University of Alberta

The Role of Ugandan Nurses in the Care of Individuals with HIV illness

by

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requirements for the degree of Master of Science

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Table of Contents

Introduction

Peeling The Many Layers

Our life is an apprenticeship to the truth that around every circle another can be drawn; that there is no end in nature, but every end is a beginning, and under every deep a lower deep opens.
- Ralph Waldo Emerson

My life is like a garden in which there is perpetual change. In my garden, growth is cyclical, and dependant on the seasons. During this summer season when all is emergent, I pause for a moment to enjoy the growth and diversity of my garden. Pausing for reflection, I realize that the unfolding of my thesis has been like the peeling of an onion. Like an onion, my thesis is comprised of multiple, interacting, and independent layers. As each layer is peeled away a different perspective is obtained until the core is reached. My progression through these many layers of my thesis has left me with many more questions about the world than when I began. Each time I peeled away another layer I revealed new insights about myself and about my research that were sometimes difficult to face and other times inspirational. Undertaking my Masters thesis has been a profoundly personal and professional experience that has brought me through my own empowerment, enlightenment, and emancipation. As well, it has provided me with a firm foundation of theoretical and practical knowledge.

Peeling away the layers and exposing the core has brought me back to the roots of my thesis. My interest in international work began in childhood when I realized, as most children do, that the world is not fair. I began asking the "big" questions about life. Why do human beings exist? Why am I here? Why are people starving? This last question was probably triggered by listening to my father tell me at the dinner table to eat everything on my plate because “there are children starving in Africa”. When I became angry with my parents I would yell, “I am running away to Africa”. In retrospect, I probably thought that I would run away to Africa to help save all those starving children. Consequently, for as long as I can remember I have always wanted to go to Africa. My Masters thesis is my journey to Africa, specifically, Uganda. However, at the end of this journey, I have come full circle, as I find myself again wondering why there is so much poverty in the world when there is so much abundance?

My passion to make a difference in the world is realized by my compassion for people who are often forgotten, ignored and most vulnerable. Compassion can be seen as a level of awareness, which also conveys a spiritual closeness with another human being.

Bennett (1993) believes compassion includes “sensitivity to what is weak and/or wounded, as well as the vulnerability to be affected by the other. It also demands action to alleviate pain and suffering” (p.19). Bennett goes on to say that if we are sensitive and vulnerable to be moved by suffering, we are simultaneously motivated to deal with those persons or conditions responsible for such suffering-politicians, governments, corporations, and institutions.

My compassion has lead me to Uganda to undertake a research study regarding the experience of nurses in caring for individuals with HIV and AIDS. While Uganda was the first country in sub-Saharan Africa to document cases of

AIDS in the early 1980's, it is one of the few countries reporting a decrease in HIV prevalence. Studies suggest that HIV prevalence in Uganda has fallen from a peak of 29 percent in the late 1990s to around eight percent in 2002 with infection rates highest in urban centers such as Kampala (Mbulaiteye et al., 2002). The decline has been attributed to an early and strong governments response, nationwide social marketing campaigns that increase awareness and knowledge of HIV transmission and prevention measures, and multi-sectoral programs, which involve condom distribution and promotion through popular songs, drama groups, and counseling (UNAIDS, 2002). In recognizing the social and economic consequences of the impact of AIDS, the Ugandan Government has given AIDS control the highest priority. However, there has been little emphasis placed on the role of nurses in the care and treatment of individuals with HIV and AIDS. Nurses in Uganda constitute a large group of health care workers who are frontline providers for AIDS patients. Individuals in authority often overlook Ugandan nurse's voices and cast their gaze towards physicians who are valued and regarded as experts. Consequently, little research has been conducted regarding the experience of Ugandan nurses in the care of individuals with HIV and AIDS.

The current study is entitled "The Role of Ugandan Nurses in Caring for Individuals with HIV illness" and was carried out between September 2003 and July 2004 as part of the requirements for my Masters in Health Promotion at the University of Alberta. There were two purposes for the current study. The first was to explore the experience and perspective of nurses in Kampala, Uganda, caring for HIV sero-positive patients. By discovering the experience of Ugandan nurses in providing care for persons with HIV illness, challenges and opportunities in their practice were illuminated. The second purpose was to empower nurses to take action to improve the care they provide to individuals with HIV and AIDS. Two broad research questions framed the study:

1. What is the experience of Ugandan nurses in the care of HIV sero-positive individuals?
2. How do participants change as a result of taking part in this study?

Participatory action research (PAR) was the methodology chosen for the study for several reasons. PAR embraces a variety of research methods to explore local knowledge and can be used in a diverse range of settings (Cornwall & Jewkes, 1995). Central to PAR is the use of dialogue as a way to facilitate the emergence of voice and the construction of new knowledge. Dialogue leads to gaining a critical perspective that becomes emancipatory for the participants and the researcher (Freire, 1990). Related to this is the concept of voice; which, according to PAR, marginalized individuals have an opportunity to articulate their perspective. According to Hall (1993) "PAR is fundamentally about the right to speak" (p. xvii). Additionally, PAR is about building democratic, participative, pluralist communities of inquiry, which is only possible with, for, and by persons and communities (Reason & Bradbury, 2001). PAR encourages participation through a shared ownership of both of process and outcome, whereby decision-making and control are shared by all participants (Baylis & Bujra, 1995). This principle of shared power is a fundamental component to PAR.

This thesis has been organized into two publishable papers and a concluding chapter. The first paper focuses on the methodology and the second research question, "How do participants change as a result of taking part in this study?" The second paper highlights the major findings and concentrates on the first research question, "What is the experience of Ugandan nurses in the care of individuals with HIV illness?"

Discovering Voice: A Participatory Action Research Study with Nurses in Uganda

The first paper is entitled "Discovering Voice: A Participatory Action Research Study with Nurses in Uganda". I have chosen to write this paper in the first person to emphasize my role in the research process. Webb (1992) argues that "participatory action researchers are obliged as part of the research to describe and evaluate their own personal contributions to the research, and should do so openly using the first person" (p.751). In this paper the process and philosophical basis of participatory action research (PAR) are discussed by reflecting on the challenges, opportunities, outcomes, and ethical issues in conducting this international research project. Six nurses from Mulago Hospital, a large national referral hospital participated in a focus group that met during a period of 10 months, for a total of eleven meetings. The nurses have become aware of influences and constraints that affect their nursing practice. Knowledge has been generated in relation to the roles of nurses in caring for individuals with HIV and AIDS. Evidence from the current study suggests that group members, by reflecting on their experiences as nurses and as participants in the study, were able to change their current understanding of their practice to make sense of their experiences, collectively, as nurses. This new understanding created a deeper self-awareness, which also was empowering.

The Experience of Ugandan Nurses in the Care of HIV sero-Positive Individuals

In the second paper, "The Experience of Ugandan Nurses in the Care of HIV sero-Positive Individuals", I report the findings of the study. This current study was conducted in two stages and took place over a 10-month period. Participatory action research was the methodology that guided the research and in-depth interviews, focus groups, and photovoice were used to collect the data. The findings indicate that nurses generally provide care using a holistic nursing approach, and believe their role is to provide ongoing counselling and to cultivate hope. Nurses face many challenges in their daily care including: poverty, insufficient resources, fear of contagion, and lack of ongoing education. Nurses' experienced moral distress due to the many challenges they faced during the care of their patients. Their caring resulted in significant emotional and physical stress. Nurses used various innovative strategies to cope with these challenges. Further research is required to explore Ugandan nurses' experiences of moral distress.

In the conclusion of thesis I reflect on my growth during the past two years. I argue as citizens of a wealthy country such as Canada, we have a moral obligation to prevent unnecessary suffering in the world. The implications of the research for nursing are considered and recommendations for future research initiatives are summarized in the conclusion. As well, I consider, in hindsight, how I might have improved the research study.

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Discovering Voice: A Participatory Action Research Study with Nurses in Uganda

Participatory action research, referred to as "the enlightenment and awakening of common peoples," (Fals-Borda & Rahman, 1991, p.vi) is often associated with the Southern approach[1], which evolved from confronting inequalities produced by class, race, age and gender. Rather than merely recording observable facts, PAR has the explicit intention of collectively investigating reality in order to transform it. (Hall, Gillette & Tandon, 1982). Feminist, critical, and emancipatory theories buttress the southern traditions. Common tenants associated with the southern PAR methodology are enlightenment, empowerment and emancipation. This article will describe a PAR project that utilized photovoice to highlight the many challenges and opportunities faced by nurses in Uganda. The article will link the methodological rationale to PAR theorists (Reason 1994, Reason & Bradbury, 2003 and Kemmis & McTaggart, 1988; 2003), emancipatory theory (Freire, 1970) and critical traditions (Habermas, 1971; Lather 1991).

Background

Historically, women in Uganda have suffered from low status within their social structure. Before colonialism, Ugandan social structure was based on a hierarchy of authority-wielding chiefs and clan heads, all of whom were by tradition men. Under this system, power relations marginalized women and rarely allowed them rights over productive resources such as land (Nuwagaba, 2002).

Ugandan women continue to experience oppression due to the social structure in their country. As most nurses are women, Kaseje (1995) believes that "the nurse is the mirror in which is reflected the position of women throughout the ages." (p.12)

Nursing in Uganda is not a highly valued profession; consequently, nurses experience a decreased sense of self worth as they work within a hierarchical structure that respects higher education and experts such as physicians. Nurses' opinions are not often sought by authority and their voices remain silenced. Little is known about Ugandan nurses' experience and their role in the care of Persons' With AIDS (PWAs), which further conceals the visibility of nursing in Uganda. Many studies (Adelekan & Jolayemi, 1995; Kohi & Horrocks, 1994; Mbanya et al., 2001; Walusimbi & Okonsky, 2004) have identified the deficiencies, such as negative attitudes and lack of knowledge, of nurses who care for individuals with HIV and AIDS. These studies fail to recognize the contribution nurses are making. While these studies are important, they further marginalize nurses' voices by focusing on what is wrong with nurses and exclude them from finding solutions to these issues. Voice is central in PAR. Reason (2004) points out that "sometimes in action research what is most important is how we can help articulate voices that have been silenced." (p.16)

Methodology

PAR is defined by Reason & Bradbury (2001) as "…a participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes… It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities" (p.1). According to Reason (2001) there are two objectives of PAR: to produce knowledge and action directly useful to a group of people. This can be done through research, through adult education, and through sociopolitical action. The second aim is to empower people at a deeper level through the process of constructing and using their own knowledge. People "see through the ways in which the establishment monopolizes the production and use of knowledge for the benefit of its members." (p. 1)

PAR was chosen as the methodology to guide the study for several reasons. The roots of PAR are informed by the ontology and epistemology of critical theory (Lather, 1991) with the assumption that knowledge is related to power and power is related to change (Reason, 1994). Research conducted in other cultures is often done by individuals who come from a privileged vantage point of being white, middle class, and well educated. This may create a cultural, economic, and educational divergence between the participants and the academic. However, PAR challenges the researcher to work alongside and adapt to the participants' culture instead of invading it (Travers, 1996), thereby minimizing the gaps between the researcher and the participants. Central to PAR is building democratic, participative, pluralist communities of inquiry, which is only possible with, for and by persons and communities (Reason & Bradbury, 2001). PAR provides a socially and culturally flexible framework to guide the research process (Cornwall & Jewkes, 1995).

The emphasis on the formation of partnerships in PAR, and the acknowledgement that research is influenced by values, is advantageous when conducting research in another culture (Mill, 2000). PAR encourages participation through a shared ownership of both of process and outcome, whereby decision-making and control are shared by all participants (Baylis & Bujra, 1995). This principle of shared power is a central component to PAR. In conducting research with oppressed groups, PAR sets out to facilitate the empowerment of the participants through the creation of knowledge and the taking of action that leads to change on a personal and structural level (Maguire, 1996). As well, PAR uncovers hidden knowledge by excavating individuals and communities' root causes of their situations (Schoepf, 1994). Utilizing a PAR approach encourages critical thinking through a dialogical process, which enhances critical awareness in participants about their lives and world around them (Freire, 1970). Finally, PAR embraces a variety of research methods to explore local knowledge and can be used in a diverse range of settings (Cornwall & Jewkes, 1995).

Theoretical Underpinnings

The current study was based in a critical ontology and epistemology in which reality and knowledge are viewed as human constructions that are value-laden and rooted within a social and historical context. Critical theory is embedded in humanity's 'emancipatory interest', which aims to rid communication and interaction of its distorted elements, and seeks to create knowledge which allows humans to be self-reflective and self- determining (Craib, 1992, p.234). Critical theory provides a language and a method to examine why individuals and communities are marginalized and "openly takes sides in the interest of struggling for a better world" (Giroux, 1997, p. 44). The emancipatory interest works through the universal human form of power, and is rooted in humans' ability to think and act self-consciously, to reason, and to make decisions based on known facts (Held, 1980, p. 317). Lather (1992) argues that critical pedagogy is "intended to interrupt particular historical, situated systems of oppression." (p. 121) Examining these ideas and events leads to critical consciousness, that is, being able to read the world (Freire and Macedo, 1987).

Practical Underpinnings

The study was guided by Freire's (1970) emancipatory approach to critical education and a participatory approach to documentary photography called photovoice (Wang & Burris, 1997). Because nurses' voices have been obscured within the health care system, Freire's model (1973) of emancipatory education served as way to work with nurses to give them voice. Freire's approach involves four elements: (a) listening; (b) participatory dialogue; (c) envisioning action and change; and (d) acting (reflecting on action and action again with new insights [praxis]). This model stresses the importance of people speaking from their own experience, identifying a common theme among their individual situations, creating an analytical perspective from which to relate their situation to root causes, and developing solutions and strategies for change (Freire, 1970; Wallerstein & Bernstein, 1988, Wallerstein, 1992). This dialogue is often referred to as consciousness- raising, which involves the recognition of social, political, economic, and personal constraints on freedom, and provides the forum in which to take action to challenge those constraints. As presented by Friere (1974) consciousness-raising involves dialogue between those with a theoretical understanding of oppression and those who are oppressed.

By engaging in critical and liberating dialogues, individuals uncover the hidden distortions within themselves that help to maintain their oppression. Freire notes that one means of enabling people to think critically about their community, and to begin discussing the everyday social and political forces that influence their lives, is the visual image. In Africa, it is said that the most important thing to do is to listen to peoples' stories because many Africans are rooted in oral cultures and traditions. Storytelling in the current study was facilitated by an approach to documentary photograph called photovoice. The process of creating visual images is often a source of empowerment, as are group dialogues that affirm individual's collective struggles and insights (Wallerstein & Bernstein, 1988). Freire (1970) argues that collective knowledge, and then action, arises from the shared experiences of a group and an understanding of the dominating institutions that affect their lives.

Methods

PAR is an approach that guides the research process but does not prescribes the methods (Seng, 1998). Therefore, a range of methods can be used in pursuit of its transformatory aims. Some of these can be nontraditional for instance, storytelling, sociodrama, plays and skits, puppetry, song, drawing and painting (Reason, 1994). This diversity of data gathering methods is one of PAR's strengths when working in international settings. Focus groups, interviews, and photovoice were the data collection methods chosen for the study. However, the findings from the interviews are discussed in another paper (Fournier, 2004b).

Photovoice

Photovoice entrusts cameras to the hands of people to enable them to act as researchers of their communities. Freire (1970) notes that one means of enabling people to think critically about their community and to begin discussing the everyday social and political forces that influence their lives is the visual image. Freire argues that visual images can stir up a group to analyze critically many social relations and conditions within their own community. The method known currently as photovoice is one way of giving voice to peoples' experiences by recording their life conditions as they see them, which then becomes the focal point for critical dialogue. Taking photographs may spark critical consciousness with participants and the photographs may initiate collective action by making a political statement about the participants' reality. By informing policy makers about their community concerns, people become potential catalysts for change

(Wang & Burris, 1997). Wang (1999) states the practice of photovoice has three main goals: to enable people (a) to record and reflect their personal and community strengths and concerns; (b) to promote critical dialogue and knowledge about personal and community issues through group discussions of photographs; and (c) to reach policymakers. In Wang and Burris's study, photography was used with Chinese women, in conjunction with dialogue about the photographs, to allow the women to discover commonalities and differences in their views of the world.

The focus group meetings served as a means for group discussion with the nurses utilizing a participatory approach. We were guided by Friere's (1974) three stage process of participatory analysis that are described as selecting (choosing those photographs that most accurately reflected the nurse's concerns); contextualizing (telling stories about what the photographs mean) and codifying (identifying the issues, themes or theories that emerge). In the first stage, the nurses chose the photographs, and by doing so, defined the course of discussion. The second stage, occurred during group discussion. A framework for telling stories (Wallerstein, 1987) was utilized. The acronym SHOWeD: What do you See here? What's really Happening here? How does this relate to Our lives? Why does this problem or strength exist? What can we Do about this? was used to guide the discussion. The purpose of this "root cause" questioning was to identify the problem or the asset, critically discuss the roots of the situation and develop strategies for changing the situation (Wang & Burris, 1997). The third stage is framed by the understanding that the participatory approach may generate many different meanings for a single image. According to Wang and Burris, people may identify three dimensions that arise from the dialogue process: issues, themes and theories.

The Study

Nurses working in resource poor countries face many challenges in the care they provide to individuals with HIV and AIDS. Research indicates that these challenges include stigma; lack of resources; fear of contagion; and perceived stress (Baguma, 1992; Mbanya, et al., 2001; Simmoff, Erlen & Lidz, 1991; Mill, 2003; Baguma, 1992; Uwakwe, 2000; Kaimenyi & Ndung'u, 1994; Mkuye et al., 1991; Mill, 2000; Mbanya et al., 1998 [as cited in Mbanya et al., 2001]). The main purpose of the current study was to explore the experience of Ugandan nurses in caring for individuals with HIV and AIDS, while at the same time, including nurses in a participatory approach that would enable them to define their issues, find solutions, take action and then reflect on the process and outcome (praxis). The aims of the study were: (a) to improve the understanding of the practice of nursing by nurses; (b) to improve nurses' practice; and (c) to improve the situation in which the practice takes place. This paper will now turn to the process whereby a small group of Ugandan nurses found their voice. The study was carried out over a 10-month time frame and involved two separate trips to Uganda by the researcher.

Sampling and Recruiting

Six nurses participated in a focus group that met during a period of 10 months, for a total of eleven meetings. I was part of the group for the first four months, and for the final month. Participants spoke fluent English as a Second Language and were native Ugandans. Therefore, each focus group was conducted in English. The nurses worked in paediatric, medical, cancer and tuberculosis units in a large government hospital situated in Kampala, the capital city of Uganda. The inclusion criteria for the nurses included: able to speak English, caring for PWAs on a regular basis (at least one patient every shift or every day), over the age of 18 years, and working in a hospital setting. Student nurses, visiting nurses from other hospitals, and nurses working in non-clinical areas were not considered.

Recruitment was done at a nurse manager meeting where managers nominated an individual that fit the criteria. The nurse managers were then approached two days later to collect the names of the individuals willing to participate. Hospital administration fully supported the study and approved nurses time off during their working day to attend the focus group. The study was explained, an opportunity for questions was provided, and oral and written informed consent was obtained from each participant during the first meeting. A room at a nearby guesthouse was used for each focus group. Following each focus group, nurses were given an honorarium to compensate them for their time.

Implementing Method

The first meeting began with introductions, which allowed the participants to become familiar with each other and me. Next, the goals, methods, and consent for the study were discussed and questions were answered. The study aimed to involve the participants at every level of the study, directing and implementing it to ensure it was responsive to their needs. During the initial meeting, I emphasized the idea that by participating in the study nurses were co-researchers who would be involved in planning and implementing the project, and analyzing the data. My intent was to build research capacity. In an effort to enhance decision making during our first meeting, I introduced the concept of photovoice and advised the group that the research process was negotiable. The nurses' first task together was to decide if using the photovoice technique was culturally appropriate and would be of value to them. Other group decisions made on the first day included length, timing and dates of each meeting. Group norms were developed which included values such as trust, respect and confidentiality. Engaging the group immediately in the decision making process allowed for ownership of the project to take root. Although I came with cameras and film to Uganda, being flexible and encouraging the group to make important decisions enhanced the overall impact of the study. The non-negotiable part of the study was the initial focus on the experience of nurses in caring for individuals with HIV and AIDS. Ideally, the topic of inquiry should come from the people concerned, however, as Baylis and Bujra (1995) point out, this is rarely achieved in practice. A truly participatory process cannot be generated spontaneously, given the power relations at all levels and the deep-rooted dependency relationships of the people (Burkey, 1993).

During the second half of the meeting, the nurses decided to use the cameras and the photovoice technique. Training in the photovoice technique included exploring ways to approach people to take their picture. Each participant received a 35mm Polaroid camera with one roll of 24-exposure color film and batteries. The nurses loaded film and took several practice photographs during the training session. I suggested that the initial theme for taking pictures would be "nurses' work". It has been recommended when using photovoice that it may be advantageous to provide a theme for what people might photograph (Wang, YI, Tao & Carovano, 1998). The nurses were encouraged to refine or redevelop the theme. However, the nurses decided that the theme was valuable and commented it was too difficult to create a theme on their own so early in the research process. Therefore, "nurses' work" provided guidance for the first round of photographs. The inquiry started with the nurses' working knowledge of their everyday activities. The number of pictures taken and the photographs they shared was left up to each individual nurse. Developed photographs were delivered to each nurse 2-3 days in advance of the next focus group meeting to allow the nurse to choose their pictures and begin meaning making using a story telling process.

The entire photovoice process lasted 4 months, which included 2 photovoice meetings and 4 research process meetings for a total of six meetings.

After the initial meeting the participants spent the next three weeks photographing their responses to the initial theme. During that time the group met once to discuss issues related to picture taking and camera usage. Many of these issues involved the mechanics of the camera, reactions from patients and colleagues, consent, and logistics of film pick up, drop off and development. By discussing these issues the group members assisted each other in solving problems related to the cameras and the research process in general. As a result of taking pictures about their work and thinking about the story behind each picture, the nurses began to realize how challenging it is to be a nurse. Taking pictures gave the nurses an opportunity to stand back and look at their nursing practice from a different perspective. Freire (1973) argues that individuals need to gain a distance from their everyday lives so that they can see their situation in a new way. This distance allowed the nurses to see that they were not living up to the expectations of being a nurse. This confession sparked a discussion about the challenges of being a nurse in Uganda. And their critical consciousness began to develop.

During the photovoice meetings, the nurses told stories about their pictures using the framework outlined by Freire (1971) and Wang and Burris (1997). Their stories were often about the many challenges they faced in their daily work. It was by sharing their stories that the nurses had another opportunity to stand back and reflect on their practice. Through this reflection their critical consciousness deepened. The nurses revealed that their opinions were not sought by hospital administration, which created feelings of powerlessness. As we talked further about what they could do about their challenges, participants continued to feel powerless. They felt "there's nothing we can do". Poverty was often discussed as the reason why many of their challenges existed. As we talked about poverty, issues related to power and money emerged. The nurses began to wonder how change could ever happen on a political level when their country was plagued by corruption. The nurses commented that if an individual was wealthy they could buy anything, including laws. When looking at the big picture we all began to feel that many of the nurses' issues were insurmountable. I recognized the feelings of powerlessness and suggested to the group that change needed to occur in small steps. I directed them to think about their nursing practice. We dissected each issue to find a solution that was realistic and practical. Sometimes we were unable to find a solution.

After each photovoice meeting the nurses filled out an evaluation form that asked them to respond to four statements about what they liked/disliked about the meeting, what they learned and if they needed clarification about any particular part of the study. These self-reported comments served as a way to evaluate the change that was occurring with each participant. As the research study progressed, it was evident that the nurses were not only gaining research skills but were also teaching each other what they understood research to be. As well, the nurses began to informally teach each other about certain diseases and nursing interventions.

After 4 months in Uganda, I returned to Canada. The nurses continued to meet once a month on their own for the subsequent 5 months. During these meetings the nurses discussed how they could take action to improve the care they provided to individuals with HIV and AIDS and to evaluate the process. The research study was designed in this manner with the aim of raising feelings of autonomy and a sense of control over the research process. It was hoped that ownership of the project would grow, which would enhance the sustainability of the group. A leader was chosen from the group through a democratic voting process. I provided telephone support to the group once a month from Canada. As well, my field supervisor was available to the groups for guidance and support.

Data analysis

The photovoice method provided participants with a way to critically analyze their stories. Therefore, this informal type of data analysis was ongoing. The nurses also analyzed data in the more traditional way. I gave a brief discussion about the research process including how to analyze data. During our data analysis session as a group, emphasis was placed on the fact that there was no right or wrong way to do data analysis and that we needed to be flexible and adapt our strategy as needed. One meeting was spent analyzing the data from the nurses stories. They were asked to review all of the stories on their own, write down common themes and come back to the entire group with their analysis. They nominated a group leader to facilitate their discussion. The categories were recorded on sticky notes and organized into broader themes as the group progressed through the data analysis process. My Canadian supervisor was present during this meeting. At the end of the meeting she reflected on the experience and commented, “you are all very skilled at analyzing the data and it’s very interesting that you all came up with the same thing, there was consensus about the same themes”(focus group meeting, Oct 15, 2003). This reflection gave the nurses confidence in their research ability. Many Ugandan nurses believed that only highly educated people can do research. However, working through this process we were able demystify the research process. Data analysis also occurred when I returned to Canada. An additional 2 months was spent analyzing the data utilizing techniques described by Miles & Huberman (1994).

Rigor

Discussion of rigor in the PAR literature is scarce. Lather’s (1991) criteria and procedures of triangulation, construct, face, and catalytic validity were used as a guide for establishing trustworthiness and authenticity in this study. Triangulation occurred through the various data collection methods and sources, which included focus groups, interviews, and photovoice. Construct validity was established by writing summaries after each meeting, which were made available to all of the group members. The nurses validated the data in the summaries and made corrections as necessary. Face validity occurred when the nurses began to analyze their stories by reading the summaries. Reading their stories also gave them new insights about their practice. Face validity also occurred during the dissemination of the findings. One of the nurse educators in the audience commented that she felt the finding related to moral distress was important and needed further exploration in Uganda. After the presentation she asked me about accessing the literature to begin her own study focusing on moral distress. Reason and Rowan (1981) introduce the idea of catalytic validity in participatory research, which is concerned with an emancipatory outcome and may be defined as the "degree to which the research process reorients, focuses, and energizes participants toward knowing reality in order to transform it" (Lather 1986, p. 272). As co-researchers, the participants commented that they now had research knowledge and skills and felt confident that with guidance they could conduct another PAR study. However, McNiff (1994) claims that rigor in action research is not about methodology but is concerned with personal and interpersonal issues. I will discuss the personal and interpersonal issues that arose during the study in the next section.

Reflections

The remainder of this paper will highlight the challenges, opportunities, outcomes, and ethical issues in conducting international research using PAR. As well, reflections on future research will be explored.

Challenges

Conducting international research poses many challenges especially when in unfamiliar settings. Mill and Ogilvie (2003) suggest that acknowledgement of one's own inadequacies in new and culturally different environments are needed to conduct culturally competent scholarship. There were a number of challenges that emerged during the course of this study and many were related to being in a new culture. This phenomenon is referred to as culture shock, which describes the experience on individuals when they become immersed in a culture that is different from their own (Oberg, 1958). Culture shock has four phases: honeymoon, crisis, recovery, and adjustment. The ideal situation is when a person moves through these phases, fully adapts, and becomes well adjusted in the other culture. I entered the crisis phase soon after arriving in Uganda. The initial crisis occurred when I discovered that my key contact would be out of the country for two weeks. Therefore, gaining entry was slow and it took longer than anticipated to establish the nurses' focus group. As well, it was a slow process to obtain approval at the national, university and the hospital level. As the research project progressed and I moved through the phases of culture shock I was exposed to the extreme poverty and suffering of the Ugandan people. I did not anticipate how deeply I would be drawn into the nurses' stories of patient suffering and death. A reflective diary illuminated the sadness I felt hearing the stories from the nurses. Upon return to Canada I discovered that it was possible that I was experiencing compassion fatigue. Compassion fatigue is defined as the consequence of caring about and for people who have experienced extremely stressful events (Figley, 1995). I was at greater risk of developing compassion fatigue because my sense of control over my life had been stripped away by living and working in another culture.

Challenges also emerged related to conducting a PAR study. A researcher facilitating a PAR study must be flexible, willing to give up the idea of control, and adapt the approach as needed. Therefore, a potential dilemma can occur when the researcher is held accountable for producing a product such as a thesis at the end of the study. If PAR is to evolve, as it should, power and control should remain with participants. Conducting research for a Masters thesis has the potential to conflict with the principles of PAR. Expectations of time, funding and producing immediate and practical research findings, may result in the researcher controlling the research process with a predetermined agenda. Consequently, true collaboration cannot be obtained and the interests of the powerful (the researcher) may take precedence over those of the participants. Therefore, I needed to be cautious about the types of expectations from all involved in the research. In the current study, tension surfaced for me regarding the disparate, yet valid reasons for carrying out the research: for academic qualification or for altruistic ends. I began to question my role as a researcher. Questions such as "What did I really hope to accomplish?" And "Who was I to think that by using this methodology and acting as a change agent that I would influence these nurses to begin to make changes at either an individual, organizational, community or government level?" Reflecting on these questions and issues while in Uganda heightened my awareness and sensitivity to potential power issues between myself and the participants. In a sense I began a conscientization process. Freire (1996) states "A person who has reached conscientization has a different understanding of history and of his or her role in it. He or she will refuse to become stagnant, but will move and mobilize to change the world. He or she knows that it is possible to change the world, but impossible without the mobilization of the dominated. He or she knows very well that victory over misery and hunger is a political struggle for the deep transformation of society's structures." (p.106)

During the study, I also became aware of many other challenges, including my own inefficiencies. Being an "outsider" proved to be a challenge. Understanding the local setting and issues developed slowly as the study unfolded. As a result, I often felt ineffective when facilitating discussions. I was also conscious of the decisions I made in isolation and how they impacted the direction of the study. Since time with the nurses was relatively short for a PAR study, I made a decision to focus discussions on their nursing practice rather than the larger power structures that influenced their lives. Also, as friendships grew within the group I decided to keep my relationship with the participants on a research basis only. Evaluating the impact of the study after only 10-months is neither feasible nor appropriate. Consequently, emancipation of the group members cannot be adequately expressed. Blacker warns that 'one who aspires to articulate emancipation must acquire a certain theoretical modesty' (Blacker, 1998, p.357). As a result of time and theoretical modesty I was cautious about claiming any significant effect of the study.

Finally, I had difficulty saying farewell to the nurses in the focus group. How does one say goodbye to a group when so much time was spent sharing our lives with one another? In this study I was forced to leave due to academic constraints. There comes a time in a PAR study when researchers are faced with saying goodbye. When should the academic exit? How does one determine the "end" of a project? When the funding runs out? When the goals have been achieved? Never? Completion depends on the purpose and aim of the study. However, if the study is truly collaborative with emancipatory aims, do I have an obligation to ensure that sustainability is built into the project? Should sustainability be a goal in itself? Researchers using PAR need to examine their deeply and often hidden beliefs about the goals of their project before the project begins. I argue that more attention needs to be placed on the process of saying goodbye to allow psychological preparation for this exit.

Opportunities

Many opportunities emerged that facilitated change in the study and had implications for its success. The opportunity to include decision makers with power was a positive side effect of the research study. The local supervisor, Mariam Walusimbi, was a key person who positively influenced the project and acted as an internal change agent. As a principle nursing office at Mulago Hospital she was in a key position to facilitate sustainable change at an organizational level. In 2002, Walusimbi carried out a survey for her Nursing Master's thesis of nurses and midwives in Mulago Hospital to determine their knowledge and attitudes toward the care of patients with HIV and AIDS. Walusimbi found significant knowledge gaps in relation to transmission, agent, and immunology. Walusimbi's research provided her with insider information and a deep understanding of the local issues related to nurses and HIV. She attended two focus groups with the nurses, which served two purposes. First she was able to help the group think about practical solutions that would improve their practice, and second, she was able to provide encouragement and show the group members they were fully supported by hospital administrators to make change. While I was back in Canada, Walusimbi was promoted to the most senior position in the hospital, Assistant Commissioner of Nursing. Walusimbi's promotion is yet another opportunity that will ensure change will occur and be sustained within the hospital.

Ethical Issues

Mill and Ogilvie (2002) argue that researchers in international settings must ensure their work is ethically sound by meeting international standards for protection of human participants, while continuing to examine cross-cultural ethical issues. That is, there needs to be an ongoing dialogue between ethical structures and a willingness by the researcher to discuss difficult ethical issues. Obtaining local ethical approval became a potential dilemma for me. National and institutional (Mulago Hospital) approval had been granted, however, I discovered while I was in Uganda that approval was also needed by the University. After many visits to the appropriate faculty, I discovered that the process could take up to 3 months. With this information in hand I spoke with one of my local contacts and was advised to continue on with the research as planned. This direction went against everything I knew and understood about ethics. How to proceed? I began to ask all of my local contacts about this dilemma. Each person stated that the University approval was not needed immediately but that institutional approval was required to begin. I used this culturally relevant advice to carry on with the study while waiting for ethical approval from the University.

During one of the focus groups the nurses raised an issue regarding informed consent with patients. The nurse was to explain the study to the patient by reading the consent form and then have the patient sign it if they agreed to have their picture taken. However, the consent form stated they would be involved in a study about HIV. As many patients do not know their status or do not want to know their status, having HIV on the consent form deterred many from participating. The nurses began to improvise and some would conceal the words "HIV" with their thumb when asking the patient to sign or would leave out the part about being in an HIV study, as many patients were illiterate. When the nurses reported at the second focus group how they were improvising a discussion began and the group decided that the word "HIV" needed to be changed to "immunosupression", a word that did not have stigma associated with it. The group members commented that they felt more comfortable explaining to their patients that it was a study about immunosupression rather than about HIV. In retrospect, how does the process of obtaining informed consent differ with illiterate, disempowered individuals?

Informed consent became an issue again when the nurses mentioned that the patient would not agree to have their picture taken if their neighbor had refused, but if their neighbor had agreed they would also agree. This need to behave in a socially acceptable manner impacts the patients understanding of the research study. This phenomenon is known as social desirability and occurs when patients intentionally or unintentionally modify their behavior to match how they are expected to behave (Hays & Ware, 1986). Social desirability can occur between individuals and their peer groups or between the researcher and participants (Hays & Ware). As a group we discussed this issue but action was not taken to minimize the risk.

Outcomes

The study generated many changes at the individual and institutional levels. Specifically, the changes that occurred within each study participant, within their nursing practice, and within their work setting will be illustrated. As well, the action taken collectively by the group to solve a practice issue, that is, nurses' lack of knowledge about ARV's is also being reported as an outcome of the research.

"The first step in action research turns out to be central: the formation of a communicative space"...and to do so in a way that will permit people to achieve mutual understanding and consensus about what to do, in the knowledge that the legitimacy of any conclusions and decisions reached by participants will be proportional to the degree of authentic engagement of those concerned (Kemmis, 2001, p. 100). Reason (2003) argues that this formation of communicative space is in itself a form of action. "It may well be that the most important thing we can try to do in certain situations is to open, develop, maintain, encourage new and better forms of communication and dialogue" (p.20). In the current study, a group of strangers converged, sharing their experiences and understandings through story telling. They discovered that they shared many similar issues. The research process enabled these six strangers to develop a friendship with one another which deepened their sense of social support and propelled them into action to improve their nursing practice and the setting in which their practice took place. The group work permitted the nurses to support each other in exploring their views within their own 'framework for understanding the world' (Kitzinger, 1994, p. 108). They discovered they shared many similar issues, concerns and hopes. Over time the group of nurses became more willing to share their lives with one another. We built a community of trust by our shared experiences and the nurses gained confidence in their nursing knowledge and skills. Participation in the research had more meaning for the group members because their lives were now intertwined with one another. The nurses involved in this project found the experience of participating in the research process empowering. I compiled the nurses self reported comments that were collected throughout the research process. The following is their account of their experience in participating in the PAR study.

Emoit. During the last 10 months, I have learned that I can influence others to make change especially in Mulago Hospital and the community at large. However, it is difficult because you have to involve many people and it is time consuming. I have gained more confidence in my nursing practice and I also recognized my weak areas, such as counseling skills. My attitude has changed towards individuals with HIV and AIDS, as I no longer stigmatize people. I have also gained knowledge about HIV and TB illness.

Josephine. I used to fear to touch HIV and AIDS patients but now the fear has gone. Stigmatizing is not there and I now see them as any other patient in the ward. I am freer with individuals with HIV and AIDS and listen to their problems and advise them accordingly. I did not know how to solve our challenges before the study, however, now I feel more confident to solve our issues. The study was an "eye opener" in helping me realize the gap in the care of these patients. I am now empowered with the knowledge of problem solving, new knowledge of HIV, communication skills, confidence, and how to do research. I hope we continue with more.

Flavia. The story telling process increased my awareness about patients with HIV. Working together as a group made me learn more about my colleagues and the challenges they encounter on their wards. We were able to solve some of challenges, which have changed my role as a nurse. Working on the research proposal has been eye opening, though time consuming but rewarding in the long run. I am more patient with patients with AIDS as they have a lot of psychological torture. I feel more devoted to nursing.

Sarah. Photovoice is a good method of data collection since it gives what is on the ground and not just in someone's imagination. As a group we shared our experiences and were exposed to different opinions. We respected our differences and maximum cooperation was the outcome. I have been able to recognize my strengths and weaknesses and increased my confidence as a nurse by expressing my views about caring for patients with HIV. My knowledge of HIV and TB has increased. I realized that making change is not an easy process as it may meet resistance but can be rewarding. We as a group can influence change. I learned practical skills of how to conduct research and to write a proposal.

Aisha. I learned how to care for patients with AIDS in the research group. I am more sympathetic and empathic towards these patients than I was before the study. I realized that I need further training and education about ARV's and counseling skills. However, my knowledge has increased about many diseases such as HIV and TB. I learned practical nursing skills such as how to give TB medications using the DOTS system.

Janet. During the study I realized the problems of nurses and patients, is that HIV and AIDS is a disease of stigma. I have learned that it is good for nurses to discuss their nursing experiences in a group as it helps to solve problems. By contributing to the research study I have gained confidence and skills in proposal writing and the research process. I have realized that the process of making change is time consuming but rewarding because the nurse gains confidence and the patients are satisfied with the services. I have more interest to study so that I can aquire further knowledge and skills as how to care well for patients. I have decided to go back to school to obtain my degree in nursing.

There was also evidence of change that occurred within the hospital as a direct result of group discussions and nurses taking on a leadership role to address an ethical dilemma. During our meetings it became evident that the nurses were facing many ethical issues that had remained hidden until the nurses began to discuss their practice issues in the group. For instance, Emoit commented to the group that on his ward, patients' files were kept at the bedside. A lively discussion broke out about how patient confidentiality could not be maintained with this practice. Emoit had already addressed this issue with his supervisor, however, he was told that it was the Doctors who insisted that this was the way it had always been done and would continue this way for Doctors' convenience. Once Emoit related this practice, the nurses began to share with him how they kept the files on their nursing units. I facilitated the discussion by asking the nurses about the ethical code for nurses in Uganda. I asked if they viewed this as an ethical issue. As we discussed nursing ethics, the ethical code for Doctors was also discussed. In the end, Emoit decided to approach the next person in authority to explain this issue. Two meetings later, Emoit shared with the group the outcome of his action. The files were moved and were now being kept at the nursing station. Upon hearing this positive feedback the nurses broke out into applause. It was truly an empowering experience for all the nurses including myself.

While I was in Canada the nurses took action on their identified challenge of not having enough knowledge about ARV's. It is interesting that they decided to solve this issue by developing a research proposal. This could indicate that research capacity was built. The nurses were very resourceful and used a proposal from a non-government organization as a guide to develop their own proposal. The nurses in the group had never been involved in writing a research proposal. They met once a month bringing together their ideas and drafts of the proposal. At the final meeting their proposal was complete and given to Walusimbi for her comments and corrections. Drafting a proposal was fully supported by Walusimbi.

Presenting research findings also opened up a new communicative space where one did not exist. This process also gave nurses a voice. PAR projects may open space for communication and dialogue, creating space for muted and silenced voices (McArdle, 2002); or where there are no forums for democratic dialogue (Gustavsen, 2001). After hearing the findings presentation a nurse stated "I feel like I have just awoken from a deep sleep as a nurse at Mulago Hospital". This awareness demonstrated a consciousness-raising moment for this particular nurse. Another nurse commented, "on a daily basis we keep reducing ourselves, devaluing ourselves and because of this nurses do not believe in themselves. So that is one reason why nurses voices are invisible". Central to PAR is the concept of hegemony (Hagey, 1997). Hagey believes it is through an awareness that individuals contribute to their own oppression that an empowerment process can begin. Following a subsequent presentation a nurse stated "we have taken for granted these challenges and have continued to work by improvising. You helped us to see these things we always do in a new light. We can refuse to use IV tubing and then they will have to supply us with the proper oxygen tubing". Also, during the dissemination of the findings with nurses at Mulago Hospital, Walusimbi took the opportunity to introduce her new position, as the Assistant Commissioner of Nursing, and to advise the nurses in the audience that change based on the findings would occur. This discussion encouraged the nurses in the audience to speak freely about other challenges they were experiencing. Walusimbi was responsive to the issues raised and suggested that she would personally look into these challenges. A positive energy was felt in the room during our discussion. The energy was manifested by the realization that change was possible. This in turn fostered a sense of empowerment among the 50 nurses who attended the presentation. Reason (1994) believes that there exists potential for the empowerment of people through the reflective processes of constructing and reconstructing meaning through retelling of participants' experiences and knowledge. By presenting the findings, empowerment stretched beyond the participants and touched the audience.

In PAR, knowledge is created through participatory processes in the context of human relationships (Maquire, 1987). Knowledge that is constructed with participants reflects their own experiences, encouraging them to use their own language and hear their own voices in understanding what is happening to them and around them. This obtained knowledge becomes a source of power and builds group ownership of information as people move from being objects to acting as subjects of their own research process (Maguire). Taking ownership of the project was evident by group members who initiated the research agenda and subsequent action. As co-researchers the nurses were involved in all phases of the research process, which helped to develop a sense of ownership, with the aim of raising feelings of autonomy and a sense of control. Carr and Kemmis (1986) argue that these feelings of autonomy and control in the long term could improve the position of collectives of individuals in society and therefore enhance their lives. The nurses demonstrated ownership of the research agenda and the collaborative process. Ownership of the project occurs if each participant feels they have an equal share of the power base (Stinger, 1996). The participants made decisions about which issues were important to them, which facilitated their participation and empowerment. Authority, control and responsibility for the study were spread across all participants. Most of the practical applications of the research framework were directed by the nurses. This authority established their own power within the research context. Consensus was evident by the participants discussing decisions and ensuring everyone was heard and at the same time were willing and able to challenge their colleagues. Fostering ownership also facilitated the possibility of sustainability of the research group. According to

Bamberger and Cheema (1990) sustainability refers to the capacity of a project to continue to deliver its intended benefits over a long period of time.

What about the change that occurred with myself? In a PAR study, the researcher is also influenced by the research process and changes as a result of being part of this type of study. I have learned many things about Ugandan nurses, Ugandan culture and myself. I have learned how to conduct a PAR study in an international setting, and became aware that issues at the local level are often a reflection of broader issues at the global level. I gained a deep appreciation for the many structural challenges nurses face in their daily care of individuals with HIV and AIDS. With this greater appreciation comes a motivation to take action at the global level.

Weiler (1988) believes that changing people's consciousness is not enough: real relationships and forms of power must be changed. As Freire points out, it is not enough for the oppressed to recognize their own oppression. That recognition is only the starting point for a movement to destroy that oppression and to become free in fact and not simply in the mind. Though it is true that awareness and consideration of new possibilities is not complete transformation or emancipation, it is positively the place where consciousness raising must begin. The nurses have become aware of influences and constraints that affect their nursing practice. Knowledge has been generated in relation to the roles of nurses in caring for individuals with HIV and AIDS. Evidence from the current study suggests that group members, by reflecting on their experiences as nurses and as participants in the study, were able to change their current understanding of their practice to make sense of their experiences, collectively, as nurses. This new understanding created a deeper self-awareness, which also was empowering. Being part of PAR study was an empowering process. As the members were involved in all phases of the research study, their feelings of study ownership were evident. I also felt empowered in conducting PAR and successfully facilitating change.

Reflections on future research

Working from an emapancipatory perspective was challenging while experiencing culture shock, compassion fatigue, and conscientization. In emancipatory action research, the focus is clearly broad and the responsibility for the process lies with the group. As Carr and Kemmis (1986) pointed out, emancipatory action research leads the group involved to 'take responsibility for its own emancipation from the dictates of irrationality, injustice, alienation and unfulfillment' (p. 30). The group looks at the policies and practices typical of the institution in which it works, and the group's own responsibility in maintaining these. The group investigates whether the culture in which it works is just and equitable, and tries to determine how to improve the culture if deficiencies are noted. In the spirit of emancipatory research these goals were not explicitly achieved. Perhaps this could be the next phase of the PAR process with the participants. In discussing ways of making change with individuals and communities, McTaggart (1995) suggested that "it is possible (and sensible) to start small, because social life is manifold – not complex or made up of separate bits – to change one aspect inevitably means changing others". (p.35) In retrospect, I could have spent more time on encouraging the nurses to share their views and experiences of doing research to help them feel more relaxed with the 'idea of research'. Due to academic constraints (time and funding), which did not allow for me to be involved for a longer duration, the long-term impact of the research cannot be fully assessed.

Limitations

During the recruitment process the managers of the ward were asked by hospital administration to nominate a nurse who fit the selection criteria. In retrospect, I recognize that were power relations operating in how the nurses were selected. It is quite possible that the nurses nominated were not as 'voiceless' as others who could have been chosen. I felt the influence of the selection process was out of my control and that I should follow the cultural protocol. Therefore, the findings related to the themes only reflect the stories of a small group of Ugandan nurses and may not reflect the experiences of the most marginalized group of nurses at Mulago hospital.

Conclusion

This study utilized photovoice methods, to explore the experience of nurses in caring for individuals with HIV and AIDS. By opening a space for new conversations to take place about their experiences as nurses, enlightenment took root. This enabled empowerment to grow and the idea of emancipation to be nurtured by the group. My role in this process resembles the work of a gardener. I nurtured already existent sprouting thoughts and dreams and at the same time facilitated others to find their green thumb to continue the process of growth, regeneration, and transformation. It may be some years before this PAR process reaches full maturity. As my thesis becomes nearer to completion the nurses are transforming into a new group. The purpose of the group may change, what is important to the group may change, and the relationships of the participants may change. PAR as a continuous process does not end with the completion of one project. When successful, it lives on in each individual (Park, 1989). Street (1995) proposes that actions create changes for more people than the participants because PAR is life altering for all concerned. The idea of having voice and of giving voice are central to enlightenment, empowerment and emancipation.

Throughout this study my passion to make a difference underpinned my motives and actions. This intense emotional drive enabled me to continue my work amidst the many personal challenges I faced conducting research in an international setting. My connection to the research deepened through my own conscientization process, which I would argue could have only occurred in a PAR study. This conscientization process caused what Lincoln (1997) refers to as, "yearning," defining it as "a powerful, heartfelt driving impulse toward some world which is only dimly glimpsed, but profoundly desired." (p. 21) The desire to live in a world where everything is possible creates energy for me that drives all my actions. I have gained critical knowledge and skills during this research study that will equip me with the basics I need to advance democratic principles based on social justice and equity. My passion to make a difference comes from a place where peoples' voices have value and should be heard. I see that my role as a researcher is to ensure that people speak and are heard by their peers and policy makers. Pearpoint (1989) suggests "we all have the power to listen to 'voices' that are seldom heard. If we choose to make the time, to learn, to listen and to struggle with the pain and frustration that disempowered people feel, we will see new visions, feel new energy and find hope in our future" (p.503). According to Canadian political and cultural theorist, Mark Kingwell, "the world we want always lies beyond our grasp but we can not give up wanting it." (xxii) PAR is a way to move toward a world based on justice. As a researcher living the philosophy of PAR, I am becoming the change I want to see in the world. Living this philosophy has the potential to make the world a better place to live.

Footnote

[1] The Southern tradition focuses on empowering marginalized groups. The Northern approach uses a problem solving approach in organizational change (Brown, 1993).

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The Experience of Ugandan Nurses Caring for Individuals with HIV Illness

The AIDS pandemic has been documented in every country in the world and has now surpassed the Black Death in scale, claiming more than 20 million lives (UNAIDS, 2004). The main burden of the pandemic has fallen on resource-constrained countries, particularly these in sub-Saharan Africa. Due to its high morbidity and mortality in African countries, AIDS is re-shaping cultures and changing the fabric of social, economic and political systems on the continent. Many African countries have a history marked by colonialism, civil war, political unrest, and the emergence of many infectious diseases such as AIDS. Uganda shares this history.

In recognizing the social and economic consequences of the impact of AIDS, the Ugandan Government has given AIDS control the highest priority. The decentralization of health care in Uganda, in combination with a critical shortage of physicians and the high morbidity rate associated with AIDS, has led to nurses playing a central role in the care and treatment of individuals with HIV illness. However, little is known about the Ugandan nurse's experience and their role in the care of persons with AIDS (PWAs). Thus, the everyday experience of a key group of health care providers has been obscured. In 2003, a study was undertaken by the author to explore Ugandan nurses' perceptions of the various components of their roles, activities, expectations, and feelings in relation to the care of patients who are HIV sero-positive. In this article, the findings from the study are presented and discussed. In addition, implications for nursing practice and research are highlighted.

Background

AIDS in Uganda

Uganda has experienced multiple impacts of AIDS. The effects of this pandemic include a drop in life expectancy, declines in nutritional status as agricultural productivity deteriorates, declines in educational status as children are forced to leave school to care for their dying parents, and changes to the social system as the number of orphans and rural poor increase (UNAIDS, 2004). The AIDS pandemic has also negatively shaped the economic sector through its impact on the labour force. AIDS-related sickness and eventual death reduces the family labor force, land under cultivation, income, food security, and educational opportunities. The agricultural sector has seen a shift from high to low labor-intensive crops, a decline in production of cash crops, and an attempt to sell food crops for cash (Barnett & Blaikie, 1992). One of the most visible and immediate social impacts of the epidemic is the rapidly growing number of AIDS orphans. In 2002, it was estimated that a cumulative total of 4 million Ugandan children had lost either one or both parents due to AIDS (World Health Organization [WHO], 2003).

Nurses' Role in Care of PWAs

AIDS offers special challenges to nursing care because the course of the disease, and its possible complications, are unpredictable and highly variable

(Corless & Nicholas, 2000; UNAIDS, 2000). The pathology of HIV, paired with the psychosocial aspects of having a "socially unacceptable" terminal illness, can be completely consuming for the HIV infected individual. Nurses play a major role in not only clinical, but also psychosocial support for these patients. In addition to the nurse's role in caring for the patient's basic needs, including monitoring for infection and drug side effects and providing psychological and spiritual support, the nurse may also be responsible for recognizing and reporting abnormal laboratory results to the primary care physician (Corless & Nicholas, 2000). It is evident that caring for individuals with AIDS is complex and requires nurses to have specialized knowledge and skills.

In general, nursing research on HIV and AIDS has focused on various aspects of symptom management in respiratory infections (Coyne, Lyne & Watson, 2002), nutritional problems (Karlson & Nordstrom, 2001), recurrent painful mouth infections (Newshan & Sherman, 1999), malignancies (Neill, 2001), and cerebral changes, blindness, deafness, paralysis and early dementia (Coyne, et al., 2002). These studies outline the nursing intervention relevant to each symptom, for example, frequent mouth care for individuals with mouth infections. Research has also focused mainly on acute care settings in North America, with few studies conducted about the nurses' care-giving role in sub-Saharan Africa.

The literature highlights several barriers to care of PWAs in sub-Saharan Africa. These barriers include: stigma and discrimination (Baguma, 1992;

Mbanya, et al., 2001; Simmoff, Erlen & Lidz, 1991; Mill, 2003); inadequate knowledge (Adelekan & Jolayemi, 1995; Kohi & Horrocks, 1994; Mbanya et al., 2001; Walusimbi & Okonsky, 2004; Klewer et al., 2001) negative attitudes (Adelekan & Jolayemi; Kohi & Horrocks; Mbanya et al. 2001); lack of resources (Kaimenyi & Ndung'u, 1994; Mkuye et al., 1991; Mill, 2000; Mbanya et al., 1998[as cited in Mbanya et al., 2001]), and fear of contagion (Baguma; Uwakwe, 2000).

Caring for PWA's in Uganda

Ugandan nurses face many challenges in caring for individuals with HIV and AIDS in their work environment. Nurses working during the initial emergence of the HIV epidemic in Uganda in the late 1980's did not know how the disease was spread and continued to work as they always had, without gloves or other protection (personal communication, Rita Matte, Oct 3, 2003). As a result, many nurses became infected and, without treatment, have died. Today, occupationally acquired HIV is still common and the government does not cover the cost of antiretroviral therapy (ART) for nurses. However, regardless of how HIV is acquired, nurses who are HIV sero-positive are becoming too weak to work and are dying. This is having a major impact on the human resources available to deal with the pandemic (personal communication, Rita Matte, Oct 3, 2003).

Often nurse's voices within the health care system are invisible as they work within a system that values experts such as physicians. This invisibility is especially true for nurses in Uganda. Ugandan nurses are trained and socialized to accept directives without question, and are not accustomed to speaking out on public issues. Nursing is not a highly ranked profession in Uganda where physicians (mainly men) control the management and administration of health care institutions, are protective of their responsibilities, and maintain control over all aspects of decision-making (personal communication, Walter Kipp, May 2003).

Purpose

There were two purposes for the current study. The first was to explore the experience and perspective of nurses in Kampala, Uganda caring for HIV sero-positive patients. By discovering the experience of Ugandan nurses in providing care for persons with HIV illness, challenges and opportunities in their practice were illuminated. The second purpose was to empower nurses to take action to improve the care they provide to individuals with HIV and AIDS. The empowerment process is discussed in a separate paper (Fournier, 2004a).

Design and Methods

Participatory action research (PAR) was the methodology that guided the study. This approach can be defined as "collective, self-reflective enquiry undertaken by participants in social situations in order improve the rationality and justice of their own social...practices" (Kemmis & McTaggart 1988, p. 5). The aim of participation is to include all of the participants in the process of planning, acting, observing and reflecting to achieve these changes (Grundy & Kemmis, 1988). As a methodology, PAR provides a flexible, socially and culturally adaptable framework to guide the research process (Cornwall & Jewkes, 1995). PAR facilitates critical thinking and encourages individuals to explore the root cause of their situation (Schoepf, 1994).

The research was conducted in two stages and took place over a 10-month period. In September 2003, the author made a four-month long trip to Uganda to begin the PAR process with the nurses, and to collect and analyze the data from the interviews and focus groups. The second trip took place in June 2004, five months later. The main purpose of the second visit to Uganda was to discover the constraints that the nurses faced in taking action to improve the care they provide to PWAs. At this time, two additional focus groups were conducted and all of the findings were validated and disseminated with the focus group participants. A senior administrative nurse working at Mulago Hospital agreed to participate as the author's field supervisor.

During the second visit, two presentations were conducted at Hospice Uganda for a group of nurse educators who were from all regions of Uganda. The focus group participants co-facilitated two presentations at their hospital setting with the author. A written summary was prepared for policy makers. The final study report was distributed to the Ugandan Ministry of Health, and the Uganda AIDS Control Program.

Ethical approval for the study was obtained from the University of Alberta as well as the National Council for Science and Technology, Makerere University and Mulago Hospital in Uganda. The researcher explained the study to each participant and provided an opportunity for questions. Oral and written informed consent was obtained from each participant.

Setting and Sample

Data were collected at Mulago Hospital in Kampala, the capital city of Uganda. Kampala is a large urban centre where nurses' responsibilities differ from those of their counterparts in rural areas. Mulago is the national referral public teaching hospital that treats complicated conditions through intensive monitoring. The hospital has a capacity of 1,500 beds and currently employs 1280 individuals, of whom 757 are full time nurses. The hospital is comprised of specialized clinics and allocates one day per week for an HIV/AIDS outpatient clinic.

Six key informants (nurses, non-nurses) from governmental and non-governmental agencies participated in an interview. The key informants were recruited using purposeful sampling. The author's field supervisor recommended different agencies to approach for interviews. Inclusion criteria for the key informants included: able to speak English, affiliated with an HIV/AIDS organization (government or non government), and over the age of 18 years. Six nurses from Mulago Hospital participated in the focus groups. The focus group participants worked in the government referral hospital and came from a variety of areas including medical, cancer, tuberculosis, and paediatric units. Five of the nurses were female and one was male. The inclusion criteria for the nurses included: able to speak English, caring for PWAs on a regular basis (at least one patient every shift or every day), over the age of 18 years, and working in a hospital setting. Student nurses, visiting nurses from other hospitals, and nurses working in non-clinical areas were not considered. Recruitment was done at a nurse manager meeting where managers nominated an individual that fit the criteria. The nurse managers were then approached two days later to collect the names of the individuals willing to participate. Following each interview and focus group, participants were given an honorarium to compensate them for their time. All participants were native Ugandans and spoke English.

Data Collection

Three methods were used for generating data: (a) in-depth interviews (b) photovoice and (c) focus groups. The core data collection method was the focus group, which served as a means for the photovoice method and was essential for the emancipatory aims of PAR.

Interviews

The six key informants were interviewed using a semi-structured format. Individual interviews took place at the key informants' work settings. Themes that emerged from the individual interviews were used for two purposes: (1) to develop an understanding of the local context and issues surrounding nursing care of PWAs, and (2) to initiate discussion and generate broad themes for the Photo Voice technique within the focus groups. The one-hour interviews were audio taped and transcribed verbatim.

Focus Groups

The focus group met every two weeks over a 3-month period for a total of six meetings. These group meetings served as a means for group discussion with the nurses utilizing a participatory analysis described below. The focus groups lasted approximately 2 hours and were re-negotiated as required. The nurses in the focus group continued to meet between the researcher's first and second visits with the goal of taking action to improve the care the nurses provided to PWAs. By a process of voting, a team leader was chosen and the author provided ongoing support via telephone to the nurses through this team leader.

Photo Voice

In Africa, it is said that the most important thing to do is to listen to stories (Haegert, 2000). Street (1995) describes a process of raising consciousness through story telling that involves asking each person to "give a thumbnail sketch of their own personal life, making links between their current attitudes and experiences" (p. 61). Story telling was facilitated in the current study by the use of photographs taken by each nurse. Each nurse was given a camera, took pictures and brought the pictures to the meeting. A framework for telling stories (Wallerstein, 1987) was utilized. The acronym SHOWeD was used to describe the photographs. SHOWeD refers to: What do you See here? What's really Happening here? How does this relate to Our lives? Why does this problem or strength exist? What can we Do about this? According to Wang (1999), the practice of photovoice has three main goals: to enable people 1) to record and reflect their personal and community strengths and concerns 2) to promote critical dialogue and knowledge about personal and community issues through group discussions of photographs, and 3) to reach policymakers. In this study Photo Voice was used as a data collection tool and a participatory process.

Data Analysis

Data analysis occurred simultaneously with data collection and was guided by general methods for data management and analysis as described by Miles and Huberman (1994). The themes, issues, and questions that emerged from the individual interviews were explored with the nurses in the focus group. Analysis was achieved by repeated re-reading of the summaries and field notes, to become familiar with the data. Coding data occurred and themes were drawn from the data. The process of ensuring that the interpretation and meaning were accurate, acknowledged and validated local beliefs, thereby enhancing rigor (Mill & Ogilvie, 2003). Summaries were written immediately after each focus group and were reviewed with the participants for validation, which often included correction and comment. Field notes were also taken after each meeting to record the researcher's thoughts and feelings about the process as well as to document the process. Data analysis also occurred when the researcher returned to Canada. An additional 2 months was spent analyzing the data. It was during these two months that the researcher discovered that the emotional anguish expressed by the nurses reflects the concept of moral distress. As the nurses did not label their experience as moral distress I refer to this concept as emotional anguish in the findings and further explain this issue in the discussion section.

Findings

Three main themes and several subthemes emerged from the data. The themes included: providing care, challenges to caring, and coping with challenges. The themes are being reported separately; however, in reality they were often interrelated. Pseudonyms have been used to protect the anonymity of the participants.

Providing Care – "You dig deeper than just the physical"

Providing care was a common theme in the interviews, photos and focus group discussions. Subthemes included: practicing holistically, providing ongoing counselling, and cultivating hope.

Practicing Holistically

In the study, nurses often mentioned that they addressed the needs of their patient through a holistic model of nursing care. Nurses talked about holistic care as a way of looking at the social, physical, emotional, and mental needs of a patient. During an interview, a key informant said, "the best care that I can give is holistic care. Not looking at the physical problems alone but looking at all the other components- the psychological, spiritual, social, and the family members because they also care for the patient". By providing holistic care nurses recognized that, if one aspect of the person is affected, then other aspects are as well. Another key informant said, "You look at the patient as a whole. If the patient has a symptom like severe TB…we have to ask them the question on the spiritual side because the patient may have another problem but it is hidden" This same nurse went on to say that "you dig deeper than just the physical. It may be something bigger than that and it may be at the root".

Nurses also discussed the different tasks they performed in caring for individuals with AIDS. For example, a key informant commented, "physical comfort is making sure they are eating, sleeping comfortably and giving them relief of pain, which may be physical or psychological". Nurses felt it was part of their role to be empathetic especially with patients they knew were HIV sero-positive. Jackie, one of the focus group participants stated:

> The nurses are also more empathetic [towards HIV patients] than to any other patients. You feel bad for the state that patient is in and maybe one time or another you have nursed someone who is a close relative. You think that maybe this could happen to me or to my relatives so you become very empathetic and that is a big difference between nursing someone with HIV than with others.

Nurses referred to religion as one way to address a patient's needs. This is reflected in the following statement from a key informant. "We tell them that God will forgive everything and loves you the way you are". As well, nurses also felt it was important to provide spiritual comfort by telling their patients that they were not the only one with the disease and that there were many others with the same problem. Nurses would refer patients to spiritual leaders and to other AIDS organizations that could provide support after discharge from the hospital.

The nurse-patient relationship was central to providing holistic care. One key informant reflected on this relationship and asserted that, “the patient goes to the nurse and they build a relationship. The nurse is the first person the patient sees and the patient becomes closer to you than the doctor”. Building respect and trust with their patients was vital in the nurse-patient relationship. For example, a key informant acknowledged “we should allow them to have confidence in us which means, be with them, talk with them. [Together] we create the nurse patient relationship. When this happens the patient will tell you everything without fearing or hiding anything”. Nurses felt that it was by showing love, concern, and having a nonjudgmental attitude toward the person, that respect and trust were able to grow. This was an important aspect of providing care.

Providing Ongoing Counselling

Counselling also emerged as a subtheme in caring for patients with HIV and AIDS. The nurses often spoke about health education and counselling as one concept. They believed that an important part of the nurse’s role was to teach patients and their caregivers about the illness, including its treatment, and prevention. As well as teaching patients and family members, they also felt their role was to educate the public about HIV and AIDS.

Nurses believed that counselling should be ongoing because it promoted adherence to drugs and acceptance of illness as well as contributing to overall support. The need for ongoing counseling was reflected in a statement by Anne, a nurse in the focus group "[the patient] is happy for 1 to 3 days but once a week he will always flashback to 'I am going to die, I am going to die' so it becomes a problem you must keep counseling [the patient]". Nurses recognized the need to have good counseling skills, which included knowing about the various aspects of HIV and AIDS. Mary, another nurse in the focus group, spoke about the challenges counseling people with HIV. She stated, "[Nurses] need to have counseling skills but most of us are not going through this training so it may be difficult to counsel these patients". Most nurses recognized that they needed to obtain knowledge and skill in counseling so that they could provide quality nursing care. Peggy said:

> Maybe for this business of explaining, the nurses should have the information and should appeal to every nurse to have the knowledge. You should go back for the courses so you have the techniques for counselling. But if you are not a counselor you may find it difficult for you to counsel this patient.

Nurses believed that counseling helped the patient face the reality that they would eventually die. Counselling involved showing patients that the nurse cares, giving support, showing love, and fostering hope.

Cultivating Hope

Many of the nurses commented that one of the challenges in caring for a person with AIDS was dealing with patients who had lost hope. As a result, the nurses felt that an important aspect of their role was to cultivate hope. A key informant stated, “We give hope to these patients [so] that they can live longer in spite of the virus”. Giving hope arose many times in the interviews and focus groups. It was believed that there were different ways to instil hope but most nurses suggested it was done through counseling the patient. Counseling helped the patient to express their fears and asks questions. The nurses frequently responded to the patients’ fears by normalizing the disease as a way to foster hope. Elizabeth, a focus group participant said, “it’s important to tell them that they are not the only one and there are many others with the same problem”. Similarly, a key informant said “I counsel them that they are not the first person to get AIDS and that even with AIDS they will not die in one day - it takes many years”. Cultivating hope allowed the patient to feel they still had a future. As one key informant said, “[We] really have to make them understand that there is still a chance to live”. By counseling patients about their future, providing treatment options, and making referrals to clinics, the nurses felt they were giving hope. It was also common for nurses to recognize that giving hope took time and that it was not easy to do.

Challenges to Caring – “They are ALL admitted”

Nurses spoke about their working environment and the many challenges they faced in caring for someone with AIDS. The subthemes related to challenges to caring included poverty, inadequate resources, personal factors such as fear of contagion, and lack of continuing education. These issues often led to nurses experiencing emotional anguish.

Poverty

Poverty was frequently mentioned, as the reason a patient would not receive medications, linens or food while in the hospital. Reflecting on the lack of medicines Jackie said,

> There may be a starting dose, then when it comes to a second dose it is finished and she is told to buy it but she has no money because those drugs are very expensive…they say they don't have money, you [nurses] don't have money to contribute to them, and the government does not have money to contribute to them, so it becomes a problem for the nurses.

One of the nurses expressed feeling "hard" in not being able to give the best care because of poverty: "But by the time they get to our ward they don't have drugs and you tell them to buy but they do not have money. And you feel hard because you want to treat the patient but you can't". Relatives become the patient's life line in the hospital, bringing food, bedding, and medications. As the following passage illustrates, the poverty of the patient, combined with hospital constraints, greatly impacted his/her life especially when there were no relatives to care for the patient:

> One of the challenges is that patients come without linen so as you can see [referring to the patient in the picture] she came in with

> only her jacket and her slippers….and she relied on the hospital food that did not come on time. At times the hospital could not provide the necessary meal for her so she went without lunch or supper. So as time went on she deteriorated and she became anemic and eventually died. (Focus group)

Nurses also spoke about not having enough beds. Shannon, a focus group participant said:

> The beds are not enough. On my unit you may find three children on one cot and most mothers here are low income and they cannot afford to go to [a] private [hospital] so they have to share a bed with five other kids. You have no choice.

Florence, another focus group participant agreed. "On our ward when you are supposed to put a patient on a drip but the patient is on the floor and you are to put up blood. Yes, because there are no beds". Alice, while examining another participant's photograph, exclaimed, "oh my God! Look at how congested the ward is. How about cross infection. This is a big problem". Ensuring privacy and maintaining dignity is challenging in an environment where the spacing of the beds are close and there are no curtains. A common thread that links these issues together is that some patients experienced prolonged suffering or premature death as a direct result of poverty, at the individual, institution, or government level.

Inadequate Resources

The nurses reported a lack of resources including supplies and equipment, nursing staff, and funding. Nurses commented that the policy of the hospital often influenced the care of patients. The government hospital is the national referral hospital for the country. This meant that patients could not be turned away and all patients were admitted. Due to the overwhelming numbers being admitted on a daily basis, hospital wards were continuously full and patients frequently used the floor as hospital beds. Overcrowded wards, in combination with the shortage of nurses, compounded the problem of insufficient resources. The nurses felt that the hospital policy of admitting everyone who walked in the door added to their frustration over inadequate resources. Mary said, "Being a referral hospital we don't reject patients. They are all admitted. I don't have to go and look again. I know we do not have room for the next patient admitted. We try to improvise by finding room." A key informant reflecting on the working environment, summarized the situation:

> The ward is congested, some patients are sleeping on the floor and it's difficult to make them comfortable when they are lying on the floor. Sometimes there is not enough lighting and a nurse needs to use a lamp or a small candle for stitching. The equipment may also be lacking. You want to cut out a dressing but you are lacking the necessary forceps. You may not have enough supplies such as cotton wool or gloves. A nurse has to protect herself and a lack of

> supplies like gloves can hinder nurse from delivering services.
>
> Nurses may find themselves fearing to handle the patient.

The shortage of nurses was mentioned consistently throughout the focus groups and interviews. Peggy, describing her photograph of patients sharing a large oxygen tank, commented:

> …Another thing, the nurse is not seen [in the picture]. Sometimes there is a shortage of nurses on the ward. The picture does not show the nurse but the nurse is supposed to be there…. The role of a nurse is compromised because of this shortage.

Jasmine, a focus group participant said:

> You can see one nurse [in the picture] carrying out about three duties. One she is admitting, second she is administering drugs and then she must go to look for beds. There really is a shortage of staff. You have so many things to do at the same time.

When discussing the reasons for the shortage, participants felt that many nurses had been trained but many are not working because the government recently stopped recruiting them. As a direct result of the shortage, the nurses were experiencing an increased patient workload. For example, it was not unusual to have nurse-patient ratios of 1 to 50 during the day, and 1 to 100 on evenings.

Fear of Contagion

Nurses reported that gloves, gowns and masks were often not available within the hospital setting. Isolation facilities either did not exist or if available they would not have the supplies to practice universal precautions. Shannon said "on our ward we only have pediatrics and they are all intermingled. That is a problem. We should isolate them if they are infectious….that is cross infection." As well, there may not be enough nurses to give the proper one-to-one care required. Consequently, the risk of spreading an airborne disease, such as TB within a particular ward was great. Nurses expressed fear of being infected and would take measures to protect themselves. However, protection without the proper supplies meant patients would not get the care they needed. Anne recalled:

> Patients present with all stages [of an infectious disease] and yet the barrier nursing is not up to date. So sometimes we fear these patients with such an infection and we will not provide good nursing care because we are fearing to risk and you may be infected by providing care to the patient.

Florence interjected:

> The nurse is working much more careful. She has a lot of precaution to herself because she knows this person has HIV and could prick herself or any problem like blood, diarrhoea, vomiting she becomes more careful than when she is nursing other patients like a malaria patient so they [nurses] are more careful - more protected - and actually when the nurse does not have gloves or protection they will not do the procedure because of fear.

Finally, Elizabeth reflected on her story and expressed emotional anguish:

> It's haunting you but you are fearing for your own health also. But you remain haunted because you know what should be done because of the condition you are not doing it so its haunting you. You have done this but you have not done that. And somehow you become tortured over this….you know you are not doing your service but because of the situation it is a problem.

Lack of Continuing Education

During our focus group discussions, the nurses reported that they did not have enough knowledge about antiretroviral drugs (ARVs). Their concerns are reflected by Elizabeth in this passage:

> We also have a challenge that we as nurses are supposed to know about ARVs. But some of us have not ever seen these drugs. A patient comes with those drugs, and that were bought from another pharmacy, and asks you "how do I take this drug?" So we need to be educated on these new drugs because it comes at a time when we are not in school.

Nurses did not trust themselves to provide the patient with current health information. Because of their inability to provide information to patients, such as the side effects of ARVs, nurses felt ashamed. The nurses believed that seminars or workshops would be helpful in updating their current level of knowledge about ARV's. Jackie said, "In my opinion if a new drug is introduced we should all be oriented to it. So at least they [the patient] know how to take it".

Coping with challenges: “It is haunting, but there is no way out”

Nurses used a variety of strategies to cope with the many challenges they face in their daily care. Improvising was a common way to deal with the challenges. Nurses coped with the shortage of staff and increased workload by teaching the relatives to perform nursing procedures. Anne shared a picture of her role in caring for patients with AIDS to demonstrate the need for such teaching:

> We have so few nurses that I was trying to indicate to the relative how to feed the patient. You know how risky it is to feed the patient through the NG tube but once we pass it we teach the relatives how to feed these patients. We explain that you have to see whether the tube is still in the same position….we have no alternative we have to teach the relatives…but what I have realized is it is a risky procedure. I think if it weren’t the shortage of nurses it would have been us feeding the patients with the NG tube.

Anne went on to say that it was better to teach the relative how to do the procedure than to have the patient go without feeding. Despite this necessity, she questioned if she had done the right thing. The nurse was compelled to trust the relative to provide basic nursing care for the patient. Shannon recalled her feelings when she was not able to carry out her role because of the shortage of nurses:

> It is haunting but there is no way out. Now there is a shortage. If you spend all your time with one patient the others will feel neglected and they

> will want you to do the same with them. It's haunting but there is no way out.

Nurses stated that the frequent shortage of oxygen often resulted in the premature death of patients. Anne, reflecting on a recent experience, gave the following description of her reaction to a perceived preventable death: "When we are on the ward we often transfer a patient to another ward. At times, when you reach [the other ward] the patient has died because the oxygen ran out on the way and you feel guilty". Shannon, after listening to Anne's story agreed, "It is haunting". She described the improvisation that was required to cope with inadequate resources on the ward. She shared a very powerful picture of the paediatric ward in the following passage:

> In the picture we are seeing some beds, there's an oxygen cylinder high, children are sleeping, there are so many kids. What is happening is these [children] are sharing this oxygen cylinder. Every tube has a patient, so oxygen is flowing through these tubes to different patients... This is happening because we are having so many patients that need the facility and need oxygen but we don't have enough beds at the facility for the patients.... so we have to improvise. There are so many tubes and so many patients.

As Florence pointed out, improvising with oxygen meant:

> The connecting tubes are not oxygen tubes but are IV tubes. You can imagine what that must be like. The patients do not get what they need

> because of improvising. This is another problem that needs to be fixed. Improvising also means that the IV tubing is used over and over again. Each time a new patient uses the old tubing new holes are poked and the old holes are covered with tape. If the old holes begin to leak more tape is used.

In general, nurses felt that they used various coping strategies such as improvising to provide the best care possible while dealing with insufficient resources. While this meant being creative with solutions, it also had a negative impact on the nurses. One nurse summarized this experience as:

> It's quite hard to be a nurse [in Uganda]. And it's quite challenging because sometimes we are not living up to the expectations of a nurse. But in this process you realize that the nurse is supposed to do A-B-C-D but sometimes you are short of what you are supposed to do. You are not working up to your expectations.

Discussion

The findings of this study revealed that Ugandan nurse generally provide care from an holistic perspective. Sarkis & Skoner (1987) argue that holistic nursing is grounded in the perspective of human beings as biological, psychological and social beings. The claim that Ugandan nurses practice from a holistic perspective is consistent with Kramer's (1990) findings regarding nurses in general. Chin (1985) argues that the holistic view is now a central tenet of nursing. By practicing holistically, Ugandan nurses look beyond just treating the symptoms of AIDS, which allows for a new way to connect with their patients and creates a space for healing.

The nurses in the study identified two specific roles in caring for individuals with HIV and AIDS. First was their role as counselors for individuals with HIV and AIDS. However, nurses admitted that they were providing counseling without the proper training. Voluntary Counseling and Testing (VCT) is an important entry point to HIV prevention and HIV related care (UNAIDS, 2000). Nurses have a responsibility to educate the public about HIV prevention and in order to give accurate information they must be well informed. However, if nurses do not have the knowledge and skills necessary to provide proper counseling, effective prevention and care is limited. Secondly, nurses felt it was their role to cultivate hope for individuals with HIV and AIDS. Many individuals with AIDS develop feelings of hopelessness and a sense that it is too late for behavior change. However, by providing counseling, nurses can instill a sense of hope, which can empower their patients to maintain control over their lives, specifically their future behavior. Akinsola (2001) explored the role of primary health care workers in fostering hope in people living with AIDS in Africa. Akinsola argues that fostering hope is a way to improve the quality of life of PWAs. Other authors who have conducted research regarding the concept of hope have recognized the role of nurses in fostering hope (Herth, 1990; Owen, 1989; Farran, Herth &Popovich, 1995).

Nurses in the study felt that they are unable to provide quality nursing care due to the many challenges they encounter. These challenges to caring included poverty, inadequate resources, fear of contagion, and lack of continuing education. In combination the challenges contribute to nurses experiencing emotional anguish. While the researcher was in Canada analyzing the data she discovered that the anguish expressed by the nurses exemplifies the concept of moral distress. Moral distress arises when one is unable to act on one's moral choices due to constraints interfering in what one believes to be right (Canadian Nurses Association, 2003). As a result, the nurse feels an unpleasant emotion stemming from her inability to take action on what is believed to be morally correct. Once the nurse realizes that her actions do not promote quality care for the patient, the nurse experiences moral distress. It is important to recognize that it is the nurses' belief system, in conjunction with the particular situation that leads to moral distress (Canadian Nurses Association, 2003). Therefore, one nurse may suffer from moral distress while another may not in a similar situation. The emotional anguish experienced by the nurses in the current study is consistent with the concept of moral distress described by other researchers (Austin, Bergum & Goldberg, 2003; Kalvemark, et al., 2004; Sundin-Huard & Fahy, 1999). During the researcher's second visit to Uganda she introduced the concept of moral distress with the focus group participants. The participants validated that moral distress reflected their experience. One of the participants stated that it was helpful to know that nurses in other part of the world also experience moral distress as it allowed her to see that she was not alone in feeling haunted and tortured.

In the study, adherence to universal precautions was challenging in an environment where resources are scarce. Compounding the issue of universal precautions, guidelines are not readily available in Mulago hospital, and nurses lack knowledge in their use (Dinah, 2002). The issue of inadequate supply of materials and equipment for nurses is not new and has been reported in many sub-Saharan African countries (Kaimenyi & Ndung'u, 1994; Mkuye et al., 1991; Mill, 2000; Mbanya et al., 1998). These studies have discussed nurses' concerns with lack of protective supplies such as gloves, gowns and masks, disinfectants, disposable needles, and syringes available to provide care for HIV sero-positive patients. It has also been reported that there is a reluctance to treat PWAs due to a shortage of supplies and equipment in health facilities in resource poor countries (Igboanugo, 1998; Onibokun, Egunjobi, Uwakwe, & Onibokun, 1999), which contributes significantly to the practices adopted by nurses. While many studies attribute fear of contagion to insufficient knowledge and negative attitudes, the current study suggests that fear of contagion could be due to a lack of resources. Studies in Uganda and Nigeria have also found fear of contagion related to a lack of supplies and equipment (Baguma, 1992; Uwakwe, 2000). Universal precautions cannot always be followed when supplies are scarce, therefore, knowing the patients HIV status becomes salient. This is not possible however, because most patients do no know their status nor do they want to be tested.

The author found that the nurses did not express negative attitudes towards their patients with AIDS. On the contrary, the nurses showed compassion and love, especially for these patients. This finding is consistent with a study conducted at Mulago Hospital by Walusimbi (2002) regarding the knowledge and attitudes of nurses toward the care of patients with HIV and AIDS. However, other studies in Africa have found negative attitudes among health care workers, including nurses, towards their patients with HIV and AIDS (Adelekan & Jolayemi, 1995; Kohi & Horrocks, 1994; Mbanya et al., 2001).

Nurses used a variety of strategies to cope with the many challenges they face in their daily work. However, despite feeling distressed regarding the risks these strategies posed for patient care and safety, they felt it was their only option. Similar findings were also reported by Lutzen & Schreiber (1998) in a study in Canada. However, Ugandan nurses need to begin to look at how they are contributing to the status quo by continuing to cope as they always have done. By finding practical solutions to these challenges that would not jeopardize patient care and safety, nurses may minimize their experience of moral distress.

Study limitations

Policy makers were not included at the beginning of the project but rather at the end, which limited policy change to the institutional level. An effective strategy to promote change related to HIV policy in Uganda would have been to include policy makers during the initial phase of the project. This could have been achieved by the formation of an advisory committee. Typically, in PAR and specifically utilizing photovoice, an advisory board is created to "serve as a group with the political will to put the participants' ideas into practice" (Wang, 1999, p. 187). Participants from Mulago Hospital were recruited through a nomination process. The researcher did not question this process, as she believed she was following this cultural protocol. However, the nurses who were chosen may not reflect the most 'voiceless'. As a result, the findings related to the themes may not reflect the most marginalized group of nurses. Also, some may argue that the major limitation of this study is the generalization of the findings. However, the nature of qualitative research, specifically, participatory action research, does not attempt to generalize about a group of people. Therefore, the findings of the study should not be generalized and the reader should keep in mind that the voices in this paper reflect the everyday experiences of a small group of Ugandan nurses.

Future Considerations

In order to provide quality care, nurses urgently need ongoing education about HIV disease, including VCT and the administration and monitoring of ARVs. With the limited number of physicians in Uganda, nurses will play a greater role in the monitoring of people on ARVs, and prescribing narcotics for palliative care patients. Thus, nurses urgently need a sound knowledge base to provide quality care to patients with HIV and AIDS. Nurses should be more involved in seminars and workshops regarding all aspects of HIV and AIDS. Also, teaching relatives and caregivers nursing procedures and care in a more formalized approach could help prepare the family members to care for the patient at home. If nurses are to become more visible they need to be actively involved in promoting research in their clinical settings. By fostering a milieu of research, nurses are more likely to view research as important for their nursing care. This can be done initially by having discussions about research, facilitated by the many nurse managers who have research experience.

Further research is required to explore Ugandan nurses' experience of moral distress. It would be beneficial if nurses were able to discuss their moral distress in a group so that nurses experiencing similar feelings could be supported. Future research questions regarding moral distress could include: How does moral distress impact nurses' health status? How does moral distress impact the patient? How does the moral distress impact the organization? How can moral distress be minimized in resource poor settings? As well, further research regarding using VCT as a way for nurses to cultivate hope and improve the quality of life for individuals with HIV would be beneficial for effective HIV prevention and treatment. The current study showed that nurses are teaching relatives as a way of coping with the many challenges they face in the daily care of their patients. Future research could focus on exploring this phenomenon and how it impacts the workload of nurses. By recognizing that a wider range of methods can be used in PAR, a survey could be created to document the change that occurred in the organization. This addition could be helpful in communicating to policy makers the effects of empowerment.

Conclusion

Nurses working in a resource-restrained country such as Uganda are faced with the dilemma of how to fulfil their role and responsibilities to promote health, prevent illness, restore health and alleviate suffering. Bringing together a group of nurses who are usually isolated from research and giving them an opportunity for their voices to be heard and to participate in the research process as co-researchers was empowering. Fostering hope is central to the care that Ugandan nurses provide to individuals with HIV. It is just one of the many ways nurses make a difference in the care of individuals with HIV. It is through fostering hope that healing can take place. The challenges that nurses face while caring for patients with HIV contribute to their moral distress. However, nurses must begin to look at realistic solutions to decreasing their distress, which may give them new insight into how to challenge the status quo. This will enable nurses to advocate for change within their work setting, nursing profession, community and government. However, nurses require support from authority to facilitate change. As well, the international nursing community must also find a way to support these nurses to influence change.

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Conclusion

Reaching the Core

> ***When planning for a year, plant corn.***
> ***When planning for a decade, plant trees.***
> ***When planning for life, train and educate people.***
> - *Chinese Proverb*

As the seasons come and go, I continue to tend to my garden, planting what I need and harvesting when the time is right. This season I chose to harvest an onion to help me discover my many layers. Peeling away the layers of my thesis has not been a simple process. Peeling any good onion usually produces tears. When the tears came I was tempted to close my eyes and abandon the onion, as this was far easier than continuing to peel. However, I forced my eyes to stay open allowing the tears to stream down my face as I continued to peel each new layer. In reaching the core of the onion, I have many new insights regarding the roots of poverty. I now see how global issues such as globalization impacts local issues. As my awareness grew, I began to cultivate a sense of responsibility. The genus of this responsibility is an intense moral obligation.

In resource poor countries, moral interest should be about the unnecessary suffering created by global economic and political structures. The questions that continue to linger at the end of this season are related to the global concerns. Why is there so much poverty and suffering in a world when there is so much abundance? On an intellectual level, I know many reasons. One reason is the neo-liberal policies[1] of the World Trade organization. These policies are generating wealth in the industrialized countries while keeping other countries poor. But on a deeply spiritual level, my question remains. As citizens of a wealthy country, like Canada, what is our moral duty to prevent suffering created by global economic and political structures? Whose responsibility is it to challenge these structures? Individuals? Advocacy networks? States? From a global perspective, the origins of poverty and the responsibility to address it must be on the agenda of the affluent states. Instead, and sadly, corporate values are dominating the policies of many states. These corporate values are based on narcissism, individualism, and economics. I have come to realize that the immense poverty and suffering is symptomatic of a deeply moral failing in our humanity. Juxtapose the challenges of nurses in Uganda with our moral failing and what bears fruit is a clue to our societal values in our globalized world.

At times throughout this thesis, my sense of responsibility overwhelmed my psyche. During my field research in Uganda, I felt the weight of the world on my shoulders. However, I realized quickly that having a fatalistic view of the world was not helpful mentally or spiritually. As I peeled away more layers I recognized that I needed to cultivate my own hope for a better world. Freire (1994) suggests that human existence, especially in the struggle to improve it, fundamentally requires hope. It is a necessary condition, for the possibility of transforming the world into a more equitable place.

While writing my thesis I have spent many hours reflecting on my garden and specifically the many layers of this thesis. As a gardener I have realized there are many things I cannot control, such as the weather. But I can create the set of conditions where different plants in the garden thrive and bloom. As a researcher, who uses participatory action research, I cannot control the change that will occur among participants but I can create the conditions that make change possible. Gardeners plan, as do researchers, but they know that plans have to be changed all the time and that they are not in control of the garden. In order for change to take place, there must first be hope that change is possible. According to Freire (1994) the central task of any leader "is to unveil opportunities for hope, no matter what the obstacles may be" (p.9).

Similar to my own peeling away of personal layers, the thesis is not perfect. There are a few things I would do differently were I to begin again. Mainly, I would take better quality cameras with me to Uganda. While the quality was adequate during the study the life span of the cameras is questionable. As well, I would have the film developed at a higher quality photo lab. The pictures were often blurred due to the development process. Additionally, I would have included journaling as a method of data collection with an assortment of specific questions to reflect on the process, blank pages for drawing pictures, and pasting cut outs. Journaling would have allowed the nurses to reflect on their own conscientization process on a deeper level.

Implications

This exploration has confirmed a number of important themes in relation to the experiences of nurses caring for individuals with HIV and AIDS. Foremost is the affirmation that hope is central to the care that nurses provide. McGee

(1984) identified hope as “a force that guards against death” (p.34). While there is no cure for HIV there is hope. Nurses have a unique opportunity within the AIDS crisis to help people find hope amidst so much death. Individuals who talk about their fears of death are unintentionally talking about a commitment to life. By encouraging patients who are HIV sero positive to talk about their fears of death, nurses are nurturing the patients’ commitment, allowing hope to take root. To have hope is to consider the future.

This exploration also confirmed that there is immense potential for nurses to expand their role in the care of individuals with HIV and AIDS. Currently, there are plans to distribute antiretroviral drugs in Uganda through the “Global fund to fight AIDS, Tuberculosis and Malaria”, however Ugandan nurses have limited opportunity to take a leadership role in their provision. With so few doctors, an expanded role for nurses may contribute to a more comprehensive approach in the treatment and care of HIV sero positive individuals. Nurses in the study supported an expanded role for nurses to include the administration and monitoring of individuals on ARV’s. They believed that nurses would be open to this new role with the caveat that further training and education would be needed.

Recommendations for further research

The current study highlights the need for research in several areas. The findings related to the challenges nurses encounter in their daily care, document the urgent need for further research to understand the relationship between poverty, education, fear of contagion, and moral distress. Additionally, nurses should be encouraged to form small groups as a way to normalize their experiences of distress and powerlessness by discovering that they are not alone in their everyday challenges.

The realities of our world are that almost half the world, close to three billion people, live on less than 2 dollars a day; and more than one billion live on less than 1 dollar a day (UNDP, 2003). Every day, 8,000 people die due to AIDS (WHO, 2004). And for the first time in history we have the resources, knowledge, and technology to bring the AIDS pandemic to a halt. What we don't have is the moral and political will to do so. In reaching the core of my onion, and becoming aware of this fact, I have a moral obligation to help people and governments find the will to do something about the AIDS crisis, and more generally global poverty.

Footnote

[1] Policies that are market-oriented, export-led and characterized by commercialization/privatization of public sector functions (Lamy, 2001).

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Appendices

Appendix 1: Guiding Questions for Interviews

Key informants and Nurses will answer:

1. What is the role of a nurse in caring for PWAs?
2. What is quality nursing care?

-What is the best care that you feel you could give?

3. What hinders a nurse from providing good/quality care to PWAs?

-If you are doing your best how do you want to improve your care?

4. What else could nurses be doing to care for PWAs?

-Do you feel you could be monitoring people on ARVs?

5. Tell me what it is like to be a nurse in Uganda
6. Tell me about your experience of nursing PWA's
7. What do you think about nurses taking a role in monitoring people on ARV's?

   -is it possible? What would need to change to make it possible?

Nurses will also answer:

8. Describe your typical day nursing a PWAs. Start from the beginning of your shift until the end of your shift.
9. What challenges do you face in your daily care of PWAs?
10. What are the positive contributions you are making in caring for PWAs?

-What are you doing well in caring for people with HIV illness

Appendix 2: Information Letter Interviews

Title of the Project: The Role of Ugandan Nurses in Caring for Individuals with HIV illness

Investigator:
Bonnie Fournier

I am a graduate student in Health Promotion ay the University of Alberta. I am doing a research study and request that you consider taking part in it.

Purpose/Background:
The purpose of the study is to learn about the role of nurses when caring for Persons With AIDS (PWAs). Not much is known about Ugandan nurses experience in caring for PWAs. I hope that by sharing your thoughts, feelings and ideas of nursing care that changes to nursing policies may happen.

Procedures:
Your perceptions of nursing practices will be explored in an interview. All interviews will last approximately 1-2 hours. All interviews will be tape recorded and transcribed for analysis. You may refuse to answer any questions in the interview or ask that the tape recorder be turned off at any time. The interview will begin with general questions about your opinion of care provided by nurses for PWAs.

Benefits:
The benefits that you may receive as a result of participating in this study are:

- You will have the opportunity to contribute to the body of knowledge of the care provided by nurses for PWAs.
- The study should also enhance your understanding of your nursing practice.

Risks:
You could become upset at discussing these issues. If this happens I will refer you to a counselor

Confidentiality:
All information will be held confidential (or private), except when professional codes of ethics or legislation (or the law) requires reporting. Where possible, you are guaranteed privacy and anonymity, and your responses will be treated with

confidentiality. If anonymity and confidentiality cannot be assured or granted, you will be made aware of the limitations and of the possible consequences before you are asked for your consent to participate. The information you provide will be kept for at least five years after the study is done. The information will be kept in a secure area (i.e. locked filing cabinet). Your name or any other identifying information will not be attached to the information you give. Your name will also never be used in any presentations or publications of the study results.

The information gathered for this study may be looked at again in the future to help us answer other study questions. If so, the ethics board will first review the study to ensure the information is used ethically.

Freedom to withdraw:
Your participation is voluntary. Refusal to participate will not affect your employment.

Additional contacts:
If you have any concerns about any part of this study, please contact Prof. Fred Wabwire-Mangen, Institute of Public Health, Makerere University at 532-6314.

Thank you for your consideration of this request to be part of this research.

Sincerely,

Bonnie Fournier

Appendix 3: Information Letter-Focus Group

Title of the Project: The Role of Ugandan Nurses in Caring for Individuals with HIV illness

Investigator:
Bonnie Fournier

I am a graduate student in Health Promotion ay the University of Alberta. I am doing a research study and request that you consider taking part in it.

Purpose/Background:
This study is talk about your experience caring for Persons With AIDS (PWAs). Not much is known about Ugandan nurses experience in caring for PWAs. I hope that this study will facilitate a sharing of ideas that there are working for you and if there are any problem areas to provide the opportunity to hear what others are doing in this area.

Procedures:
Your nursing practices will be explored by story telling using photographs. This means that you will need to be an active participant in the data collection and analysis procedures.

Meetings will be 2 hours, every two weeks from Sept 2003 to Dec 2003 and then once a month from Jan 2004- June 2004. Participation in this research will involve a contribution of your time and effort. This study will involve you taking pictures and analyzing data concerning your nursing practices. You will need to ask the permission of any individual you photograph. As data is gathered, we discuss our photographs within the group. We will work together to form tentative interpretations. These interpretations will then be used to focus successive decisions about the research process. Before the group discussion begins, I will remind the group that what is said needs to remain confidential. If there is something you would not like to be discussed or known, please do not feel any pressure to share it with the group. All meetings will be tape recorded. I will write down what is talked about and I will bring it to the next meeting for you to read and make changes.

Benefits:
The benefits that you may receive as a result of participating in this study are:

- You will have the opportunity to contribute to knowledge of nursing PWAs.
- The study may enhance your understanding of your nursing practice

Risks:
You could become upset at discussing these issues. If this happens I will refer you to a counselor.

Confidentiality:
All information will be held confidential (or private), except when professional codes of ethics or legislation (or the law) requires reporting. Where possible, you are guaranteed privacy and anonymity, and your responses will be treated with confidentiality. If anonymity and confidentiality cannot be assured or granted, you will be made aware of the limitations and of the possible consequences before you are asked for your consent to participate. The information you provide will be kept for at least five years after the study is done. The information will be kept in a secure area (i.e. locked filing cabinet). Your name or any other identifying information will not be attached to the information you give. Your name will also never be used in any presentations or publications of the study results.

The information gathered for this study may be looked at again in the future to help us answer other study questions. If so, the ethics board will first review the study to ensure the information is used ethically.

Freedom to withdraw:
Your participation is voluntary. Refusal to participate will not affect your employment.

Additional contacts:
If you have any concerns about any part of this study, please contact Prof. Fred Wabwire-Mangen, Institute of Public Health, Makerere University at 532-6314.

Thank you for your consideration of this request to be part of this research.

Sincerely,

Bonnie Fournier

Appendix 4: Consent Form -Interviews

Part 1: Researcher Information

Name of Principal Investigator: Bonnie Fournier
Affiliation: Centre for Health Promotion Studies
Contact Information: University of Alberta

Name of Co-Investigator/Supervisor: Dr. Judy Mill, Faculty of Nursing, 492-7556
Uganda Contact Information: Dr. Margaret Muganwa at Makerere University at 532-6314.

Part 2: Consent of Subject

	Yes	**No**
Do you understand that you have been asked to be in a research study?		
Have you read and received a copy of the attached information sheet?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had an opportunity to ask questions and discuss the study?		
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care.		
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records/information?		

Part 3: Signatures

This study was explained to me by:

____

Date:

____

I agree to take part in this study.

Signature of Research Participant:

____

Printed Name:

____

Witness (if available):

____

Printed Name:

____

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

Researcher:

____

Printed Name:

____

* A copy of this consent form must be given to the subject.

Appendix 5: Consent Form Focus Group

Part 1: Researcher Information		
Name of Principal Investigator: Bonnie Fournier Affiliation: Centre for Health Promotion Studies Contact Information: University of Alberta		
Name of Co-Investigator/Supervisor: Dr. Judy Mill, Faculty of Nursing, 492-7556 Uganda Contact Information: Dr. Margaret Muganwa at Makerere University at 532-6314.		
Part 2: Consent of Subject		
	Yes	**No**
Do you understand that you have been asked to be in a research study?		
Have you read and received a copy of the attached information sheet?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had an opportunity to ask questions and discuss the study?		
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care.		
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records/information?		
Do you understand that you will need to ask permission of each person you photograph?		
I agree to have the pictures used for educational purposes		
Part 3: Signatures		
This study was explained to me by: ______________________ Date: ______________________		
I agree to take part in this study. Signature of Research Participant: ______________________ Printed Name: ______________________		

Witness (if available): ____

Printed Name: ____

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

Researcher: ____

Printed Name: ____

* A copy of this consent form must be given to the subject.

Appendix 6: Consent Form-Pictures

Title of the Project "The role of Ugandan Nurses in Caring for Individuals with Immunospression"

Name of Principle Investigator: Bonnie Fournier, Centre for Health Promotion Studies, University of Alberta, Contact 077 671 782
Name of Contact Information: Dr. Margaret Muganwa, Public Health Institute, 041 523 6314

Dear Sir/Madam,

By signing this form, you agree to have your picture taken by a nurse for research purposes only. Where possible you are guaranteed privacy and anonymity and the pictures will be treated with confidentiality. Your picture will be used to help nurses talk about their role and will contribute to the knowledge of care provided by nurses. Thank you for your agreement.

Sincerely,

Bonnie Fournier

______________________________ ____________

Signature of Nurse Researcher Date

_____________________ ____________ ______________________

Signature of Patient Date Signature of Staff Nurse

Date

___________________________ ________________________

Printed Name of Patient Printed Name of Staff Nurse