in Ghana are sexually transmitted, 15% are vertically transmitted from mother to child and 5% are acquired from blood and blood products (UNAIDS, 1999). Researchers and health professionals increasingly argue that if HIV prevention strategies are to be accessible, affordable and effective, the broad context of disease transmission and prevailing views of health and illness, including indigenous knowledge and traditional beliefs, must be considered. Such knowledge is critical to the development of culturally sound HIV prevention strategies.

Preparing an explanatory model of illness (Kleinman, 1978; Kleinman, 1980) is a useful strategy that can be used to describe the views of illness held by a defined group of people. An explanatory model includes information about the etiology and pathophysiology, symptomology, course of illness and methods of treatment for an illness (Kleinman et al., 1978; Kleinman, 1978; Kleinman, 1980). Explanatory models of HIV illness are useful for the identification of areas of convergence and divergence between traditional and professional explanations of illness. Traditional or lay views of illness influence the interpretation of symptoms, health behaviour and the relationship between the patient and the health practitioner (Bolognone & Johnson, 1986). Kleinman (1980) differentiates between the concepts of disease and illness. He suggests that disease refers primarily to the breakdown in a biological process, whereas illness is a concept that encompasses the individual, cultural and social response to the disease. This paper will outline an explanatory model of HIV illness described by HIV sero-positive Ghanaian women that was developed as part of a larger study. In addition to the usual elements of an explanatory model as described by Kleinman, the participants' beliefs relating to HIV illness will be discussed.

Background

Traditional healing in Ghana

Ghanaians have traditionally and historically sought health advice from a variety of traditional healers, including herbalists, cult healers, fetish priests and church leaders (Twumasi, 1979). With the establishment of the Gold Coast Medical Department by Great Britain in 1880 (Patterson, 1981), a western medical system was gradually introduced to Ghana. The idea of scientific medicine initially received some opposition from the indigenous population (Twumasi, 1972) and its parallel existence with the traditional healing system often led to confusion for patients because each system was based on a different philosophical worldview (Twumasi, 1979). Twumasi argues that "in modern systems, disease and illness are most often seen as natural phenomena hence subject to investigation and study by scientific methods...In traditional systems, diseases are seen as manifestations of supernatural powers and causal explanations take on a magico-religious viewpoint" (Twumasi, 1979, p. 352).

Several authors (Fosu, 1981; Twumasi, 1975; Warren, 1979; Wyllie, 1983) have explored theories of health, disease causation and healing associated with the traditional healing system in post-colonial Ghana. Illness is usually believed to be the result of natural or spiritual agents (Fosu, 1981; Senah, 1997; Warren, 1979; Wyllie, 1983). Although the majority of illnesses are perceived to be natural, some illnesses, such as gonorrhoea, are believed to be caused by natural or spiritual agents (Warren, 1979; Wyllie, 1983) or by a combination of the two (Fosu, 1981). In a recent study, Senah (1997) reconfirmed the belief in the occurrence of ordinary or natural illnesses and spiritual illnesses. Natural illnesses tend to be minor, respond to drug therapy and their etiology is known. Spiritual illnesses, on the other hand, are typically more serious, less responsive to drug therapy and believed to be caused by ghosts, witches, sorcery, curses or the Gods. Determining the etiology of illnesses, whether due to natural or spiritual causes, is an essential aspect of the healing process (Fosu, 1981; Senah, 1997; Twumasi, 1975; Wyllie, 1983). Frequently illness is seen to represent punishment for antisocial behaviour on the part of the patient, his relative or an ancestor, and serves as a method to reinforce the moral and social order of society (Bannerman-Richter, 1982; Senah, 1997; Twumasi, 1975). Traditional healers serve as intermediaries between the people and spirits, and rely on their guidance for the treatment of disease (Twumasi, 1975; Wyllie, 1983).

HIV illness as a spiritual illness?

In the pre-AIDS era in Ghana, several authors noted that venereal disease and other sexual diseases could be attributed to spiritual causes. Impotence, barrenness (Bannerman-Richter, 1982; Debrunner, 1961; Wyllie, 1983) and gonorrhoea (Debrunner, 1961; Wyllie, 1983) have been identified as spiritual illnesses caused by witchcraft. Since the onset of the AIDS epidemic, researchers in sub-Saharan Africa have found that HIV illness has also been given a supernatural explanation. In one study to explore the sociocultural aspects of AIDS in the Ivory Coast (Yelibi et al., 1993), researchers found a widespread belief among urban adults in the transmission of AIDS through witchcraft. Similarly, Campbell and Kelly (1995) reported that witchcraft is often suspected as the cause of death from HIV infection in Zambia. Based on extensive research in West Africa, Caldwell and Caldwell (1987) suggest that illnesses caused by supernatural agents such as witches "often take the form of wasting diseases as witches eat the life-soul of their victims" (p. 417). The mysterious nature of HIV illness, in combination with its incurability, increases the likelihood that it will be attributed to supernatural causes in countries of West Africa (Caldwell et al., 1992). This assumption is confirmed in a recent study of HIV infected patients in Ghana. Infection with HIV was given a supernatural explanation, based on the fact that the etiology could not be readily explained (Awusabo-Asare & Anarfi, 1997).

Religion and healing

In traditional Ghanaian society the practice of medicine and healing is contiguous with religion. There is evidence in the literature that the healing practices of Ghanaians continue to be influenced by their religious beliefs and that the relationship between religion and healing is complex. Concurrent with the introduction of a western medical system to Ghana at the end of the 19th century was the introduction and spread of Christianity. Christian missionaries, both Protestant and Catholic, ardently discouraged and disapproved of traditional religious beliefs and practices that included witches and witchcraft (Meyer, 1992). Today, God is central to most Ghanaians' lives (Anane, 1999; Meyer, 1995) and "in Ghana, at least in the central and southern regions, Christianity reigns supreme" (Meyer, 1995, p. 236). Christian fundamentalism, prevalent within the Ghanaian school system, has been cited as an obstacle to the discussion of HIV prevention strategies because of the tendency to defer to God for solutions to the problem (Awusabo-Asare et al., 1999). Opposition by religious leaders to the use of condoms to prevent HIV infection is another barrier to prevention in Ghana (Anane, 1999).

The influence of Christianity during the twentieth century has developed upon a foundation of traditional spirituality that continues to be practised by many Ghanaians. The belief in witchcraft continues to be prevalent, and at the same time feared, among Ghanaians (Bannerman-Richter, 1982; Meyer, 1992). In a recent analysis of conceptualisations of "evil" and the "devil", Meyer (1995) argues that a conversion to Christianity is not necessarily accompanied by a decrease in beliefs in witchcraft and demons. Bannerman-Richter (1982) and Meyer (1992; 1995) argue that the increasing popularity of spiritual and Pentecostal churches in contemporary Ghanaian society is related to the ability of these churches to provide assistance for a wide range of illnesses, including those attributed to evil spirits. As well, the popularity of spiritual churches in Ghana has been related to the integration of traditional music, drumming and dancing into their services and the concurrent belief that "noisy" music can be effective in driving away evil spirits (Bannerman-Richter, 1982). The increased popularity in faith-healing offered by spiritual churches is also fuelled by the increasing cost of medical treatment and services (Bannerman-Richter, 1982; Caldwell et al., 1992).

Current biomedical treatment for HIV illness in Ghana

The current emphasis in the biomedical treatment of HIV illness in Ghana is the alleviation of symptoms through the use of drugs. Health policies introduced in1985, including the introduction of user fees and charges for drugs, have made the acquisition of medicines extremely difficult for most Ghanaians (United Nations Development Programme, 1997). The prohibitive cost of anti-retrovirals prevents their inclusion on the Ministry of Health's list of essential drugs; however, they are available from a few private pharmacies. Consequently, the use of anti-retrovirals in Ghana is restricted to a very small number of wealthy individuals who can purchase drugs privately. The Ministry of Health is exploring the possibility of providing anti-retrovirals to pregnant women to reduce transmission to their unborn child, but there are economic, logistic and ethical considerations that must be addressed prior to implementing this type of program (personal communication, Manager, National AIDS Control Programme, April 30th, 1999). For example, what are the ethical implications of providing prophylactic treatment to protect the baby, when there are insufficient resources to provide on-going anti-retroviral treatment to the mother or the father? An equally profound issue concerns the implications of using scarce health resources to provide life-saving treatment for an unborn infant who, because his parents are likely to die from HIV disease, will have limited educational opportunities and be destined to a life of poverty as an orphan (Mill, 2000).

This literature review demonstrates the need for research to explore Ghanaians' beliefs about HIV illness and their attitudes toward its treatment. Indigenous or lay perceptions of illness influence health behaviour (Bolognone & Johnson, 1986; Kirby, 1997; Schoepf, 1991) and therefore have implications for prevention (Aggleton, 1997). Few studies have focused on the perceptions of HIV illness among individuals living in sub-Saharan African countries (Kielmann, 1997). Ghanaians' perceptions of health (Avotri & Walters, 1999a; Walters et al., 1999) and illness (Fosu, 1981; Kirby, 1997; Warren, 1979; Wyllie, 1983) have been described. There has however, been limited exploration of views about HIV illness. Findings from recent research in Ghana will be used to describe Ghanaian women's explanatory model of HIV illness.

Design and Methods

Participatory action research was the methodology used for a study of HIV illness among women conducted in Ghana between January and May 1999. Twenty-seven HIV sero-positive women were recruited from the outpatient clinic of a large, urban teaching hospital in Accra, the capital of Ghana. Four additional women were recruited from the government and mission hospitals in Agomanya, a town serving a rural population. The demographics of the sample are detailed in Table 1. Five HIV sero-positive men, eight nurses, two traditional healers and ten professionals were also interviewed to reflect on the women's comments and the themes emerging from the data. The professionals included physicians, research assistants, nurse educators and HIV counsellors. HIV counsellors are usually social workers or nurses, who have received training in the counselling of HIV positive clients.

In-depth interviews were conducted with all of the HIV infected women and one man, the traditional healers and the professionals. Focus groups were carried out with four HIV infected men and the nurses. All of the interviews and focus groups were tape-recorded. Most interviews with the HIV positive participants, and the focus group with men, were carried out in one of the local languages: Twi, Ga, Ewe or Krobo. Two research assistants assisted with the recruitment and interviewing of the participants and completed the translation into English of the interviews and one focus group discussion. The participants for individual interviews were recruited using non-probability convenience sampling, whereas network sampling was used to recruit the members of the male focus group. At each of the study sites HIV counsellors provided initial information to potential participants about the study. One of the research assistants provided more in-depth information about the study and obtained oral, taped consent. Written informed consent was obtained from the nurses and other professionals.

Analysis of data occurred concurrently with data collection and was initiated early in the interview process. The qualitative software program NUD.IST (Non-numerical Unstructured Data Indexing, Searching and Theorizing) was used to assist the researcher to organize the data into thematic categories. Analysis focused on the identification of themes relating to the women's explanations of HIV illness. The names of the participants whose stories are shared in the following section have been changed to provide anonymity.

Beliefs about HIV Illness

"I'm not a basabasa woman"

The women held two recurring beliefs in relation to HIV illness that permeated the data. They believed that HIV illness was associated with leading a 'basabasa' life and with travel outside Ghana. 'Basabasa' is a Twi word that means improper behaviour or conduct and, when used in relation to sexual behaviour, implies prostitution, promiscuity or extra-marital relationships. As Ellen explained:

> If you stay with one man or one woman, it means you are not leading [a] basabasa life. But if you have sex with so many men or women, it means you are leading [a] basabasa life.

Many of the women actually used the word 'basabasa' in relation to HIV illness, and ardently denied being a 'basabasa' woman. Other women used phrases that conveyed the same meaning to distance themselves from being associated with 'basabasa' behaviour: "I did not roam from man to man to man", "I am not the undisciplined type", "I am not the playgirl type" or "I don't walk about". Nettie was asked what she felt had caused her HIV infection and her response demonstrates her association of HIV infection with a basabasa life. "When I came here and was told I had this disease, I was lost in thought because I didn't walk basabasa".

"I've never travelled"

The belief that HIV infection was linked to travel was a very common theme emerging from the data, although only eight participants had ever travelled outside Ghana (see Table 1). Despite Maria having had a husband who had died of AIDS, she was still shocked when she too was diagnosed with AIDS:

> I was also invited for a blood test. I came for the report a week later and I was told that I had AIDS and that my husband's illness was also AIDS. When I was told that I have AIDS what I said was "Oh, I have not travelled outside Ghana, why should I have AIDS?"

The association of HIV infection with a basabasa life and travel was so strong that it led some women to question the source of their infection. Dorothy believed that her HIV illness was "the work of God" because she had not travelled to Abidjan, the capital of the neighbouring country Ivory Coast. When asked how she had become HIV positive, Charity stated emphatically:

> I believe it is evil spirits, but I will not believe it was through sex because I did not have any bad life. I have not travelled outside Ghana to practice prostitution.

Many of the participants recalled being asked their history of travel by the nurse or doctor at the time of diagnosis and some reacted to their diagnosis with shock and disbelief because they had "not travelled". The theme of travel and HIV infection was also apparent in the HIV prevention strategies suggested by the participants. Several commented that Ghanaian men and women must avoid sexual activities with anyone who had travelled outside Ghana.

The professionals validated the prevalence of these beliefs in Ghana. Most, however, did not subscribe to the belief that HIV illness was associated with a basabasa life or with travel outside of Ghana. For example, one specialist in HIV prevention stressed:

> It's not a disease from outside [the] country, but it's a disease of the whole...That is why "I don't lead basabasa" is out. We tell them and it is during our education that we tell them. "Don't say it is *their* disease, but it is *our* disease".

A few professionals, however, made comments that demonstrated their own adherence to these two core beliefs about behaviour and HIV infection. One nurse during a focus group informed me, "When you have HIV it means you've led a bad life. You've been a prostitute". In a similar manner, another health professional continued to believe that there was a strong link between HIV illness and travel. She maintained "I haven't in my practice met anybody who stayed in Ghana and had HIV". When informed that the majority of the women in the current study had not travelled, she replied "then it means that they were in Ghana, but had the disease from people who have come from outside". This dialogue demonstrates the entrenchment of some common misconceptions concerning HIV disease in Ghana and highlights the need for ongoing research and education about the epidemiology of the disease.

Other researchers in sub-Saharan African countries, including Ghana, have documented the belief that HIV illness is associated with particular groups such as prostitutes (Awusabo-Asare & Anarfi, 1995), caused by foreigners (Caldwell et al., 1992; Ocholla-Ayayo, 1997; Swart-Kruger & Richter, 1997; Swart-Kruger & Richter, 1997) and related to travel (Ankomah, 1998). Two of the professionals attributed the beliefs and attitudes of the participants to the early epidemiology of HIV infection in Ghana and the subsequent focus in prevention messages. Early in the epidemic, migration was a significant factor in the spread of the virus in Ghana. The proportion of AIDS cases with a history of travel outside of Ghana declined from more than 90% in 1986 to less than 50% in 1999 (personal communication, Dr. Anarfi, April, 1999). In addition, the first cases of AIDS in Ghana were diagnosed in women who had travelled outside of Ghana to engage in prostitution (Anarfi, 1993). Based on this reality, early prevention campaigns emphasized that HIV infection was associated with travel and prostitution. These early messages have influenced many of the women's, and a few of the professionals', beliefs about HIV illness and appear to be counter-productive to prevention efforts.

Pathophysiology and Etiology

The women's knowledge of HIV transmission reveals their understanding of the pathophysiology of the virus. Most of the women were aware that the virus was transmitted sexually. Some believed that this was the only mode of transmission, indicating that they were unaware that the virus could be transmitted through blood or vertically from mother to child. Three women stated that they had never heard of the disease before receiving their diagnosis and had no knowledge of how the virus was transmitted. Several of the participants believed that the HIV virus could be transmitted through sharing razor blades or needles with an infected person or from an infected insect. Uncertainty about whether the virus could be transmitted through food and dishes was an issue for some women. These women stated that they had been advised by the HIV counsellors not to continue to share meals with their family. Francesca was so upset by this advice that she had contemplated suicide:

> They say nobody should eat with me. Nobody should eat my food. So I have even asked them if they could not give me an injection to kill me if I have this disease. Because if I have to live with the disease until it kills me, then it is a problem.

Many of the women assumed that they would know a person's HIV status by their outward appearance. This attitude may have been based on a misunderstanding of the difference between HIV infection and disease. One of the men in the focus group pointed out, "In Ghana here not everybody knows we have HIV, but everyone knows we have AIDS". A South African study of street youth also documented the association between HIV infection and appearance (Swart-Kruger & Richter, 1997).

Recent research in Ghana (Awusabo-Asare & Anarfi, 1997a) found that although people are well informed about HIV transmission heterosexually, they lack information about other methods of transmission. Similarly, in the Ivory Coast misunderstanding about the concept of sero-positivity and inaccurate beliefs about the transmission of HIV through mosquitoes and donating blood has been documented (Yelibi et al., 1993). Kenyan women associated AIDS with sexual activity, but misunderstood the transmission of the virus through body fluids (Kielmann, 1997). Incorrect knowledge about sexual transmission and a belief that HIV could be transmitted through casual contact was found in a recent study of women in Botswana (Norr et al., 1996). A gap in the knowledge of the participants in relation to the course of HIV illness and the latency period was also identified.

The women expressed a range of views in relation to the cause of their HIV infection. Twenty-six of the women mentioned their sexual partner as a possible source of their infection. Some participants felt very confused about the cause of their illness, however, because they had not had a sexual partner for several years or their sexual partner looked healthy. As a result, 11 of the women gave more than one explanation for their illness. For example, Amanda stated that she believed "it was the devil" that caused her illness, but in her next comment she said her infection might be due to "the following of men". Faith was one of the few women who felt very certain about the source of her illness: "I know a man transferred it to me...I can't tell you which one, but I know one of them transferred it to me". Three women postulated that they had acquired the virus from contaminated razor blades used to trim nails, but one of these women had also considered the possibility that her boyfriend had infected her.

Almost half of the women (13) suggested that their illness had been spiritually caused; ten of these women also mentioned that a sexual partner might have caused their illness. These women thought that the virus might have been transferred to them spiritually through juju[1], evil spirits, the devil or God. Many of the women did not directly voice the belief that their illness had been caused by supernatural forces. They repeated comments made by relatives, pastors or health practitioners regarding this possibility. Susan recalled that at the time of diagnosis, her physician had commented,

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[1] "Juju" refers to an event such as illness that is caused by witchcraft.

"the devil can also infect one with HIV". She mentioned that the relatives who had communicated with the devil to cause her illness were now paying for their evil deeds; one had died and another had suffered a stroke. Catherine articulated the cause of her illness by describing the advice her brother had given her following her husband's death from HIV disease:

> He rather advised me that I should not worry too much about the sickness because there is no new illness in this world and I must know that it is God who brought the illness and if God does not allow the illness to come to you, it will not come and that every illness is a disgraceful one.

Margaret had visited a Pastor to determine the cause of severe body pains in her chest and was told that her cousin was fighting with her spiritually. She was very firm in her belief that "...it is my cousin who transferred the bad spirit to me to get this illness".

Two women associated their HIV illness with their reproductive system. Anne was the youngest woman in the study and was seven months' pregnant at the time of her interview. She believed that her illness had resulted from her attempt to "spoil" her pregnancy:

> When the pregnancy started, those things [symptoms] also came along...They asked me how I got it. I explained that I had the disease not long after I became pregnant, but I did not know how...I don't know how I got the disease but if one attempts to spoil pregnancy then one falls sick...That's why the disease came.

Francesca stated that her early menopause had resulted in her HIV illness and may have been the result of juju. Later in the interview, however, she mentioned that she had had a boyfriend three years earlier in Benin who might have given her the virus.

The finding that 13 women believed that their illness could be attributed to spiritual causes is interesting, although not unexpected. Several of the professionals mentioned that it was still quite common for Ghanaians to believe in a spiritual or supernatural explanation for HIV illness. Diseases that are mysterious, that are associated with wasting or that threaten the reproductive system are more likely to be given a supernatural explanation (Caldwell et al., 1992). All three dimensions characterize HIV disease! The belief that HIV illness can be attributed to spiritual causes, in combination with beliefs about death, influences how HIV is viewed as an illness. Mill (in press) found that a belief in pre-destination influenced Aboriginal women's views about their HIV illness. In West Africa generally, and Ghana specifically, it is commonly believed that death is pre-destined by God and that there is survival after death (Caldwell et al., 1992; Sarpong, 1974). A recent survey of students in Central Ghana identified the attitude "all die be die" as an obstacle to sexual behaviour change among youth (Awusabo-Asare et al., 1999). The authors relate the meaning of "all die be die" to the belief that not only death, but also infection with the HIV virus, is pre-determined and therefore cannot be altered through individual behaviour change. Caldwell, Orugoloye and Caldwell (1992) suggest that "...the most fundamental reason why the great majority of Africans are more sanguine than might have been predicted with regard to the AIDS epidemic is that they are not fully convinced that biomedical determinism is the only force operating in the world" (p 1179).

Symptomology

All but three women had experienced symptoms that they attributed to their HIV illness. Most of the women did not know exactly how long they had been living with the virus, but the length of time since diagnosis ranged from one day to 13 years, with the average time being one and a half years (see Table 2). The women noticed symptoms for a period ranging from a few weeks to approximately three years prior to being advised to have an HIV test. The severity of the symptoms was not necessarily related to the length of time the women had known their diagnosis. For example, one 35 year-old woman had known her diagnosis for six years and appeared and felt very healthy at the time of the interview. Another younger woman, knowing her HIV status for only two years, was extremely emaciated, coughing profusely and short of breath during the interview. The most common symptoms described by the women were weight loss, diarrhoea and body weakness. Ellen stated that she had become so weak that “when the wind blows strongly I will be falling down. I [have] become very light”. The range of symptoms described by the women is shown in Table 3.

Treatment

The participants in the study sought treatment for their illness from traditional, biomedical, or spiritual healers, or from a combination of sources. Counselling and support were also mentioned by many of the women, particularly as part of biomedical treatment. The nurses believed that it was common for patients to seek treatment from all three sources and one nurse commented: "In our culture, even when they have conditions that can be treated by going to hospital, they want to have backup by going to the traditional healers. Some go to their pastors so while they are here, they are prayed for". The nurses, traditional healers and some of the other professionals spoke of the need to try to integrate or "marry the two [biomedicine and traditional medicine] together" because of the devastating nature of HIV illness. One of the nurses raised the possibility that traditional healers were capitalizing on the treatment of AIDS patients because biomedicine was unable to cure HIV illness.

The influence of Christianity on the women's decision-making about treatment was evident during the discussions. About one third of the women stated firmly that they did not believe in using traditional healers because they were not part of the Christian belief system. When Martha was asked if she had visited a traditional healer she replied "Believers [Christians] don't do that". Susan's reference to a passage in the Bible suggests her association of traditional healers with false Gods:

> Never, never, never. I don't deal with juju. As I know [how to read] Ga, if you read Psalm 115, those jujus have eyes but can't see, they have ears but can't hear, so anyone who puts his hopes in them is just like them. I have no trust in them.

Heather, on the other hand, stated that she did not trust traditional healers but was willing to consult an herbalist that had been recommended by a nurse at the hospital.

Traditional healing

Despite nurses believing that the use of traditional medicine was very common, only 12 women reported visiting traditional healers, including witch doctors[4], herbalists and fetish priests. Ten women had visited herbalists to obtain herbal remedies for their symptoms, one woman had consulted with a fetish priest seeking treatment for her swollen feet and one woman had visited a witch doctor. Some of the findings in relation to the use of traditional healers were incongruous. Early in the interview, Hope said that as a Roman Catholic, she totally disagreed with the practice of traditional healing. In the following passage, however, her comments about the positive outcomes she had witnessed from herbal medicines suggest a much more tolerant position:

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[4] Witch doctor is a broad term used to define healers who serve as intermediaries between Gods and spirit entities. A herbalist (Dunsinyi) specializes in herbal medicine and a fetish priest (Okomfo) is a healer attached to the shrine of his respective God (Bannerman-Richter, 1982; Wyllie, 1983).

> They say if you take them [herbal medicines], you would grow fat; you would eat; you would become fine. But it would not cure the disease, it doesn't cure it. It would only make you fine. The viruses would be weakened. The viruses would not be removed. They would relax so that you too would feel relieved.

The two traditional healers who were interviewed were very divergent in both their experiences as healers and their claims about treatment. Mr. Kofi, following a vision that prompted him to become a healer, had provided symptomatic treatment to several HIV positive individuals. Although one of the men treated by this healer had died, three others reported weight gain and improvement in gastro-intestinal symptoms following treatment. Mr. Kofi was working collaboratively with the Ministry of Health and had been given permission to recruit patients through the HIV outpatient clinic at the teaching hospital where the study took place. The second traditional healer, Dr. Abane, had posted a sign "AIDS Can be Cured" in the town where his clinic was located. The researcher travelled to his clinic, accompanied by a research assistant, and obtained permission for an interview. Dr. Abane explained that he used a herbal preparation that included the roots, bark, leaves and fruits of several trees not only to treat AIDS illness, but also to prevent HIV infection. While the treatment was very expensive (approximately US$1300.00), Dr. Abane claimed that he had cured more than 2000 patients, including Ghanaian physicians and government officials and individuals in Holland and the United States.

"We only come for drugs"

All of the women who had experienced symptoms attributed to their HIV illness had consulted biomedical professionals at hospitals or clinics. Some women turned to biomedicine in search of a cure, after finding traditional healers unable to alleviate their symptoms. Ellen recalled "when I took herbal medicine there was no improvement and so I concentrated only on doctors for treatment". Dorothy believed that the hospital "is our last place of resort". The most critical component of the women's treatment when they visited a doctor was the prescription and procurement of drugs. Several women echoed Giftie's sentiment that "we only come [to the hospital] for drugs". Kelly's comments portray the significance of and reliance on drugs:

> The doctor will ask you if you have any problems or bodily pains. If you have, he will prescribe drugs for you to go and buy. Even if you don't, he will prescribe drugs for you. He will advise you to come back if you have any problems.

Most of the women reported that drugs had been very helpful in alleviating their symptoms and believed that through drugs their illness could be cured. One of the professionals explained that patients were anxious to obtain drugs because the drugs could help them maintain weight, thereby avoiding being visibly associated with HIV illness.

Many of the women mentioned that 'taking care of oneself' had been emphasized during their visits to the hospital. They believed that by 'taking care' they could stay healthy and live longer lives. The meanings associated with 'taking care' ranged from eating healthy foods to reducing or eliminating sexual relationships. The women stated that following their diagnosis with HIV infection, nurses had counselled them to avoid sexual relationships with men to reduce the possibility of re-infection with the virus. In the following passage, Hope explains why she wanted to avoid re-infection: "If my blood is not strong, and he adds his [virus] to mine, I will die early". Several of the women remembered being advised by the HIV counsellors not to "think too much" about their illness. Catherine recalled being told by a nurse that "the illness hates too much thinking".

In the hands of God

In addition to taking the drugs prescribed by biomedical professionals and visiting traditional healers, the women sought the assistance of their church and pastor to help them cope with their illness and pray for a cure. The belief that there was a God who influenced the treatment of and cure for their illness was shared by every woman and was reinforced by health professionals during visits to the clinic. Some women mentioned that during prayers they would ask God for forgiveness, suggesting that they believed they had done something wrong. The association of HIV illness with immoral behaviour has also been reported by researchers in Uganda (Ogden & Kyomuhendo, 1996) and Kenya (Ocholla-Ayayo, 1997). Many women believed that any possibility of a cure for their illness was in the hands of God. Margaret's faith in the power of God for a cure was paralleled by an acceptance of death:

> Everything is in the hands of God and if God says I should be cured, I will be cured and if death I am ready for it because it is the same God who created me.... It is only God who decides what will happen to me.

Susan, believing that the devil had caused her illness, had faith that through prayer and supplication "...God himself will remove this disease which has been imposed on me and the devil would escape". Similarly, Gladys commented that "through prayers God will heal me. God moves in mysterious ways". Some of the women suggested that their faith in God was essential because there was no biomedical cure for HIV illness.

Several of the women attended 'spiritual' or 'charismatic' churches whose leaders were believed to possess the power to cure illness. Margaret recalled that her Pastor had "prayed for God to remove the bad spirit he has planted in me...". One woman, herself a Roman Catholic, commented that "they say the spiritual churches cure the disease but I haven't seen anyone who has been cured". In addition to assisting with the cure for the illness, it was believed that the pastors of spiritual churches could identify the cause of the illness. Amanda believed fervently in the possibility of a cure through the prayers by the members of her spiritual church and her faith in God:

> I know when I go to church and pray God will listen because he is the one who created us and it is not his wish that we get sick. Only the Satan gives us sickness. God can cure me spiritually.

Two of the participants stated that they had participated in 'deliverance' in their church in an effort to drive out evil spirits.

Counselling and Support

In Ghana, pre and post-test counselling was the common practice for any person receiving an HIV test. This counselling was provided by professionals, usually nurses and social workers, who had received additional training provided by the National AIDS Control Program. When the test was positive, the client and one family member were invited to the HIV clinic by the counsellor to be given the results and information about HIV illness. One nurse counsellor stressed the importance of "breaking the news" at the hospital:

> The problem is breaking the news in the house creates another problem, because most of the people don't exactly understand what HIV is, so when you tell them [the relative] in the house there will be problems. They [the patient] will be neglected and we don't want that.

A high level of stigma and misunderstanding surrounding HIV illness in Ghana usually resulted in the process of diagnosis and counselling being "shrouded in secrecy" (Mill, 2000). Counselling was perceived as an ongoing process that dealt with the emotional, financial and housing needs of the women. Family members were also advised about the importance of providing emotional support to the member of their family who was ill.

During the focus group discussions with the nurses, they discussed their frustration with being unable to give emotional support to their HIV patients because most patients did not want others to know of their condition. As a result, the nature of the patient's illness was not discussed openly:

> It's only when the woman opens up that you can also have that chance of telling her or you know adding a little to what she's been taught in the counselling unit. They don't open.

Many of the comments made by these nurses and the HIV counsellors reflected an attempt to "normalize" HIV illness during interactions with patients. This was accomplished by advising women not to "think" or "worry" too much about their illness and not discussing the terminal nature of the illness. For example, one of the nurses in the focus group stated that she would "tell the patient that maybe this is like any other disease you can get. When you get it you can die, so you shouldn't worry too much about it". It is interesting that the women were advised not to "think too much" or "worry too much". In a recent Ghanaian study (Avotri & Walters, 1999a) psychological health concerns, expressed by "thinking too much" and "worrying too much" were identified as the most prevalent health problems for women. It may have been that the health professionals in the current study did not feel comfortable discussing the emotional and psychological concerns of their HIV sero-positive patients.

The women provided a range of perspectives in regard to the counselling and support they had received. Several of the women stated that they had not been given any advice on how to cope with their illness. They came to the HIV outpatient clinic primarily to see the doctor and hopefully to receive a prescription for medicines. "We come to see the doctor. If he gives you your prescription, you go away". Most of the women, however, recalled specific advice that they had been given by the counsellors to help them improve or maintain their health: continue my drugs, eat a good diet, don't share my personal effects, don't share food with anyone else, don't tell anyone about my illness, don't re-infect myself or spread the virus to anyone else through sex, use a condom if I have sex, don't get pregnant and don't think of marriage again. A few of the women were very appreciative of the support they had received from health professionals and believed that it had contributed positively to their health status. Jennifer was convinced that the counselling she had received from her physician was a fundamental component of her treatment. She expresses this in the following passage:

> But if you have good counselling and you look after yourself well, you are going to live for a long time. I am even stronger than a lot of people...The only medicine is the counselling...If you have a good and proper counsellor, you are going to understand things, you going to understand re-infection and you [are going to] prevent the re-infection.

Course of Illness

The women's emotional reactions to their diagnosis ranged from confusion and disbelief to sadness and withdrawal. Several of the women were so overwhelmed by their diagnosis that they had contemplated suicide and one woman had figuratively "died" after being told that she was HIV positive. Hope, consumed with worry and "thinking too much" about her diagnosis, recalled:

> When I was first told I was HIV positive I went to the world of the dead and came back. I became like a skeleton because I was always thinking...until I was told that this disease does not go hand in hand with thinking – one has to be happy.

Most of the women had experienced negative social, financial and occupational repercussions as a result of their illness. Some women had been thrown out of their homes when their landlords learned the cause of their ill health and many were no longer able to work to support themselves. As a result, the women's meager financial resources were rapidly depleted. Francesca explained, "I have saved some money but because of sickness all the money is finished". In addition, many of the participants had experienced profound losses through the death of a family member: nine women had lost a partner due to confirmed or probable AIDS and five women had lost children to illnesses with symptoms suggestive of AIDS.

The women's health was influenced by the profound stigma surrounding HIV illness in Ghana. Although most of the women had one family member as a confidante, they kept their diagnosis secret from other family members and their communities, fearing negative repercussions if the cause of their ill health became public. The secrecy surrounding the women's illness impacted their ability to seek treatment and resulted in fewer resources being requested from and offered by the extended family. After experiencing discrimination from community members who had learned of her diagnosis, Sarah felt that she must leave her home and community. With nowhere to go, she often slept on the hospital grounds:

> So that some of the time my home has been the hospital here...Sometimes [I sleep] under mango trees or I walk about.

Stigma and fear of being told one has AIDS has been found to contribute to a delay, particularly among women, in seeking treatment (Kaharuza, 1996) and to an increase in the use of home treatments for their symptoms (Ogden & Kyomuhendo, 1996). In addition to the influence of stigma on care and treatment, one nurse explained that some relatives refused to help family members because HIV was a terminal illness and they would just be "wasting [their] money".

A prevalent and recurring theme in the study was a focus on finding a cure. Catherine's comments illustrate this theme:

> Well, doctors say I have the 'bad disease' and at that moment I was desperate for a cure and so anything that anybody will tell me, I have to do it.

The meaning and understanding of 'cure', however, appeared to vary among the women. Faith demonstrated an understanding of the chronic nature of the illness: "What I know is that if you keep on taking the drugs, you will be healthy but the germs will still be in your blood". Martha, on the other hand, realized that she could transmit the virus sexually but was misinformed about the incurable nature of her illness. She believed that if she infected a man, "the man will take the disease from me and I would be free of it". Cure was frequently associated with the use of drugs. The popularity and prevalence of medicines, particularly Western medicines, for the treatment of illness in Ghana has been noted by other researchers (Avotri & Walters, 1999b; Senah, 1997). Women often lacked the necessary financial resources to purchase the drugs required for the treatment of symptoms and maintenance of health. One of the health professionals believed that survival rates for HIV positive individuals from lower socio-economic backgrounds were decreased due to poorer nutritional status and inadequate resources to purchase drugs for treating opportunistic infections.

Discussion

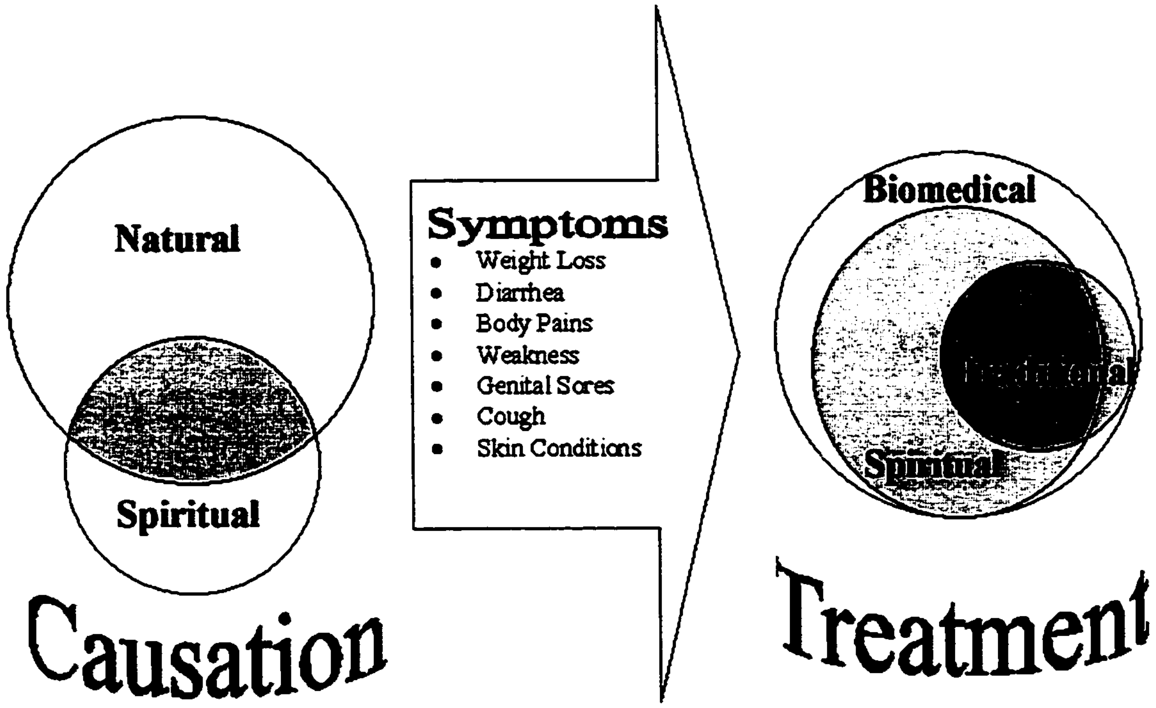
In this paper, HIV positive Ghanaian women's beliefs and experiences with their illness have been examined. These narrative accounts provide insights in relation to areas of divergence and convergence between traditional and professional explanations of, and treatment for, HIV illness. Beliefs described by the women revealed a misconception that HIV infection was confined to particular groups. As a highly stigmatized illness, AIDS may provide a symbol that enables individuals to direct their negative attitudes toward the already marginalized segments within society (Herek, 1999). The association of HIV illness with travel and with leading a 'basabasa' life can be traced to the early epidemiology of the epidemic. The continuing prevalence of these beliefs may result in individuals being unaware of their vulnerability to infection. Further, they highlight the urgent need to refocus HIV prevention messages. Mr. Tetteh, one of the professionals interviewed, had many years of experience in HIV prevention. He was asked to comment on these beliefs and attitudes. His response provides one example of consciousness raising that occurred during the research process:

> Some of the findings of your study are very interesting. They brought out some policy issues, because your study has come out with some misconceptions that people still have about HIV/AIDS in the country and we think that is very useful input for us to properly reflect in our educational messages and interventions.

The finding that some health professionals continue to subscribe to these misconceptions highlights the need for further research relating to their knowledge and attitudes about HIV illness. Ongoing professional education may be required to ensure that health care providers have current knowledge about the epidemiology of HIV disease in Ghana.

Figure 1 depicts the explanatory model of HIV illness described by the women. The explanatory model of HIV illness in Ghanaian women is influenced by their beliefs in natural causation, including mainly sexual partners, but also razor blades and pregnancy. These beliefs in natural causation overlapped with beliefs in spiritual causes of HIV illness that included juju, evil spirits, the devil or God. Similarly, the women shared three overlapping spheres of beliefs in relation to the appropriate treatment for their HIV illness. These were strongly grounded in the western biomedical tradition, but included interacting elements of belief in spiritual and traditional medicine. The interaction of these treatment and causation beliefs were linked by a shared range of classic HIV symptoms. Collectively these beliefs in causation and treatment, derived from the women's narratives, constitute their explanatory model of HIV illness.

Figure 1. Ghanaian Women's Explanatory Model of HIV Illness



It was interesting that all but one of the participants (who was Muslim) stated that they belonged to a Christian religion. There may have been an element of social desirability associated with being Christian. It has been suggested that in Africa, Western education and Christianity are viewed as synonymous (Ward, 1956). The participants, therefore, may have assumed that, as a Western educated researcher, the author was a member of a Christian religion. This assumption may have influenced some of the participants' willingness to discuss supernatural causes of their HIV illness and traditional treatments for their symptoms.

Bannerman-Richter (1982) argues that some Ghanaians, particularly the well educated, privately believe in witches but publicly feel compelled to deny their existence. Earlier research on the health-seeking behaviour of HIV positive individuals in Ghana (Awusabo-Asare & Anarfi, 1997a) reported a low rate in the use of traditional healers and spiritualists for their illness. Regardless of the influence of Christianity on the women's responses, 13 participants either believed that their illness had resulted from supernatural forces such as juju or evil spirits, or had contemplated that possibility. One HIV counsellor, who regularly worked with HIV patients, felt it was her responsibility to convince patients that a belief in spiritual causes of infection was erroneous:

> They think it's spiritual, juju and a lot of things, but as time goes on we continue with the counselling and we explain things to them, gradually, gradually they come back to their senses to know that it's not juju. But some of them too, still we do the counselling, we do all that we can, but that mentality is there.

Knowledge of the range of causes that individuals attribute for their HIV illness is highly relevant for health care providers. Fosu (1981) argues that the cause of an illness is the most important factor in choosing the treatment for its remedy. The women in the study sought treatment from traditional, biomedical and spiritual healers. Although the traditional healers and some of the nurses and professionals argued that the devastating nature of HIV illness necessitated greater integration of biomedical and traditional treatment, many Christian-based churches ardently discourage the use of traditional medical treatments.

The findings in relation to beliefs about the cause and treatment of HIV illness among Ghanaian women suggest the need for a broad, multi-disciplinary approach to HIV prevention and treatment. The powerful influence of the church in Ghana demands that Christian, spiritual and Muslim religious leaders are included in the planning, implementation and evaluation of HIV prevention programs. Traditional leaders, including chiefs and elders, could also provide valuable input to this dialogue by ensuring that programs are culturally sensitive. Similarly, the use of traditional healers in the development of HIV prevention programs has the potential to enhance their cultural appropriateness (Mtshali, 1994; Somsé et al., 1998).

The belief that HIV illness may be due to spiritual causes, in combination with the conviction that death is pre-determined, poses unique challenges for HIV prevention. These perceptions of HIV illness suggest a belief, among some, that HIV illness is inevitable rather than preventable. Currently prevention strategies are predicated on a biomedical explanation of disease that emphasizes the individual's control over infection. Similarly, treatment and care for HIV illness in Ghana is based primarily on a biomedical model. Should health professionals work to eliminate beliefs about supernatural causes of illness and to discourage traditional and spiritual treatments for HIV illness? Or should they expand the model of HIV prevention and care to incorporate traditional beliefs about disease causation and to include a range of treatment options? The purpose of this paper has been to raise the questions. It is the responsibility of Ghanaians to contemplate and formulate the solutions.

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Table 1: Sample Demographics
N = 31

	Frequency
Age	
≤ 29 years	9
30-49 years	18
≥ 50 years	4
Marital Status	
Single	13
Widowed	6
Married/Living together by mutual consent	6
Divorce/Separated	6
Travel	
No	23
Yes	8
Number of Children	
None	13
One	9
Two	4
Four or more	5
Occupation	
Trader	22
Seamstress	3
Farmer	2
Hairdresser	2
Fish smoker	1
Commercial sex worker	1
Tribal Group	
Akan	13
Ga	8
Ewe	5
Krobo	3
Kassina-nankani	1
Dagomba	1
Religion	
Christian – Mainstream (eg Roman Catholic)	15
Christian – spiritual (eg Church of Christ)	15
Muslim	1
Years of Education	
None	8
3-6 years	3
7-10 years	19
12 years	1

Table 2: Time since diagnosis
N=31

	Frequency
1 day → 5 months	12
6 months → 12 months	6
13 months → 5 years	8
6 years →13 years	5

Table 3: Symptomology
N=31

Symptom	Frequency
Weight Change	
Loss	20
Gain	2
Gastro-Intestinal	
Diarrhea	18
Loss of appetite, difficulty swallowing, mouth sores	4
Vomiting	3
Constipation	1
Systemic	
Body Pains	17
Weakness	15
Fever	10
Swollen extremities	2
Waist Pains	2
Genito-Urinary	
Genital sores, warts, discharge, or krusakrusa (rash)	9
Kooko (hemorrhoids)	5
Dysuria	3
Amenorrhea/dysmenorrhea	3
Cough	9
Skin Conditions	
Boils	11
Rashes	7
Ananse (shingles)	2

Shrouded in Secrecy: Breaking the News of HIV Infection to Ghanaian Women

Introduction

> "The third epidemic...is unlike the first two in that it is a social rather than a medical infection: the denial, blame, stigmatization, prejudice and discrimination which the fear of AIDS brings out in individuals and societies". (Panos Institute, 1990, p i).

Almost a decade ago, the Panos Institute conceptualized the evolution of AIDS disease as three successive epidemics (Panos Institute, 1990). This conceptualization continues to be relevant to the HIV epidemic today and provides a lens through which the epidemic in Ghana can be viewed. The first epidemic remains hidden and represents individuals who are infected with HIV. It is estimated that at least 600,000 Ghanaians are living with HIV (UNAIDS, 1999). The second AIDS epidemic is primarily visible and refers to the number of individuals with advanced, symptomatic disease. As of December 1998, 29,546 new cases of AIDS had been reported to the Ghanaian Ministry of Health, representing a 27% increase from 1997 (Disease Control Unit, 1999). The fear of AIDS has fuelled the third epidemic that is social in nature and results from the denial, fear and stigmatization that have followed in the footsteps of the first two epidemics. In Ghana, the third epidemic is often hidden, sometimes visible, and always present.

The need for understanding of and sensitivity to the context of HIV transmission is now well entrenched in the literature (Aggleton, 1996; Standing, 1992; Zwi, 1993). The phenomenon of stigma and discrimination surrounding HIV/AIDS illness is one component of this broad context (Aggleton, 1993). Knowledge of the factors that influence AIDS stigma and the extent of stigmatization is important for several reasons. The stigma that surrounds HIV may have a profound impact on the process of disclosure and the subsequent care and treatment of infected individuals (Chesney & Smith, 1999;

Moneyham et al., 1996; Muyinda, Seeley, Pickering, & Barton, 1997). In addition, AIDS stigma has been found to negatively affect the emotional, financial and social lives of HIV positive individuals and families. Finally, AIDS stigma has the potential to interfere with the efficacy of AIDS prevention efforts (Herek et al., 1998). Knowledge about AIDS stigma, therefore, is essential to understand the type and extent of HIV education needed within a community. In this paper, findings from recent research to explore the experience of HIV positive women in Ghana will be used to document the presence and impact of AIDS stigma. The secrecy surrounding "breaking the news" of HIV infection will be examined as one manifestation of AIDS stigma in Ghana.

AIDS and stigma

Stigma is a term originally used in Classical Greece to mean a bodily sign cut or burnt into individuals, such as slaves, traitors and criminals, whose moral character was considered tarnished (Goffman, 1963). Today, the meaning of stigma is more commonly associated with the disgrace and shunning directed toward those individuals that are outcast by society, rather than with the physical evidence of it. As an illness, AIDS has several attributes that render it likely to evoke stigma: HIV illness is frequently viewed as the result of immoral or deviant behaviour that is viewed as the responsibility of the individual; it is perceived as a threat to the community because of its contagiousness; and HIV illness is considered as a degenerative disease resulting in death (Alonzo & Reynolds, 1995; Herek, 1999). In addition, frequent misunderstandings surrounding HIV illness (Alonzo & Reynolds, 1995) and the visibility of the illness to others (Herek, 1999) increase the likelihood that its victims will be stigmatized. Herek et al (1998) argue that AIDS stigma exists at both the individual and the community level. At the individual level AIDS stigma takes the form of behaviours, thoughts and feelings, whereas at the community level it is manifested in laws, policies and popular discourse.

Definitions, representations and metaphors of HIV/AIDS have contributed to its stigmatization as an illness. The early definition of AIDS as a sexually transmitted disease, rather than a viral communicable disease as with hepatitis B, has had a profound impact on the social definition of AIDS (Altman, 1994; Gilman, 1988). The sexual transmission of this disease denotes, for many, a manner of infection that is self-induced (Sontag, 1989). The societal response to HIV illness has been compared to that of cholera (Herek, 1990), leprosy (Farmer & Kleinman, 1989), and syphilis (Brandt, 1988; Gilman, 1988; Pappas, 1993). Persons with AIDS have been stigmatized by society, as was the case with syphilitics, based on the belief that those afflicted have violated the moral order (Brandt, 1987; Brandt, 1991). Researchers comparing the iconography of syphilis and that of AIDS have concluded that in both cases the media has greatly affected the public image of these diseases (Gilman, 1988; Paicheler, 1992). The tendency to use military metaphors (e.g. 'war on AIDS', 'invasion of cells') to describe AIDS has also contributed to the "excommunicating and stigmatizing of the ill" (Sontag, 1989, p. 94). The image of HIV illness as a self-induced, sexually transmitted disease resulting from immoral behaviour has been fuelled and sensationalized by the media.

The process of disclosing HIV positivity is mediated by the relationships and environment that surround it (Cusick & Rhodes, 1999). Within the context of stigma the experience of disclosing HIV status becomes highly complex and often stressful for an individual. One recent American study reported that HIV positive women were hesitant to disclose their status based on a fear of violence, rejection and discrimination (Gielen et al., 1997). A Zairean study to explore the impact of HIV testing and counselling found a very low percentage of women returned with their partner for HIV testing and counselling 12 months following their diagnosis (Heyward et al., 1993). In Thailand, although overt stigmatization was rarely mentioned, most women did not disclose their HIV status to anyone except their partners due to fear of the outcome (Manopaiboon et al., 1998).

Several factors have been identified that mediate the response to HIV illness and the level of stigmatization that it evokes. In societies where women's status is lower and unequal in relation to men, women may be more vulnerable to the stigma associated with HIV illness (Long & Messersmith, 1998). American researchers, on the other hand, found that women were held less accountable for their HIV illness in comparison to men and as a result were less likely to be stigmatized (Borchert & Rickabaugh, 1995). In addition, they argued that regardless of gender, when illness was considered to be preventable it was perceived more negatively. In a review of AIDS stigma in the United States (Crawford, 1996), it was reported that lay populations expressed a higher degree of stigma toward AIDS patients than health professionals and that there was a greater degree of stigma toward individuals with AIDS than with other comparable diseases such as cancer.

AIDS and stigma in Ghana

Despite the universality of AIDS stigma, its manifestation and targets vary by country (Herek et al., 1998). A major study of the social dimensions of HIV/AIDS in Ghana documented that "AIDS patients suffer from isolation, stigmatization and withdrawal from some family members" (Awusabo-Asare & Anarfi, 1995, p. 68). In relation to disclosure, Anarfi (1995) found that 25% of AIDS patients did not tell anyone their diagnosis and more than 90% did not inform their spouses. A recent study of the attitudes of health care workers about HIV illness in Ghana found that the hysteria and stigma surrounding HIV illness often resulted in individuals denying their positive status and documented a generalized fear among health workers of becoming infected with the HIV virus when working with AIDS patients (Awusabo-Asare & Marfo, 1997). It is likely that this attitude is translated to patients during their care. The stigmatizing effect of HIV illness in Ghana was dramatically highlighted in early 1998 during a visit to Ghana by the author to prepare the current research proposal. During the inaugural meeting of a national support group for AIDS patients, many of the participants described their fear of being shunned by their families if their HIV status became known. One woman disclosed that, despite knowing of her HIV status for more than four years, the members of the support group were the first individuals with whom she had shared her secret.

Beliefs about disease causation in Ghana may also predispose persons with HIV illness to stigmatization. In the traditional healing system in Ghana, disease was believed to result from natural or supernatural causes (Senah, 1997; Wyllie, 1983). Illnesses with one or more of the following characteristics are more likely to be classified as supernaturally or spiritually caused: the disease results in deformity; the disease is contagious, but the victim is unaware of contact with a contagious individual; the disease is serious; and the victim of the disease is experiencing stress due to the violation of a cultural norm (Warren, 1979). HIV illness has the potential to be classified as supernatural on the basis of one or more of these characteristics and has in fact been given a supernatural explanation by Ghanaians (Awusabo-Asare & Anarfi, 1997). The association of HIV illness with supernatural causes contributes to its stigmatization (Awusabo-Asare & Anarfi, 1995).

AIDS stigma is often targeted at individuals and groups in society who are already stigmatized. In North America these groups include gay men and intravenous drug users (Brandt, 1991; Chesney & Smith, 1999; Herek & Capitanio, 1999), whereas in Ghana AIDS stigmatization is compounded by the association of HIV illness with prostitution (Anarfi & Awusabo-Asare, 1993; Ankomah, 1998; Mill, 2000). An individual suffering from HIV illness, therefore, may experience a double burden or layering of stigma. Although several studies have documented the presence of AIDS stigma in Ghana, few have explored the experience of disclosure within this highly stigmatized environment. The paper will present findings related to 'breaking the news" of HIV infection to women and their maintenance of secrecy following diagnosis. Although the researcher had not initially planned to explore the process of disclosure, this phenomenon emerged as an important theme during interviews with HIV positive women.

Design and Methods

The study was carried out in Ghana from January to May 1999 using participatory action research as the methodology. Participatory action research emphasizes collaboration with and 'consciousness raising' of all participants in the research about the problem being investigated (Rahman, 1991). Collaboration was initiated in May 1998 during an exploratory trip to Ghana to meet with key people in HIV prevention and research and to solicit their feedback about the planned research. Throughout the study, collaboration and consultation with other researchers, professionals, research assistants, and HIV positive individuals continued. Consciousness-raising occurred during the interviews with traditional healers, professionals and HIV positive women and the focus groups with nurses and HIV positive men. In addition, awareness of the issues related to HIV infection was facilitated during group presentations of the findings at the completion of the study. Participants at the presentations included health professionals, researchers, persons living with AIDS and representatives from government and non-government organizations.

Qualitative methods, including in-depth interviews and focus groups, were the primary data collection methods. The target population from which the HIV positive women were recruited included all patients seen in the HIV outpatient clinics of the Fever's Unit of a large, urban teaching hospital in Accra and 2 smaller hospitals in Agomanya. The Fever's Unit is situated on the perimeter of the grounds of the hospital and cares primarily for patients with cholera and HIV disease. Outpatient clinics for AIDS patients were offered at the Fever's Unit on a weekly basis. The hospitals in Agomanya, approximately 100 km northeast of Accra, provided outpatient care for AIDS patients at the same time as other patients. Non-probability convenience sampling was used to recruit 27 women from the Fever's Unit and 4 women in Agomanya. Inclusion criteria for the study were: agreement to participate; over the age of 18; HIV positive; and willing to be interviewed through an interpreter. The demographic information about the sample is outlined in Table 1.

HIV positive men, traditional healers, nurses and other professionals were asked to reflect on the women's comments and the themes emerging from the data. Five HIV positive men participated in the study. One man was interviewed individually and 4 men participated in a focus group. Two traditional healers were interviewed to explore their attitudes and beliefs about HIV illness and their approach to treatment. Eight registered nurses from a variety of units at the teaching hospital were recruited to participate in a focus group that met twice. The ten professionals interviewed included physicians, research assistants, nurse educators and HIV counsellors. In Ghana, HIV counsellors are professionals such as social workers and nurses who have received in-depth training in counselling HIV positive clients.

All but one interview with the HIV positive women and the nurses' focus groups were carried out in a local language: Twi, Ga, Ewe or Krobo. Two male research assistants with extensive experience in HIV research were hired to assist with the recruitment, interviewing and translation of the interviews and male focus group. On the advice of local researchers, interviews took place in a private room in the hospital to ensure the confidentiality of participants. It was anticipated that interviews in the home might arouse suspicion and gossip in the community. HIV counsellors at each study site provided initial information about the study to potential participants. A research assistant explained the study in more detail and obtained oral, taped consent from those agreeing to participate. Written consent was obtained from the nurses and other professionals. The interviews ranged in length from 30 minutes to one hour and 15 minutes. The reasons why the women were tested for HIV are highlighted in Table 2. The analysis of the data occurred concurrently with data collection and included the reading and re-reading of the interviews to identify themes and sub-themes. The qualitative software program NUD.IST (Non-numerical Unstructured Data Indexing) was used to assist the researcher to organize the data into thematic categories.

Breaking the News

Death is something we all face, but in different ways

The National AIDS Control Program in Ghana recommends that pre and post-test counselling be provided to everyone receiving an HIV test. The nurses in the focus group explained that all HIV patients in their hospital were referred to the Fever's Unit to receive their diagnosis and counselling from one of the specially trained HIV counsellors. It was not always easy to convince the patient to accompany the nurse to the Fever's Unit, however, because of its association with AIDS. The HIV counsellors focused on the positive and emphasized that the women should not 'worry too much' or 'think too much' about their illness. Nurses and counsellors attempted to 'normalize' death by encouraging patients to maintain hope and by avoiding discussions of the terminal nature of HIV illness. One HIV counsellor explained that in Ghana it was not acceptable to talk about death:

> Because when you tell someone they will die, they may die even before his or her death. So we don't actually tell them "you will die", but we tell them the condition they have and then how to take care of themselves. Because death is something we all face, but in different ways.

Another counsellor added that it was more acceptable to discuss death when a patient was in the terminal stages of their illness.

The finding that the health care workers often did not discuss the terminal nature of HIV illness may be related to cultural views about death. Recent research in Ghana suggests that the discussion of death is considered a verbal taboo and when it becomes unavoidable, euphemisms are used to avoid direct mention of it (Agyekum, 1997). The reticence of health care workers to discuss death with terminally ill patients was also documented in Nigeria (Adamolekun, 1997). Adamolekun suggests that this behavior is based on a cultural expectation that doctors should be able to cure all diseases and, therefore, should not be the purveyors of bad news about their patients' health. Nigerian doctors and nurses believed that it was their role to maintain hope in their terminally ill patients in the event that a miracle happened and cure became possible. Ghanaian nurses and HIV counsellors also expressed responsibility for maintaining hope in patients with a terminal illness.

Breaking the news – to whom and by whom?

Cultural beliefs appeared to influence the decision regarding who would break the news to the participants. Siblings, husbands, fathers and grandmothers often acted as intermediaries in "breaking the news" to the women. Martha recalled that her brother was given the report of her HIV positivity: "He [brother] was given the report and he gave it to my father who called me and informed me". Similarly, Patricia's husband had told her the nature of her illness after returning from the HIV clinic:

> When my husband and I came [to the clinic] before, they told me that I should take note that my husband is suffering from a disease and that I am also suffering from the same disease. When we went home he told me the particular disease that he had, saying, as it was not revealed to me at the hospital, he did not want to conceal it from me but he wanted to tell me.

Some of the women had received the news of their illness directly from an HIV counsellor, in the presence of a trusted family member. A few women, however, received the news alone either by choice or on the advice of a health professional. An older mother of four children wanted to have her son present, but her doctor recommended that she keep her news secret:

> When the doctor told me that I have the illness, I said I was going to call my son who was sitting outside to come and hear what he was telling me but the doctor said I should not tell him. I said no, I will go and call him...

The process of breaking the news was often done in a very indirect or circumspect manner. One of the male participants recalled that the HIV counsellor "...did not tell me directly that I was HIV positive, but the way he talked to me, I realized he was talking to me about AIDS...He only said I have acquired an illness which cannot be cured". Charity first learned of her diagnosis during a hospital admission: "when I was admitted, I did not know that they had gone behind me to tell my sisters. It was a sister who visited me in the evening who informed me that this is the kind of sickness I have". Similarly, some of the women avoided directly referring to AIDS or HIV illness when recounting their disclosure experience. Catherine recalled that after the blood test, she was told that she had the same "bad disease" that had killed her husband.

Reaction to the diagnosis

The women received the news of their HIV positive status with feelings ranging from shock and confusion to anger and worry. Gladys recalled that on the day that she had received her diagnosis "I was totally confused so all that I was told fell on deaf ears". Women's confusion was often based on their belief that, in Ghana, HIV illness was confined to prostitutes and those who had travelled outside Ghana (Mill, 2000). Only eight women in the interview group had ever travelled outside the country, however, and only one woman had worked as a prostitute prior to becoming ill (See Table 1). A few of the women denied that they were HIV positive. Amanda declared:

> I swear by my church, I swear by my bible that I can't accept that I have such a sickness. If I accept it, it will come true. I just can't accept it. God says put all your needs before him.

Many of the women were so worried at the time of diagnosis, and in the days and weeks following, that they suffered disturbances to their eating and sleeping patterns. Several women had contemplated suicide when told they were HIV positive. Pamela could not bear the lifestyle that her illness implied: “He [doctor] informed me and I wanted to take some drugs and die because this disease is a disgrace to someone like me who does not live a spoiled life”. This statement demonstrates the perceived association of HIV disease with prostitution and provides powerful evidence of the presence of AIDS stigma. Hope became so overcome with worry upon being told her diagnosis that she was unable to eat, lost weight and required hospitalization for two months. She believed that she began to regain her health once she learned not to “think too much” about her illness. After recovering from the shock of her diagnosis, Hope became a role model for others with HIV illness, by demonstrating the positive outcomes associated with “not thinking too much”.

Almost half of the women faced the news of their diagnosis with a quiet acceptance. This acceptance was most commonly based on the women’s belief that their fate was in the hands of God and He would determine the “right time for them to die”. Brenda, a young widow caring for four children, added that it was important for her to face her illness with strength to avoid causing her children anxiety. Another participant pointed out that AIDS was only one of many illnesses that could result in death and therefore a person could die at any time. A few of the participants expressed the belief that their HIV illness had had positive outcomes in their life. Jennifer had become involved in HIV prevention programs and reflected, “...some misfortunes are a blessing.

For me, this AIDS infection has been a blessing to my life". Mill (in press) also reported that some Canadian Aboriginal women viewed their HIV illness as a blessing that had impacted their life positively. American women found HIV discovery to be a very traumatic event that could be described as an experience of epiphany, confirmation or calamity (Stevens & Doerr, 1997). In Thailand, women living with HIV illness experienced depression, high levels of worry and stigmatization as a result of their illness (Manopaiboon et al., 1998).

Disclosure to partners and family

The women were commonly advised not to disclose their HIV status to partners and family members in the home, but rather to have them come to the HIV clinic. This was done to facilitate the screening of partners for the virus and to enable HIV counsellors to assist with the disclosure process. Heather was asked to have her boyfriend come to the clinic, but not to tell him the reason for this request: "the nurse said I shouldn't tell him but should ask him to come and see her at the clinic". Despite this attempt to mitigate negative repercussions resulting from breaking the news, some of the women were unsure if their partner would come to the Fever's Unit because of its association with HIV illness. Heather felt that "as soon as he [boyfriend] comes home he will know the reason why the nurse invited him. He knows that this place is for AIDS patients".

Although most of the women had informed one or two family members about their illness, several had not told anyone. These women felt too ashamed to reveal their news to family members. They were concerned that parents would ask them to "move from the house" and isolate them so that they "became orphans". The women's decision about whom to inform was based on consideration of which family members could maintain the secret. Ellen told the youngest of her four children, but decided not to inform the remaining three: "I do not know whether any of them has 'okra mouth'[1] and he or she will go around telling people". Several women kept their diagnosis from family members because of concerns about how they would react to the news. They believed that their families would "worry too much" and some were concerned that an elderly parent could die from the shock of the news. The women were not always the ones who informed their relatives of their diagnosis. Maria recalled, "my husband's relatives informed my parents". A few of the women suspected that a family member knew the cause of their illness, but never spoke openly about it.

Most of the women had received, or were concerned about the possibility of, negative reactions from family members about their diagnosis. Several women were devastated to discover that their families were no longer willing to share meals with them and others had been warned not to touch anything belonging to family members. Early in the interview Martha stated that her relatives continued to treat her well, but later in the discussion she admitted, "before I was told I had the disease we were eating together, but now we have stopped eating together...they say I should eat alone". As her illness progressed, Amanda had to depend on assistance from her family members. Although most were willing to offer her the care she needed, one sister treated her with contempt: "This sister of mine will not help me with anything. She will pass by when I am in need of even water. I have to depend on other people besides my sister". Cynthia was very

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[1] In Ghana, the term 'okra mouth' is used to refer to someone who is gossipy or has a "slippery" mouth. This expression is analogous to the slippery consistency of okra after it is cooked.

upset that her mother had broadcast the news of her illness to others: "As a result, my friends started teasing me and do not visit me. Then when I went out to buy something, people started pointing to me and I was censured".

Concerns about disclosing HIV status to health professionals, sex partners and children have also been noted by other researchers (Moneyham et al., 1996). Fear of stigma and rejection result in persons with AIDS selectively informing family members of their diagnosis (Bor, 1993; McGrath & Ankrah, 1993). Canadian researchers reported that HIV positive individuals weighed family and friends' ability to keep a secret and the strength of the relationship when making decisions about disclosure (Laryea & Gien, 1993). They also found that female family members, in particularly mothers, were most supportive and tolerant of HIV infected individuals.

Maintaining Secrecy

It is a disgrace

Many of the women believed that HIV infection was a disgraceful or shameful disease. They related this to the fact that AIDS was a mysterious disease, had no cure, could be transmitted sexually and was seen to be very infectious. In the following passage, Rene explains why she feels that HIV illness is disgraceful:

> It is shameful. It is a disgrace. Because if I tell you I have this disease and you told another person, you will run away anytime you see me because you may feel you will be infected with it...Anywhere you go you are shunned. If people know I have the disease, they will not sit near me in a car.

The shame and disgrace that surrounded HIV infection often resulted in the women keeping the cause of their illness secret. Patricia explained that it was important to keep HIV illness a secret because having the disease meant that you had done "something that is forbidden" and would be considered "a spoiled person". Weight loss and other visible symptoms during the later stages of AIDS also contributed to its shameful nature. A research assistant explained that HIV illness "will disgrace you before you die...You will grow lean and have a lot of symptoms like boils, coughing and rashes on the body".

Attitudes toward death from HIV illness were also permeated with stigma and shame and compounded the need for secrecy. These attitudes sometimes resulted in changes to traditional burial practices. Family members often hid the cause of death when a loved one died from AIDS, by reporting that they had died from another cause. Health professionals also approached AIDS death with secrecy. In the following passage, Catherine poignantly describes her experience at the bedside of her dying husband:

> After drinking the water, he closed his eyes as if he was asleep. I quickly went and called the nurses to come and see whether he was asleep or dead. I have never seen anybody dying in my life before and so I did not know what was happening. The nurses told me that my husband was feeling cold and that was why he closed his eyes and I should go home...I was not satisfied and so I went round the building and stood behind the window watching the nurses. They covered my husband's face with the bed sheet and I rushed back to the ward and asked the nurses "but why have you covered his face with cloth and how can he breath? They said...that I should go home. I asked them whether my husband was dead and they said, "Yes".

Catherine's desperate attempt for information about her husband's condition provides a very moving account of the secrecy surrounding AIDS death. Several of the women stated that the cause of their partner's death [AIDS] had been withheld from them. One of the male participants mourned that, "nobody told me the cause of death of my two children. No doctor told me they died as a result of HIV". Stigma surrounding death from AIDS has also been documented in Uganda (Muyinda et al., 1997) and Kenya

(Kielmann, 1997). In Kenya, stigma was particularly harsh for women who left motherless children behind and resulted in the provision of a diminished burial ceremony.

Withholding the diagnosis

The participants described situations when the diagnosis of HIV was withheld from the patient, or by the patient. Several of the counsellors believed that when patients are very ill, they should not be told the serious nature of their illness. This view is based on the belief that bad news might cause the patient to "sink more" and perhaps contemplate suicide. All of the HIV positive women had withheld their diagnosis from some family members. Some women had told one or both parents and withheld the news from siblings, whereas others had told one or two siblings and withheld the news from parents. Many were passionate about the need to keep their diagnosis secret from partners, some family members and communities to avoid the disgrace they would experience if their diagnosis became public. Hope explains:

> Now if someone hears you have it they will shun you...how they treat you will make you die at once. As soon as you enter your room you would take poison and kill yourself immediately. It won't be AIDS that killed you...That's why many people are concealing the disease.

The HIV counsellors, based on past negative experiences with disclosure, reinforced the need for secrecy to avoid stigma. Gladys recalled:

> We've been told here not to tell anyone...They said the way I was behaving wasn't good and that I shouldn't let anyone know. Maybe if someone knows, they would isolate you.

This comment demonstrates the common association of HIV illness with immoral behaviour in Ghana. Although most of the women had not divulged their secret to community members, some feared that their weight loss would reveal the nature of their illness to others.

Impact on Care

The silence necessitated by AIDS stigma also impacted the physical and emotional care received by the women. The finding that symptoms prompted most of the women to have an HIV test (see Table 2) is quite different from the findings in an American study that revealed only 10% of women were experiencing symptoms at the time of diagnosis (Stevens & Doerr, 1997). The protracted period between infection and diagnosis in Ghana may be related to the high level of stigma associated with HIV disease. It may also reflect the policy in Ghana that HIV tests requested by a physician as part of an assessment of illness are free, whereas individuals requesting a test themselves must pay a fee. Regardless of the reason for the delay in diagnosis, some Ghanaians do not receive treatment until they have advanced, symptomatic disease. Once diagnosed, stigma may also impact an individual's access to treatment. It was well known in the community that the Fever's Unit treated AIDS patients. Some women, therefore, tried to keep it a secret that they were coming to the Fever's Unit. Dorothy admitted, "when I am coming [to the Fever's] I sneak through the bushes". One HIV counsellor commented that because it was widely known that the HIV outpatient clinic was held on Wednesdays, "they [patients] feel the stigma, so we give them other days to come to the clinic". Some patients would not wait to see the physician and HIV counsellor at the outpatient clinic if they saw someone else they knew at the clinic. The stigma associated with the Fever's Unit also influenced an individual's decision to be admitted as an in-patient. One nurse remarked:

> Today we had a very sick lady and we wanted to give her IV fluids...But she refused to stay here, simply because when she's being visited, people will know she has HIV.

Keeping their illness secret resulted in some women not benefiting from the financial and emotional support families and communities were willing to offer. One HIV counsellor recalled a relative reacting to the news that her family member had died of AIDS with some remorse: "If I had known I would have supported her more than this". The potential for support from families and communities, however, was balanced against the very real possibility of being rejected. Amanda stated that people in her community, seeing that she was ill, "...have withdrawn because once you fall sick, people do not come near you". American researchers have also reported that women's concerns about confidentiality often inhibited them from seeking out necessary medical treatment and resulted in the use of extreme measures to keep their use of "HIV services" secret (Moneyham et al., 1996).

Breaking the Silence

The narratives described in this paper document many negative outcomes experienced, or anticipated, by Ghanaian women in relation to HIV disclosure. Women were shunned on the basis of physical characteristics, such as weight loss, associated with their illness. Some were asked to eat alone, a very humiliating experience in a society that places high value on communal meals. Still others were isolated by community members or forced out of their home when their diagnosis became known. These outcomes were extremely stressful for the women and acted as powerful motivators for the women to keep their diagnosis secret. Negative outcomes in relation to the disclosure of HIV status have also been reported in studies in Canada (Laryea & Gien, 1993), the United States (Gielen et al., 1997) and Thailand (Manopaiboon et al., 1998).

Despite the reality that negative consequences of 'breaking the news' did occur, a small number of the women had a much more positive experience. They reported that their families treated them the same or better, after learning of their diagnosis. Hope described the gentle care that her siblings had given her since being informed of her diagnosis:

> It is rather now that they hold me like an egg. Even before they didn't handle me like that. They realized if they didn't handle their sister like that, she would disappear from them.

A few women recalled that a family member had been supportive by reassuring them not "to think" or "to worry" too much about their illness. Rene was quite surprised that her illness had not affected her mother's love because of the stories that she had heard to the contrary:

> It [mother's love] is the same as before. This surprises me, because I come to meet some patients here complaining that rooms should be found for them because their mothers with whom they were living have sacked them.

Research in Uganda documented that although family members expressed shock and disbelief when an individual in their family was diagnosed with HIV illness, they did not reject the person or fear infection (McGrath & Ankrah, 1993). Similarly, researchers in Rwanda (Keogh et al., 1994) and the United States (Gielen et al., 1997) found that most partners were supportive when women disclosed their HIV sero-positive status. The authors of a major literature review of the intersection between HIV and violence with women concluded that although a significant number of women experience negative consequences following disclosure of HIV positive sero-status, the partners of most women are supportive (Maman et al., 2000).

During the field research, I began to question whether the secrecy that surrounded "breaking the news" of HIV illness might actually maintain and amplify stigma in Ghana. One of the professionals with extensive experience training HIV counsellors in Ghana agreed that it might be time to widen the circle of those informed about an individual's diagnosis:

> ...Secrecy is a problem to me now. It's an issue that I have to find a way of dealing with and I've started telling people that, there's no need to hide it. We need to widen the system. We can maintain the confidentiality and secrecy but we have to widen it.

This counsellor had begun to question the well-intentioned practice of encouraging HIV patients to keep their diagnosis secret to all but one, or perhaps two, family members. She recalled working with a pastor and a group of elders on behalf of a patient and being "overwhelmed" by the support that they were able to provide. Encouraging disclosure, within a trusting and supportive environment, may help to diffuse AIDS stigma in Ghana.

Researchers in the United Kingdom suggest that the disclosure of HIV positivity to sexual partners is an essential strategy to ensure the support and acceptance of HIV positive individuals (Cusick & Rhodes, 1999). These authors found that disclosure of HIV sero-positivity had a positive impact on partner relationships and resulted in the partner's willingness to share the responsibility for transmission prevention. Participants in an American workshop on AIDS stigma argued that although privacy legislation may assist the individual to handle AIDS stigma it "...may also contribute to the characterization of HIV as a dirty secret" (Herek et al., 1998, p. 38). Hall, Stevens and Meleis (1994) argue that stigmatisation is one aspect of marginalization. They suggest that secrecy, while providing protection for marginalized groups, may actually contribute to their marginalization.

Future Possibilities

Education

These findings highlight the urgent need for a multi-faceted, broad-based approach to address the complex issue of AIDS stigma. Education at the community level has been advocated as a key strategy to reduce the shame and blame surrounding HIV illness in Ghana (Anarfi, 1995), Uganda (McGrath & Ankrah, 1993) and in the United States (Gielen et al., 1997). Public education about HIV illness in Ghana, however, has been limited. This may be related to the stigma surrounding HIV illness, as well as the belief that the discussion of sexuality in schools and other public settings is a violation of traditional values. The tendency to equate HIV illness with immoral behaviour requires that prevention programs emphasize the importance of taking responsibility without communicating a message of blame toward people who are HIV positive (Herek et al., 1998). Some of the participants believed that the stigma surrounding HIV illness in Ghana had its roots in misunderstanding. One of the men in the focus group suggested, "if they [Ghanaians] have education, by all means they will understand and welcome". Several professionals advocated the participation of persons with AIDS in prevention programs in order to personalize and normalize the epidemic. This strategy has been used, and recommended, as a prevention strategy in other sub-Saharan African countries (Muyinda et al., 1997). Researchers in the United States, however, argue that AIDS stigma persists despite disclosure by public individuals with AIDS (Herek et al., 1998).

Health professionals, including nurses, must also be encouraged to participate in education programs that promote awareness of issues related to HIV illness. AIDS stigma has been documented among health care workers and can influence the quality of care provided to HIV positive patients (Awusabo-Asare & Marfo, 1997; Baguma, 1992; Chesney & Smith, 1999). Health professionals are obligated, therefore, to explore their own feelings and prejudices about HIV illness and to ensure that they provide compassionate care to persons with AIDS (Chesney & Smith, 1999). In Ghana, there is tremendous potential for nurses to extend their role in the care of HIV positive individuals. Nurses working at the teaching hospital in Accra had limited opportunity to provide emotional support and counselling to HIV positive patients. This is due in part to patients' reticence to reveal their diagnosis and in part to the hospital policy that HIV counselling should be done centrally at the Fever's Unit. The nurses who participated in the focus group believed that HIV counselling should be available throughout the hospital and stated that a program to train nurses in HIV counselling was being considered. Although supportive of this proposal, one nurse felt that this initiative would be difficult to implement due to staff shortages:

> ...At times we are few, so you don't have the time to be by the patient or maybe hours chatting with her that will take her mind off it. But I think most of the nurses have the potential of doing that. But because we are few, we tend to ignore certain things that would be of benefit to the patient.

Education of church members and their leaders may also be an important strategy to promote a more compassionate and caring environment for persons with HIV illness. Anane (1999) maintains that the association of HIV illness with immoral behavior has resulted in reticence among religious leaders to address the issue of HIV illness in Ghana. Although some participants in the current study received counselling and support from church members, others were very fearful of disclosing their HIV status to their church community. One of the male participants, himself a church secretary, believed that churches in Ghana played a significant role in the propagation of AIDS stigma:

> In the church, if you hear the comments people make about AIDS you would realize that they are in dire need of education on HIV and AIDS…Sometimes I feel as a Christian I have to face my church and tell them I am HIV positive, but second thoughts have restrained me from doing so. This is because if I am not careful, people will run away from me.

In addition to HIV education programs, this man advocated support programs to assist individuals to "come out" publicly about their illness.

Research

The current study demonstrates the need for research in several areas. The manifestation of AIDS stigma is influenced by a variety of cultural, social and political factors. Research, therefore, is required to document the prevalence of AIDS stigma in Ghana and the manner in which it is expressed. For example, the investigation of AIDS stigma among health professionals is essential because of the potential impact of AIDS stigma on the care of patients. Research to explore the relationship between AIDS stigma and other forms of societal stigma is also urgently needed (Herek et al., 1998). While AIDS stigma in North America is frequently embedded within the stigma directed at homosexuals and intravenous drug users, AIDS stigma in Ghana is inextricably linked with negative attitudes toward female prostitutes. Research to investigate the impact of HIV prevention messages in the media on AIDS stigma is also necessary. Finally, research is required on the process of "breaking the news" about HIV status in Ghana. This type of investigation has the potential to identify factors that facilitate the disclosure process and to document the nature of support required by patients.

In the early years of the HIV epidemic, Farmer and Kleinman (1989) stressed the importance of acknowledging the human suffering that accompanies HIV illness. They argued that the experience of suffering in HIV illness was often magnified by the discrimination, fear and social death associated with the illness and advocated education to allay the often "irrational" fears of the public. The secrecy surrounding breaking the news of HIV infection related by Ghanaian women is one manifestation of AIDS stigma in Ghana. The women's narratives provide compelling accounts of the stress and suffering associated with the illness. Health professionals have a pivotal role to play in efforts to ameliorate AIDS stigma by role modeling compassionate and caring attitudes toward persons living with AIDS (Chesney & Smith, 1999).

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Table 1: Sample Demographics
N = 31

	Frequency
Age	
≤ 29 years	9
30-49 years	18
≥ 50 years	4
Marital Status	
Single	13
Widowed	6
Married/Living together by mutual consent	6
Divorce/Separated	6
Travel	
No	23
Yes	8
Number of Children	
None	13
One	9
Two	4
Four or more	5
Occupation	
Trader	22
Seamstress	3
Farmer	2
Hairdresser	2
Fish smoker	1
Commercial sex worker	1
Tribal Group	
Akan	13
Ga	8
Ewe	5
Krobo	3
Kassina-nankani	1
Dagomba	1
Religion	
Christian – Mainstream (eg Roman Catholic)	15
Christian – spiritual (eg Church of Christ)	15
Muslim	1
Years of Education	
None	8
3-6 years	3
7-10 years	19
12 years	1

Table 2: Decision to Test
N = 31

	Frequency
Experiencing Symptoms	28
(weight loss, body pains, weakness, diarrhea and coughing)	
Death of a family member	
Child	1
Husband	1
Pre-marital screening	1

Conclusion

During my field research in Ghana, and since returning to Canada, I have developed a discomforting awareness that many of the factors that limited women's ability to protect themselves from infection were related to influences far beyond their sphere of control. Poverty, power imbalances in relationships with men, and limited access to education were prevalent themes in the women's stories. While intellectually acknowledging the relationship between poverty, education and power, and women's vulnerability to HIV infection, I was unprepared for my own consciousness raising that their powerful stories would provoke. Although some factors that had influenced women's susceptibility to HIV infection were based on attitudes, beliefs and cultural norms, others were synonymous with, or at least related to, broader issues of development. Their life experiences, and their ultimate infection with the HIV virus, provide compelling evidence that in Ghana HIV illness is a disease of development.

Disease and development

More than a decade before the first case of HIV disease was documented in the United States, Hughes and Hunter (1970) published an in-depth analysis on the role of development in fostering disease. The authors argue that the attempt to foster change, inherent to development programs, may result in consequences that are unanticipated, and deleterious, for health. For example, the epidemiology of many diseases in Africa, including sleeping sickness, bilharzia and malaria, has been altered, and their morbidity intensified, as a result of development programs (Hughes & Hunter, 1970; Lambrecht, 1988). Development initiatives in Africa have fostered disease because they have failed to consider the ecological ramifications of development (Hughes & Hunter, 1970;

Lambrecht, 1988). Changes to value systems and social sanctions, including the erosion of traditional systems and migration to urban areas, are examples of 'hidden costs' of development that can impact health status (Hughes & Hunter, 1970). Hughes and Hunter provide a persuasive argument of the need to include interdisciplinary input in the planning of all development programs in order to ensure that their ecological implications are considered.

AIDS is a contemporary example of a disease of development because of the social and economic factors that influence its spread (Schoepf et al., 1991). Based on research in Zaire, Schoepf argues that, "the virus is a political event the effects of which have been magnified by the conditions of urbanization in African societies, distorted development, and the current world economic crisis" (Schoepf, 1992, 279). Ocholla-Ayayo (1997) makes a similar claim based on research of sexual practices in Kenya. The author refutes previously published literature on HIV infection in Africa that asserts that the high incidence of infection is attributable to traditional marriage systems, including weak conjugal bonds, few sanctions on premarital and extramarital sex and polygyny. Ocholla-Ayayo argues, "that current sexual practices in Kenya are largely artifacts of modernization, not elements of traditional Kenyan society" (p.110). He suggests that the erosion of traditional values and norms relating to sexual behaviour in Kenya has resulted in increased vulnerability to HIV infection. Ocholla-Ayaya's argument is congruent with one of the 'hidden costs' of development referred to by Hughes and Hunter in 1970.

Economic realities in Ghana

In Ghana, the health care system, and the subsequent health status of Ghanaians, was impacted by a deepening economic crisis and burgeoning debt load in the post-independence period. Economic structural adjustment programs (SAP) imposed in the mid-1980's by international agencies such as the International Monetary Fund (IMF) and the World Bank to mitigate this crisis were tied to 'conditionalities'[1] that created hardships in many sectors of society (Thomas-Emeagwali, 1995). Decreased investment in social services, and the trend toward their privatization that were the hallmarks of the structural adjustment programs, resulted in conditions that compromised human rights (Tomasevski, 1989). External debt in Ghana more than tripled between 1984 and 1994, resulting in a dramatic increase in the percentage of the GNP required for debt servicing from 6% in 1970 to 23% in 1994 (Kibirige, 1997). Concurrent with increased debt, government health spending decreased from 10% in 1989 to less than 5% in 1994 (United Nations Development Programme, 1997). Although SAP programs were initiated to improve social and economic conditions, Tomasevski (1989) asserts that, "the negative consequences of structural adjustment on the human condition resulted in retrogression, rather than development in the areas of nutrition, education, employment and social welfare" (p. 95).

Structural adjustment programs resulted in improvements in several sectors of the Ghanaian economy; however, these gains were not reflected in improved socioeconomic conditions and health status of all individuals, particularly the most vulnerable (Anyinam, 1989; Kuenyehia, 1994; Manuh, 1994). Women and their children have been disproportionately affected by the negative consequences of structural adjustment in Ghana (Avotri & Walters, 1999; Kuenyehia, 1994) and in other African countries

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[1] The conditionalities included currency devaluation, deregulation of prices, privatization of parastatals, trade liberalization, and the removal of subsidies on food, petrol, health and other services (Thomas-Emeagwali, 1995).

(Kibirige, 1997; Schoepf et al., 1991). Kuenyehia (1994) maintains that cutbacks to social expenditures necessitated by SAP have resulted in decreased access to health services, education and sanitation for poor Ghanaian women and argues that these privations represent human rights violations. Employment opportunities for women in both the formal and informal sectors have also decreased as a result of SAP (Manuh, 1994). Brydon and Legge (1995) portray a contrasting picture of the impact of structural adjustment on Ghanaian women. These authors interviewed women in two rural areas of Ghana and concluded that life for most women had changed little since the late 1960's. These findings may reflect a differential effect of structural adjustment on rural and urban women.

Development indicators and HIV disease

Poverty, and the patterns of migration that often accompany it, are fundamental issues of development. Poverty and migration are forces that influence the spread of disease generally (Hughes & Hunter, 1970) and of HIV disease specifically. The correlation between poverty and the spread of HIV infection has been well documented (Kitts & Roberts, 1996; Wilton, 1997; World Bank, 1997). Faced with overwhelming poverty, African women are often forced to use sexual relationships as strategies for survival (DeCock et al., 1994; Ocholla-Ayayo, 1997; Schoepf, 1994; World Health Organization, 1994). This reality places women in an extremely vulnerable position because of the high rates of HIV prevalence in sub-Saharan Africa. Researchers in Zaire argue, "...linking macrolevel political economy to microlevel social analysis shows that women's survival strategies have turned into death strategies" (Schoepf et al., 1991, p. 201).

Patterns of labour migration in many countries of sub-Saharan Africa, established during colonial rule and continuing during the post-colonial period, have also been identified as contributing factors to disproportionately high HIV infection rates in women. Migration involves men, and to a lesser extent women, moving away from their usual place of residence for employment and results in long periods of separation from the family unit. Standing (1992) argues "...that contemporary forms of sexual exchange in sub-Saharan Africa have their own histories in the political economy of the colonial and postcolonial period and particularly in the resultant patterns of migration and urbanization..." (p. 478). The social disruption and changing rules for extramarital relationships that occur in conjunction with migration result in increased vulnerability to HIV infection, particularly for women (Anarfi, 1993; Decosas et al., 1995; Kielmann, 1997; Sabatier, 1996; UNAIDS, 1999). For example, labour migration may be accompanied by an increase in the use of commercial sex workers by men separated from their wives (Decosas & Pedneault, 1992; Ulin, 1992). The use of commercial sex workers results in an increased likelihood of wives being exposed to the HIV virus when their husband returns home. The economic crisis in Ghana, in combination with differential economic development neighboring West African countries, is a fundamental force driving migration (Anarfi, 1993).

Women's educational access and attainment has also been referred to as a development issue (Sutton, 1998). Women's unequal status in many sub-Saharan countries may result in their decreased access to education. Lack of educational opportunities, in combination with a marginalized economic position, increases women's vulnerability to HIV infection (Aggleton, 1996; Campbell, 1997). Some women feel pressured into partnerships at an early age in exchange for school fees (Decosas & Pedneault, 1992; Ulin, 1992) or feel totally dependent on their partners for economic survival (Campbell, 1997). In contrast, Sutton (1998) points out that increased education of girls results in lower fertility rates and improved child health, and may serve as a positive predictor of economic growth.

Gender inequity is another indicator that implicates HIV disease as a disease of development. Gender is an important variable in the health and well being of women because of the unequal relations of power and the increased rates of poverty that often accompany the 'female' role (Long & Messersmith, 1998; Wilton, 1997). Women's diminished access to productive resources such as credit, land, property and employment, in relation to men, increases the likelihood that they will be dependent on male partners (UNAIDS, 1999). Gender inequity and women's powerlessness contribute to HIV transmission and restrict HIV prevention efforts (Baylies & Bujra, 1995; Jackson, 1998; World Health Organization, 1994). Ampofo's (1993) review of violence against women in Ghana provides a courageous, and seldom discussed, portrayal of women's powerlessness in relationships with men. The author reviews interpersonal and institutional violence against women and suggests that, "the state has generally viewed women as a problematic social category that needs to be controlled and directed" (p. 102).

Women's inequity is also evident in the recent phenomenon in many sub-Saharan countries of older men choosing younger women as their sexual partners (Schoepf, 1994). Men choose younger women with the hope that they will be less likely to be infected with HIV (Campbell & Kelly, 1995; Jackson, 1998; Obbo, 1993). Therefore, in exercising their disproportionate power to choose partners, men's attempts to minimize their own risk of infection results in a concomitant increase in women's risk of infection. This gender inequity is evident in Ghana, where women's low socioeconomic status increases the likelihood that they will marry early and to an older man (Anarfi & Awusabo-Asare, 1993). The phenomenon of older men choosing younger women as sexual partners has influenced the epidemiology of HIV disease in some sub-Saharan African countries. In Ghana for example, the peak prevalence for HIV disease is 25-29 years for women, as compared to 35-39 years for men (Disease Control Unit, 1999), indicating that females become infected with the virus earlier than their male counterparts.

Women's lower status and power impact their decision-making ability in relation to reproductive health. In a marginalized position, women may be unable to negotiate safer sexual practices, such as the use of condoms (Aggleton, 1997; Campbell, 1997; Mbizo & Bassett, 1996; Ulin, 1992). One researcher in Ghana concluded that "men's influence over their wives' contraceptive attitude seems to operate both through comparative advantage in mate selection and through cultural norms that subjugate women to men" (Ezeh, 1993, p. 173). Ghanaian women's increasing economic dependence on men in the post-colonial period has also decreased their ability to influence decisions about sexuality (Awusabo-Asare et al., 1993).

Cultural beliefs and practices relating to fertility and sexuality may present additional barriers to the adoption of HIV prevention strategies by women. In most sub-Saharan countries, a woman's social status is directly linked to her ability to produce children (Ankomah, 1998; Caldwell et al., 1992; DeBruyn, 1992; World Health Organization, 1994). The promotion of condoms to prevent the spread of sexually transmitted diseases such as HIV and, coincidentally, pregnancy is therefore in direct opposition to a powerful social norm. Attitudes toward sexuality in sub-Saharan Africa also influence women's vulnerability to HIV infection. In Ghana, pre-marital sexual relationships are acceptable for men and in some instances for women, and extra-marital relationships are socially sanctioned and common for men (Anarfi, 1990; Anarfi & Awusabo-Asare, 1993). Postpartum sexual abstinence is a custom in many countries of Africa that may predispose women to HIV infection (Awusabo-Asare & Anarfi, 1997). Although there is limited research to explore the causal link between postpartum sexual abstinence and increased extra-marital relationships, there is evidence that men often seek partners outside the marriage when their wives are not available (Anarfi, 1990; Awusabo-Asare & Anarfi, 1997; Bleek, 1987). These cultural practices, in combination, may render monogamy unrealistic as an HIV prevention strategy for many Ghanaian women.

In the past, the concept 'disease of development' has been used, primarily, to refer to changes in the epidemiology of parasitic diseases as a result of the failure to forecast or consider the ecological impact of development. In this discussion I have attempted to document the relationship between several development indicators and HIV disease. In some instances infection with the HIV virus may be within the sphere of individual control; however, in many instances infection is influenced by structural, social and economic factors that are well beyond individual control, especially for women. Poverty, education, migration and power are indicators related to development, and at the same time, factors that increase the vulnerability of women to HIV infection. These indicators do not exert their influence in a straightforward manner, but rather are bound together in a relationship that is complex and synergistic. HIV disease is a disease of development.

Implications for nursing

There are important implications of these findings for nursing. HIV disease has a profound negative impact on health. The prevention of disease and the promotion and maintenance of health are fundamental goals of the nursing discipline. Nurses, and nursing, therefore, are obligated to participate in the design of strategies to prevent HIV disease and to promote optimal nursing care for individuals who are ill with HIV disease. The prevention of HIV infection is particularly relevant for public health nurses because of their expertise in health promotion and disease prevention. The importance of understanding the determinants of health is well documented and health professionals have been encouraged to promote change in health-damaging conditions at the structural level, in addition to fostering change at the individual level (Labonte, 1993; Reutter, 1995). This role "...is entirely compatible with, and indeed best reflects, the mandate of community health nursing" (Reutter, 1995, p. 235). The promotion of health, in addition to being fundamental to nursing, is also "...a constitutive part of development" (Sen, 1999, p. 623).

The findings highlight several aspects of HIV prevention, education and care in Ghana that could benefit from the increased involvement of nurses. Nurses are respected health care professionals in Ghana. Therefore, they could play a pivotal role in facilitating the discussion of the sensitive topic of sexuality and HIV prevention in families, communities and schools. Nurses, the majority of whom are women in Ghana, are well placed to participate in the design and implementation of prevention programs that raise awareness of gender inequities and include strategies that are culturally feasible for women. Several nurses, during a presentation of the research findings, pointed out the need for nurses to become more actively involved in influencing politicians and policy makers to address issues, such as poverty, that influence vulnerability to HIV infection.

There is also tremendous potential for nurses to extend their role in the care and counselling of HIV positive individuals in Ghana. Currently there is limited opportunity for Ghanaian nurses to provide emotional support and counselling to HIV positive patients. This is due in part to the stigma surrounding HIV disease and in part to hospital policies that delineate where HIV counselling should take place. The nurses in the focus group supported an initiative to train nurses in HIV counselling. They believed that nurses had the potential to be involved in counselling, but felt that the initiative might be difficult to implement due to staff shortages. Another strategy to extend the role of nurses in HIV care, and that might have greater feasibility, is to integrate the knowledge and skills required to carry out HIV counselling into the basic education of nurses.

Nurses must be encouraged to participate in education programs that promote awareness of issues related to HIV illness. Misconceptions among some of the nurses about susceptibility to HIV infection suggests that ongoing professional education may by required to ensure that health care professionals have current knowledge about the epidemiology of HIV disease in Ghana. The documentation of AIDS stigma among health workers, including nurses, highlights the need for them to explore their own feelings and prejudices about HIV illness and to ensure that they provide compassionate care to persons with HIV disease.

Recommendations for further research

The current study highlights the need for research in several areas. The findings related to the "risk environment" document the urgent need for further research to evaluate the relationship between structural factors such as poverty, education and power relationships, and women's vulnerability to HIV infection. Findings related to stigma suggest the need for research to document the prevalence of AIDS stigma in Ghana and the manner in which it is expressed. The investigation of AIDS stigma among health professionals is also essential because of the potential impact of AIDS stigma on patients. The explanatory model described in the study documented that health professionals and members of the public continue to subscribe to misconceptions about who is susceptible to HIV infection. These findings highlight the need for further research in relation to knowledge and attitudes in Ghana about HIV illness. Research initiatives to explore the issues surrounding the problem of HIV disease in sub-Saharan countries like Ghana must be undertaken within a framework that is participatory. Local knowledge and expertise must be valued and equal partnerships must be sought with research collaborators. Finally, international research must meet international standards for the protection of human subjects, and at the same time, acknowledge the ethical standards related to the institutional setting and cultural environment where the research takes place.

Several questions emerge when this research project is viewed in its entirety. The perception that HIV illness is a disease of development is implicit in all of the papers, and yet, it is only made explicit in the conclusion to the dissertation. Why has the dissertation been written in this manner? It was only after I had viewed the completed papers and reflected on their broad implications that I became aware that the influences on the women's lives were enmeshed with development issues. This awareness developed slowly and unevenly. The perspective that HIV illness was a disease of development was a discomforting one. During the analysis and write-up, I may have, unconsciously, tried to frame the findings in a positive manner and to avoid analyzing the themes as development issues. As mentioned in the final paper, I made a conscious decision to take a low profile in relation to the political implications of the problem of HIV infection in Ghana. Having become aware of this perspective now, however, I am obligated to continue to pursue HIV infection from the standpoint of development in future research endeavor in this important area of knowledge development.

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Appendix 1

Guiding Questions: Interviews with HIV positive women/Focus group with HIV positive men

General Question

Can you tell me a little about yourself?
Include discussion of the financial situation of the parents while participant was growing up - did the parents separate/divorce? Were they able to provide care for the participant?

Explanatory Model

Cause of HIV illness:

Can you tell me why you think you became HIV positive?
Can you tell me where you were living when you became infected with the virus?
Who were you living with?
How were you supporting yourself?

Pathophysiology of HIV:

How do you think HIV has affected your body? Your emotions?

Symptoms of HIV:

When did you first know you had HIV?
What kind of things did you notice at first? And then?

Course of HIV:

Have you told your partner(s) about your illness?
Has your illness affected your relationship with your partner, relatives, the community?

Treatment of HIV:

Tell me what you have done to treat you illness?
Are you aware of other ways to treat HIV illness - i.e. herbalists, traditional doctors etc?

Prevention of HIV infection in Ghana

Could you tell me about any things you could have done to prevent your illness?

If this question does not elicit information about factors (family, economic etc) leading to infection more specific questions will be used to explore this area:

What methods do you think that women could use to protect themselves from HIV infection?
Are condoms an acceptable method to prevent sexually transmitted diseases in Ghana?
How would your partner react if you asked him/her to use a condom?

Guiding Questions: Interviews with HIV positive women (cont'd)

Are you aware of programs to prevent HIV infection in Ghana? If so, were you able to participate in these programs?

Reflective question: What advice would you have for men/women? (and vice versa).

Appendix 2

Guiding Questions: Nurses Focus Group

First Focus Group: March 16th, 1999

What is the most difficult problem you face in caring for HIV/AIDS patients?

Do your patients receive counselling about their illness? Who does the counselling with your patients?

What are some of the issues related to breaking the news to patients? How do each of you feel about sending the patient to the Fever's Unit to be told of their diagnosis?

Is it common on your different units to nurse HIV patients?

Second Focus Group: April 20th, 1999

1. What are your views about HIV illness: Cause, pathophysiology, symptoms, course, treatment?
- do you see HIV illness as a clean/unclean disease?
- some women have said that AIDS is a disgraceful disease? Do you agree?
- does the type of disease affect how a family will view death from HIV illness? Good/bad death
- does this effect the type of funeral arrangements that a family will make? (One nurse mentioned that when someone died of AIDS, the family wouldn't come to the mortuary to pick up the body. Is this common? Why?

2. How can Ghanaian women protect themselves from HIV infection?

Condoms
- can a married woman ask her husband to use a condom? Is it different for a single woman?
- do most couples freely discuss family planning?

Abstinence or fewer partners
- abstinence before marriage?
- is it realistic to expect marital fidelity?

HIV blood tests
- before marriage?

Appendix 3

Information and Consent Letter: HIV Positive Women

Part 1:

Project Title: HIV Infection in Ghanaian Women

Researcher: Judy Mill, RN
Affiliation: Department of Nursing
University of Ghana
Phone: 500399

Part 2: To be read to each participant

I am a graduate nursing student in the Faculty of Nursing at the University of Alberta, Edmonton, Canada. I am doing a research study and would like to ask you to consider taking part in it. This study is to learn about HIV illness in women in Ghana. To be in this study you must have had a blood test to determine that you have the HIV virus and be over the age of 18 years.

If you agree to be in the study I will ask you some questions about your illness and HIV infection. Our talk will last about one to two hours and will be recorded on a tape recorder. An interpreter will work with me so that you can speak in your own language. The interpreter and myself will keep our talks completely private. Your name will not be used in the study. The typed record of our talk may be used in future research, after ethical approval is obtained. It may be used for the teaching of others or for writing articles.

It is not expected that there will be any risk to you if you take part in the study. You may not receive any benefit from being in the study. By being in the study you may help other women in the future. You may ask any questions that you have about the study and you may choose not to take part in it. If you decide to be in the study and change your mind, you may withdraw from the study at any time. Do you have any questions?

Part 3: Questions and responses to be recorded on tape

Do you understand that you have been asked to be in a research study?	Yes	No
Have you been read information about the research study?	Yes	No
Do you understand the benefits and the risk involved in taking part in the study?	Yes	No
Have you had the opportunity to ask questions about the study?	Yes	No

Information and Consent Letter: HIV Positive Women (cont'd)
Project Title: HIV Infection in Ghanaian Women

Do you understand that you are free to refuse to participate or to withdraw from the study at any time? If you chose to withdraw from the study, your care at the clinic will not be affected.	Yes	No
Has the issue of the privacy of this interview been explained to you?	Yes	No

I (participant's name) agree to take part in this study. The date today is (date of interview).

The consent has been obtained by (name of interviewer). I believe that the person giving consent understands what is involved in the study and voluntarily agrees to participate.

Appendix 4

Information and Consent Letter: HIV Positive Men

Part 1:

Project Title: HIV Infection in Ghanaian Women

Researcher: Judy Mill, RN Affiliation: Department of Nursing
University of Ghana
Phone: 500399

Part 2: To be read to each participant

I am a graduate nursing student in the Faculty of Nursing at the University of Alberta, Edmonton, Canada. I am doing a research study and would like to ask you to consider taking part in it. This study is to learn about HIV illness in women in Ghana. I am also interested in finding out how men feel about this problem. To be in this study you must have had a blood test to determine that you have the HIV virus and be over the age of 18 years.

If you agree to be in the study I would like to talk to you alone or with other men with the virus. I will ask you some questions about your illness and HIV infection. Our talk will be about one to two hours and will be tape recorded. An interpreter will work with me so that you can speak in your own language. The interpreter and myself will keep our talks completely private. Your name will not be used in the study. The typed record of our talk may be used in future research, after ethical approval is obtained. It may be used for the teaching of others or for writing articles.

It is not expected that there will be any risk to you if you take part in the study. You may not receive any benefit from being in the study. By being in the study you may help other women in the future. You may ask any questions that you have about the study and you may choose not to take part in it. If you decide to be in the study and change your mind, you may withdraw from the study at any time. Do you have any questions?

Part 3: Questions and responses to be recorded on tape

Do you understand that you have been asked to be in a research study?	Yes	No
Have you been read information about the research study?	Yes	No
Do you understand the benefits and the risk involved in taking part in the study?	Yes	No
Have you had the opportunity to ask questions about the study?	Yes	No

Information and Consent Letter: HIV Positive Men (cont'd)
Project Title: HIV Infection in Ghanaian Women

Do you understand that you are free to refuse to participate or to withdraw from the study at any time? If you chose to withdraw from the study, your care at the clinic will not be affected.	Yes	No
Has the issue of the privacy of this interview been explained to you?	Yes	No

I (participant's name) agree to take part in this study. The date today is (date of interview).

The consent has been obtained by (name of interviewer). I believe that the person giving consent understands what is involved in the study and voluntarily agrees to participate.

Appendix 5

Information and Consent Letter: Nurses Focus Group

Part 1:
Project Title: HIV Infection in Ghanaian Women

Researcher:	Judy Mill, RN	Contact person:	Ms. Joanna Laryea
Affiliation:	Department of Nursing University of Ghana Phone: 500399		Department of Nursing University of Ghana Phone: 500399

Part 2: To be read by each participant

I am a graduate nursing student in the Faculty of Nursing at the University of Alberta, Edmonton, Canada. I am doing research and would like to ask you to consider taking part in it. This study is to learn about HIV illness in women in Ghana. To be in this study you must be a Ghanaian registered nurse working in Korle Bu or St. Martin's hospital and be over the age of 18 years.

If you agree to be in the study I will ask you to participate in a focus group that will last about one to two hours and will be recorded on a tape recorder. I will ask you some questions about your views on HIV illness. In addition, I would like to know what strategies you think should be used to prevent HIV infection in Ghana. Our discussion will be completely private and your name will not be used in the study. The typed record of our group discussion may be used in future research, after ethical approval is obtained. It may be used for the teaching of others or for writing articles.

The nurses from St. Martin's hospital will participate in 1 focus group and the nurses from Korle Bu hospital will participate in 2-3 focus group meetings during the study.

It is not expected that there will be any risk to you if you take part in the study. You may not receive any benefit from being in the study. By being in the study you may help other women in the future. You may ask any questions that you have about the study and you may choose not to take part in it. If you decide to be in the study and change your mind, you may withdraw from the study at any time. Do you have any questions?

Part 3: Questions to be completed by participants.

Do you understand that you have been asked to be in a research study?	Yes	No
Have you been read information about the research study?	Yes	No

______ Initial

Information and Consent Letter: Nurses Focus Group (cont'd)
Project Title: HIV Infection in Ghanaian Women

Do you understand the benefits and the risk involved in taking part in the study?	Yes	No
Have you had the opportunity to ask questions about the study?	Yes	No
Do you understand that you are free to refuse to participate or to withdraw from the study at any time?	Yes	No
Has the issue of the privacy of this focus group been explained to you?	Yes	No

The study was explained to me by: ______________

I agree to take part in this study.

Signature of Research Participant	Date	Witness
Printed Name		Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Researcher	Date

Appendix 6

Information and Consent Letter: Professional Interviews

Part 1:

Project Title: HIV Infection in Ghanaian Women

Researcher:	Judy Mill, RN	Contact Person:	Ms. Joanna Laryea
Affiliation:	Department of Nursing		Department of Nursing
	University of Ghana		University of Ghana
	Phone: 500399		Phone: 500399

Part 2: To be read by each participant

I am a graduate nursing student in the Faculty of Nursing at the University of Alberta, Edmonton, Canada. I am doing research and would like to ask you to consider taking part in it. This study is to learn about HIV illness in women in Ghana, including factors that may contribute to their infection with the virus.

If you agree to participate in the study, I would like to discuss with you the findings from my interviews with HIV positive women and my focus groups with HIV positive men and Ghanaian nurses. Each interview will last about one to two hours and will be recorded on a tape recorder. I am interested in your thoughts and impressions about the research findings in terms of their implications for HIV/AIDS care, policy development and research in Ghana. Our discussion will be confidential and your name will not be used in the study. The typed record of our interview may be used in future research, after ethical approval is obtained. It may be used for the teaching of others or for writing articles.

It is not expected that there will be any risk or benefit to you if you take part in the study. By being in the study you may help other women in the future. You may ask any questions about the study and you may choose not to take part in it. If you decide to be in the study and change your mind, you may withdraw from the study at any time. Do you have any questions?

Part 3: Questions to be completed by participants.

Do you understand that you have been asked to be in a research study?	Yes	No
Have you been read information about the research study?	Yes	No
Do you understand the benefits and the risks involved in taking part in the study?	Yes	No

___ ___ Initials

Information and Consent Letter: Professional Interviews (cont'd)
Project Title: HIV Infection in Ghanaian Women

Have you had the opportunity to ask questions about the study?	Yes	No
Do you understand that you are free to refuse to participate or to withdraw from the study at any time?	Yes	No
Has the issue of the privacy of this interview been explained to you?	Yes	No

The study was explained to me by: _______________

I agree to take part in this study.

Signature of Research Participant	Date	Witness
Printed Name		Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Researcher	Date