

**University of Alberta**

The Impact of HIV Education on Nurses and Nurse-Midwives in Uganda

by

Jean Norma Harrowing

BSc, University of Lethbridge, 1978

MN, University of Calgary, 1998

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

Doctor of Philosophy

Faculty of Nursing

©Jean Norma Harrowing

Fall 2009

Edmonton, Alberta

Permission is hereby granted to the University of Alberta Libraries to reproduce single copies of this thesis and to lend or sell such copies for private, scholarly or scientific research purposes only. Where the thesis is converted to, or otherwise made available in digital form, the University of Alberta will advise potential users of the thesis of these terms.

The author reserves all other publication and other rights in association with the copyright in the thesis and, except as herein before provided, neither the thesis nor any substantial portion thereof may be printed or otherwise reproduced in any material form whatsoever without the author's prior written permission.

## **Examining Committee**

Dr. Judith E. Mill, Nursing

Dr. Judith Spiers, Nursing

Dr. Walter Kipp, Public Health

Dr. Amy Kaler, Sociology

Dr. Judith Kulig, University of Lethbridge

Dr. Leana Uys, University of KwaZulu-Natal

## **Dedication**

This dissertation is dedicated to the nurses and nurse-midwives who so willingly shared their lives with me, in honour and recognition of their courage, commitment, and passion. It was truly a privilege to witness their generous warmth and enthusiasm for learning.

## **Abstract**

Over the past three decades, the HIV epidemic has gained a stranglehold in sub-Saharan Africa, where 10% of the world's population comprises more than 60% of all people living with the disease. Recent initiatives to boost prevention and treatment interventions are beginning to yield modest but promising results, as infection rates slowly start to stabilize. However, continued improvement will require aggressive and unrelenting efforts to prepare and equip a workforce for the tremendous challenges that remain.

The purpose of this critical ethnography was to explore the impact of an intensive 6-month HIV/AIDS education program on the lives of 24 Ugandan registered nurses and nurse-midwives who worked at a large referral hospital. The study began following completion of the course and involved participant observation and semi-structured interviews for 18 weeks over a 2-year period. The findings are presented in this dissertation, which consists of four published or publishable manuscripts along with introductory and concluding chapters. The first paper describes the impact of education on the personal, professional, and social lives of the participants, and provides an account of their new ways of viewing themselves as nurses, leaders, and advocates. The second paper addresses ethical issues concerning the conduct of research in international settings. The third paper identifies the phenomenon of moral distress as it manifested in the participants, and the effects of education on their ability to transform practice and attitudes. The final paper examines the congruence between the critical qualitative

methodology used in the study and the concept of cultural safety in the context of international nursing research.

The dissertation concludes with a discussion of the crucial role of continuing professional education for the development of a strong and responsive nursing workforce that is prepared to contribute leadership and vision to addressing the obstacles presented by HIV and AIDS. Dealing effectively with the epidemic requires numerous interventions at various levels; the potential synergies offered by a small investment in education may have far-reaching effects. Finally, implications for nursing practice are presented along with suggestions for further research.

## **Acknowledgements**

The last six years represent the beginning of a profound voyage of inquiry that continues to transform my life on many levels. I am privileged to have travelled in the company and with the support of many people along the way.

It was my very good fortune to have connected with Dr. Judy Mill, my supervisor, early in my exploration of doctoral programs. Judy has been an extraordinary teacher, mentor, colleague, and friend. Her gentle wisdom and enduring patience provided me both the focus and the space to follow my passion. Her commitment to social and global justice and her deep respect for the experiences and capacity of nursing colleagues worldwide are truly inspirational.

Dr. Judith Kulig first ignited my craving to hear and honour the narratives of others in a community health nursing course many years ago. I am grateful for her fine examples of scholarship and research leadership, as well as her encouragement of my academic endeavours.

Dr. Jude Spiers never failed to challenge my assumptions and interpretations; I admire her extensive knowledge and thoughtful approach to the process of nursing research. She pushed my thinking well beyond the boundaries of comfort and familiarity, and for that I am most appreciative.

Dr. Walter Kipp's comprehensive knowledge of Uganda and its health care system as well as his public health perspective contributed greatly to my understanding of HIV in sub-Saharan Africa. I thank him for his careful review of and insightful responses to my research and writing.

Mrs. Mariam Walusimbi, Assistant Commissioner for Nursing at Mulago Hospital in Kampala, Uganda taught me much about innovation and creativity through her unceasing efforts to improve nursing care for patients and learning opportunities for staff. Her willingness to facilitate this project permitted me an invaluable opportunity to interact with and learn from the courageous and resilient people of Uganda. Mariam and her staff welcomed and guided me with a warmth and generosity that will remain a precious and fond memory.

A cadre of very special heart-centred warrior-women embraced me and kept my feet firmly on the path despite the challenges that threatened to

overwhelm me at times. I owe many thanks to Sam, Isabel, Joan, JoAnne, Bernie, Solina, Naomi, and Darlene for bestowing on me generous quantities of wine, chocolate, hugs, conversation, and friendship.

My colleagues in the Faculty of Health Sciences, University of Lethbridge, provided enormous support and encouragement during my doctoral adventure, and I shall be forever grateful. In particular, Dr. David Gregory listened as I puzzled, gave feedback when I was perplexed, and offered hope when I despaired that the words would ever come. I am honored to be a member of this wonderful group of caring people.

My family has been my anchor and compass throughout the astonishing, turbulent, and unanticipated course changes of this expedition. Mom, Dad, Eryn, Brendan, Gord, Doug, and Lois—although I have been remiss in my acknowledgment of your ongoing support, please know that I am indebted to you for your unconditional love and amazing stamina over the past few years.

JR, your enduring love and unwavering faith in my ability to succeed gave me the courage to dream and the strength to persevere. You taught me long ago that it is the journey, not the destination, that nurtures the soul. Thank you for sharing with me your enjoyment of the open road, the beauty of its vistas, and your irrepressible spirit of discovery.

## Table of Contents

<b>I. Introduction</b> .....	1
<b>The Context</b> .....	1
<i>HIV and AIDS in Uganda</i> .....	1
<i>Nursing and AIDS Care</i> .....	3
<b>Research Study</b> .....	5
<i>Methodology</i> .....	6
<b>The AIDS Support Organisation</b> .....	7
<b>The Dissertation Project</b> .....	9
<b>The Impact of Education on the Lives of Ugandan Nurses and Nurse-Midwives</b> .....	9
<b>Culture, Context, and Community: Ethical Considerations for Global Nursing Research</b>	9
<b>Moral Distress Among Ugandan Nurses Providing HIV Care: A Critical Ethnography</b> .	10
<b>Critical Ethnography, Cultural Safety, and International Nursing Research</b> .....	11
<b>References</b> .....	12
<b>II. The Impact of HIV Education on the Lives of Ugandan Nurses and Nurse-Midwives</b> ....	16
<b>Background</b> .....	17
<b>Research Study</b> .....	18
<i>Purpose</i> .....	18
<b>Methods</b> .....	19
<i>Participants</i> .....	21
<b>Findings</b> .....	22
<i>Reconceptualizing the Practice of Nursing</i> .....	24
<i>Gaining and Sharing Power</i> .....	27
<i>Challenging the Image and Role of Nursing</i> .....	31
<i>Systemic Challenges</i> .....	33
<b>Discussion</b> .....	34
<b>Limitations And Future Research</b> .....	38
<b>Conclusion</b> .....	38
<b>References</b> .....	40
<b>III. Culture, Context, and Community: Ethical Considerations for Global Nursing Research</b> .....	44
<b>Background</b> .....	45
<b>Nursing and the Global Context</b> .....	46
<b>Non-Resident Researchers in International Contexts</b> .....	47
<i>Western Bioethics</i> .....	49
<i>Vulnerability and Exploitation</i> .....	50
<i>Community Considerations</i> .....	55
<i>Doing Good</i> .....	56
<b>Conclusion</b> .....	57
<b>References</b> .....	59

<b>IV. Moral Distress Among Ugandan Nurses Providing HIV Care: A Critical Ethnography</b>	63
<b>Background</b>	63
<b>Table 4-1.</b> Examples of ‘Moral Distress’ in the Nursing Literature.	64
<b>Purpose</b>	66
<b>Method</b>	66
<i>Ethics</i>	67
<i>Participants</i>	68
<b>Findings</b>	68
<i>Called to Serve</i>	68
<i>Hurting and Haunting</i>	70
<i>Losing the Essence</i>	71
<i>Counting for Something</i>	72
<b>Discussion</b>	74
<b>Conclusion</b>	78
<b>References</b>	80
<b>V. Critical Ethnography, Cultural Safety, and International Nursing Research</b>	84
<b>Background</b>	85
<b>Critical Ethnography</b>	86
<b>Table 5-1.</b> Carspecken’s Stages for Critical Qualitative Research (Carspecken, 1996).	88
<b>Cultural Safety</b>	88
<b>Intersections Between Critical Ethnography and Cultural Safety</b>	89
<i>Aims and Approaches</i>	90
<i>Perspectives and Definition of Culture</i>	92
<i>Aspects and Components of the Research Process</i>	94
<b>Conclusion</b>	98
<b>References</b>	100
<b>VI. Conclusion</b>	104
<b>Implications for Nursing</b>	109
<b>Recommendations for Further Research</b>	111
<b>References</b>	113
<b>Appendix A</b>	115
<b>Research Information Sheet</b>	115
<b>Appendix B</b>	117
<b>Consent Form</b>	117
<b>Appendix C</b>	118
<b>Interview Guide</b>	118

## I. Introduction

As the Human Immunodeficiency Virus (HIV) continues to sweep across the continent of Africa, it is becoming increasingly apparent that control of the resulting Acquired Immune Deficiency Syndrome (AIDS) pandemic will depend in large part upon the simultaneous implementation of a series of critical interventions. These strategies need to be aimed in large measure at creating or strengthening the infrastructure necessary to provide a wide range of services to families and communities that are affected by the disease. Deployment of health care providers who are prepared to offer their knowledge, skills, and commitment to the enormous task of slowing and reversing the spread of the virus through the population is essential for effective service delivery. However, the greatest constraint on access to treatment is the current lack of health human resources in Africa, with a “critical shortage” of adequately trained care providers available to attend to the complex needs of those who are ill (World Health Organization [WHO], 2006b, p. xviii).

Education is one of the fundamental factors that drive the capacity of the workforce to respond appropriately to the pandemic. In 2005-2006, 25 Ugandan registered nurses\* participated in an intensive six-month HIV/AIDS program designed to enhance their knowledge and skills concerning the care of people infected or affected by the virus. This research study examined the impact of the educational experience on the lives of those nurses.

### The Context

#### *HIV and AIDS in Uganda*

The Republic of Uganda, one of the poorest countries in the world, is situated in Eastern Africa and has an estimated population of 30.9 million people (WHO, 2009). Life expectancy at birth is 48 years (WHO, 2009) in a country where an estimated 940,000 people lived with HIV/AIDS and about 77,000 died from the disease in 2007 (UNAIDS, 2008a). With a high level of political commitment and awareness in the early days of the epidemic, Uganda responded

---

\* Registered nurses and nurse-midwives are referred to collectively as ‘nurses’ in this document.

aggressively (Okero, Aceng, Madraa, Namagala, & Serutoke, 2003) and now reports one of the lowest infection rates in Africa (Barnett & Whiteside, 2006).

The primary mode of HIV transmission in Uganda is through heterosexual contact (UNAIDS, 2008a), with women accounting for almost 60% of infected people over the age of 15 years (UNAIDS, 2008c). Since the beginning of the epidemic, 1.2 million children in the country have been orphaned by AIDS (UNAIDS, 2008a). Although there was evidence of a “robust decline” in HIV prevalence in Uganda at the turn of the century (Garbus & Marseille, 2003, p. 6), there are new concerns that increased sexual risk-taking behaviours may result in a resurgence of the epidemic (UNAIDS, 2008a). In particular, serodiscordant heterosexual couples, where only one partner is infected, who do not use condoms are at significant risk, especially during the early stages of infection (Wawer et al., 2005). In addition, the relatively stable prevalence of HIV in sub-Saharan Africa is offset by an increasing actual number of people infected due to ongoing new infections and increased access to antiretroviral therapy (ART) (UNAIDS, 2008a).

There is hopeful news on the HIV treatment front, but many challenges remain. By 2007, an estimated 3 million people in low- and middle-income countries (LMIC) were receiving ART, a ten-fold increase in six years (UNAIDS, 2008a). In Uganda, capacity for the distribution of ART had expanded significantly by 2007; an estimated 115,000 people were receiving the life-saving drugs, compared with only 44,000 in 2004 (UNAIDS, 2008b). These figures represent about 33% of the people with advanced disease who require treatment (WHO, 2009). However, children have much lower coverage of ART than do adults and adolescents, while women have better coverage than men (WHO, 2008). As well, HIV and tuberculosis treatment services have not been effectively integrated, with the result that people who are co-infected may not be receiving appropriate treatment (WHO, 2008). The civil war in northern Uganda is associated with a prevalence rate among the internally displaced population that is higher than the national average; a comprehensive program of services is required to address the complex issues at play in this region (WHO, 2008). Despite the

great improvement in ART scale-up efforts, much remains to be done in order to provide universal access in this and other resource-challenged countries. Indeed, some authors (Hladik et al., 2008) have recently suggested that achieving such coverage is not possible, particularly in the absence of simultaneous expansion of both prevention and treatment efforts (Van Damme, Kober, & Laga, 2006).

### *Nursing and AIDS Care*

Nursing in Africa is not a highly valued or respected profession (Buchan & Calman, 2005), and little is known about the experiences of Ugandan nurses and their role in the care of persons who live with HIV and AIDS (Fournier, Mill, Kipp, & Walusimbi, 2007). Health care services reach less than half the population in Uganda; only 57% of the workers are professionally qualified, and most of those are in urban hospitals (UNAIDS, 2003). In contrast to Western countries where often there are specialized services and dedicated personnel, every health professional in sub-Saharan Africa, regardless of clinical specialty, expects to treat and care for people who are HIV-positive. Physicians, nurses, and midwives, especially in community clinics, bear the burden and meet the majority of the health care needs of the individuals who present with illness and infection.

Nurses are front line practitioners and often have early, frequent, and ongoing contact with individuals and communities who suffer from, or are at risk of contracting HIV disease. However, nurses face many challenges in their attempts to provide adequate care for this particular population (Chen et al., 2004). According to Clarke-Jones (2004), there is a lack of access to basic supplies, such as gloves and syringes in Uganda. Nurses in sub-Saharan Africa are exposed to serious health risks as a result of their exposure to dangerous body fluids (International Council of Nurses, 2000; Stallknecht, 1998). Their workload is staggering. The country reports a nurse-population ratio of 6:100,000 (Buchan & Calman, 2005), with 1-2 nurses per 100 patients reported in some units of Mulago Hospital, a large referral centre in the capital city of Kampala (Clarke-Jones, 2004). Nurses in Africa are underpaid (Uys, 2005) and have few supplementary employment benefits (Clarke-Jones, 2004). Although nurses in Africa frequently are the victims of violence because of their position at the

forefront of direct care delivery (Buchan & Calman, 2005), they have few opportunities for redress, compensation, or alternative employment.

The health of nurses in Africa, the majority of whom are women, is disproportionately affected by HIV, due to the multiple opportunities for exposure as a result of their gender and high-risk work environments. Women are considered to be particularly vulnerable to infection due to their lower educational attainment, higher unemployment, and weaker negotiating skills within relationships (Fournier, Mill et al., 2007; MacLachlan et al., 2009; UNAIDS, 2004). In addition, many customary and statutory laws discriminate against Ugandan women in areas of marriage, divorce, and property rights (Garbus & Marseille, 2003). As a result of a complex and synergistic interaction of these and other social factors, women are less able to protect themselves from infection in the first place or to obtain treatment after contracting the virus (Farmer, 1999).

HIV illness has a negative impact on the health service delivery system as a result of increasing the demand for health services and by reducing the availability and performance of health care providers (WHO, 2006b). As in other African countries, about 20 per cent of Ugandan health care workers have already died from AIDS (Clarke-Jones, 2004). Furthermore, it is difficult to recruit potential new members to the nursing profession in view of the risk to individual workers and pervasive poor morale (Buchan & Calman, 2005). According to the WHO (2006a), high workloads combined with a poor organizational climate increase by 50% the likelihood of needle-stick injuries to hospital nurses. The WHO also noted that for each additional patient per nurse, the likelihood that one of the nurse's patients will die within 30 days of admission increases by 7%. There is a link between adequate staffing levels and positive outcomes for patients (Buchan & Calman, 2005); therefore it is critical that the decline in staffing levels and recruitment of nurses and midwives be reversed in order to improve the quality of patient care.

In addition to material and fiscal assets, nurses require enhanced educational resources that can be used to prepare themselves for the practical work of caring for people living with the illness. Fournier, Kipp, Mill, and

Walusimbi (2007) discovered that without adequate opportunities for advancing their education, Ugandan nurses experienced moral distress in the face of the overwhelming burden of caring for so many who had AIDS. Indeed, without adequate information and training, particularly around the use of ART, nursing personnel may do more harm than good through unintentional misuse of the drugs (UNAIDS, 2003; Walusimbi & Okonsky, 2004). Nevertheless, there is recent evidence suggesting that an expanded role for nurses in HIV clinics has the potential to improve efficiencies (Castelnuovo et al., 2009) and physiological outcomes for patients (Chang et al., 2009). Clearly, the nursing profession holds some promise for easing the burden of the epidemic. However, the successful implementation of such strategies will depend on the development of an overall plan to provide basic tools and working conditions for nurses. Education is a critical part of that plan; without it, the crisis in health human resources will only worsen and ART distribution will fail to reach those who need it most (Parish, 2005; WHO, 2008).

### **Research Study**

The purpose of this critical ethnographic research study was to explore the influence of an educational program designed to improve care of individuals infected with HIV on the lives of nurses and midwives. Eighteen weeks of fieldwork were conducted at a large referral hospital in Kampala, Uganda between June 2006 and June 2008. I wished to explore the challenges of caring for people with HIV illness, and describe the potential effects of professional development opportunities in contributing to solutions to those challenges. I hoped to facilitate the process of building capacity among nurses and midwives so that they could participate more fully in the development of their professional competence. Although these health care providers were not formally trained in the conduct of research studies, I anticipated that their involvement in this study would expose them to the process, perhaps inspire them to reflect on their practice, and invite them to ask questions suitable for future consideration. As Fournier, Mill, et al. (2007) discovered, engaging Ugandan nurses in a

participatory action research process resulted in a new awareness of the actions that contributed to the silencing of their collective voice.

Twenty-four participants, all female registered nurses and nurse-midwives, engaged in an exploration of their perceptions and experiences of undertaking an educational program and the outcomes that followed. The research question that guided the study was: *What is the impact of an HIV/AIDS training program on the lives of a group of Ugandan nurses and midwives?*

Specific goals of the research were to: (1) better understand the implications of an educational intervention on all aspects of the lives of Ugandan nurses and midwives; (2) identify injustices and power inequalities that affect the lives of the nurses and midwives and strategies that might be implemented to address these concerns; and (3) engage the nurses and midwives in capacity-building innovations that would ultimately enable them to enhance their care of individuals, families, and communities who are affected by HIV and AIDS.

### ***Methodology***

Critical ethnography as described by Carspecken (1996) was used to situate and conduct the study. This methodology enabled me to gain understanding about how the participants interpreted their experiences and made choices that influenced their behaviours within the context of their lives as professional nurses caring for people with HIV illness in a LMIC. Rather than a standard comprehensive ethnographic study of the nursing environment in Uganda, a focused approach was used to elicit specific information about the chosen topic.

Critical ethnography has been described as conventional ethnography with a political purpose (Cook, 2005; Thomas, 1993). Breaking from a long tradition of imperialism (Smith, 2002), it responds to an ethical responsibility to address unfairness or injustices and attempts to achieve positive social change (Carspecken, 1996; Hammersley, 1992; Madison, 2005; Morrow & Brown, 1994). Guided by a belief that science is subtly biased in favour of privileged groups, the critical ethnographer endeavors to disrupt commonly held assumptions and reveal underlying operations of power and control. Critical

ethnographers refute positivist claims to the existence of value-free research (Foley & Valenzuela, 2005), and share a value orientation informed by the understanding that research should be used to uncover the subtleties of oppression that it might be challenged and changed (Carspecken, 1996). Critical theory provides the foundation upon which critical ethnography methodology is built.

Madison (2005, p. 13) asserted that critical ethnography is “critical theory in action.” According to Kincheloe and McLaren (2005), a critical researcher believes that all thought is fundamentally mediated by power relations that are socially and historically constructed, and that certain groups in any society are privileged over others. In addition, facts are seen as inseparable from values, and language is central to the formation of conscious and unconscious awareness. Importantly, research practices themselves are “implicated in the reproduction of systems of class, race, and gender oppression” (Kincheloe & McLaren, 2005, p. 304). Thus, the critical ethnographer must become aware of and articulate the epistemological and ideological presuppositions that inform his or her research, understanding that value-neutral research is not possible (Dey, 2002).

The critical researcher is one who attempts to not only study and understand society, but who also seeks to critique and change that society through his or her work (Patton, 2002). Merely increasing knowledge is not the goal of this type of research; rather, the aim is to move toward political action that can redress the injustices found or constructed during the research process (Kincheloe & McLaren, 2005; Wallerstein & Duran, 2003). Madison (2005, p. 5) observed that the criticalist moves from “what is” to “what could be” in order to contribute to emancipatory knowledge and the discourses of social justice. Critical theory is constantly evolving and refining its focus on the needs of victims of oppression in an attempt to expose the underlying power dynamics.

### **The AIDS Support Organisation**

Prior to my involvement and arrival in Uganda, the nurses completed the HIV/AIDS Counsellors Training Course, prepared and presented by The AIDS Support Organisation (TASO). TASO is a Ugandan non-governmental organization that was formed in 1987 by Noerine Kaleeba, a Ugandan

physiotherapist and educator, and 15 colleagues. Membership includes those who are infected with or affected by HIV illness. The purpose of TASO is to provide counseling, social support, and medical and nursing care to individuals and families in need; particular attention is paid to psychosocial counseling services (Brouwer, Lok, Wolffers, & Sebagalls, 2000; Kaleeba et al., 1997; Katabira, Mubiru, & van Praag, 1998).

TASO offers courses to members of health-related professions in the areas of counseling and HIV care, including substantial opportunities for field practice (TASO, 2003). The program is offered to Ugandan citizens at a cost of 840,000 Ugandan shillings (approximately \$450 US) per person. This amount far exceeds the monthly salary of most nurses in Uganda; thus, donor funding was obtained in the form of a small grant from the Embassy of the United States of America in Uganda to enable nurses to attend the program. The research study was not intended to evaluate the course itself; rather, the intention was to explore the impact on nurses' lives following completion of the course.

The HIV/AIDS Counsellors Training Course (TASO, 2003) was designed to enhance the nurses' knowledge and skills for providing HIV care. The course included information about the impact and pathophysiology of the disease, associated sexually transmitted infections, provision of care across the lifespan, treatment approaches, and communication and counseling skills. Comprising five modules, learning approaches included case studies, role-plays, group assignments and discussions, storytelling, and other participatory and interactive strategies. Two 8-week field practice components focused on counseling and psychosocial support and were completed after the second and third modules, following classroom orientation to communication and interviewing skills. Competency was assessed through written and practical exams. Participants also submitted a case study of a successful counseling intervention undertaken during the practice components. The program took six months to complete. All participants received a certificate of merit, signifying successful achievement of the program objectives.

### **The Dissertation Project**

Four published or publishable manuscripts resulted from the dissertation project and are included here as Chapters II through V. The first paper focused on the main research question concerning the overall impact of education on the participants' lives. The second paper addressed ethical issues related to the conduct of research in international settings. The third paper explored the participants' experiences of moral distress in their nursing practice. The final paper discussed the intersections among critical ethnography, cultural safety, and international research projects. A concluding chapter that addresses overall perceptions and contributions completes the dissertation. The information sheet, consent form, and interview guide are provided in Appendices A to C.

#### **The Impact of Education on the Lives of Ugandan Nurses and Nurse-Midwives**

In this paper, I explored the overall impact of the HIV/AIDS education program on the lives of 24 Ugandan nurses. Nurses who previously had viewed themselves simply as providers of advice and sympathy now saw themselves as more holistic, collaborative caregivers. They voiced an increased awareness of their role as leaders and advocates in the community with respect to policy. The education program had positive and synergistic effects on the nurses' professional practice, communication and problem-solving skills, confidence, and engagement in political and social change activities.

#### **Culture, Context, and Community: Ethical Considerations for Global Nursing Research**

High-quality research is essential for the generation of scientific nursing knowledge and the achievement of the Millennium Development Goals. However, incorporation of western bioethical principles in the study design may not be suitable, sufficient, or relevant to participants in low-income countries, and may indeed be harmful and disrespectful. Before engaging in global health studies, nurses must consider carefully the cultural and social context and values of the proposed setting in order to situate the research within the appropriate ethical framework. The purpose of this article was to examine the ethical

principles and considerations that guide health research conducted in international settings.

Application of western bioethical principles with their emphasis on autonomy fails to acknowledge the importance of relevant contextual aspects in the conduct of global research. Because ethics is concerned with how people interact and live together, it is essential that studies conducted across borders be respectful of, and congruent with, the values and needs of the community in which it occurs. Use of a communitarian ethical framework will allow nurse scientists to contribute to the elimination of inequities between those who enjoy prosperity and good health, and those who do not.

### **Moral Distress Among Ugandan Nurses Providing HIV Care: A Critical Ethnography**

The phenomenon of moral distress among nurses has been described in a variety of high-income countries and practice settings. Defined as the biopsychosocial, cognitive, and behavioural effects experienced by clinicians when their values are compromised by internal or external constraints, it results from the inability to provide the desired care to patients. No research has been reported that addresses moral distress in severely resource-challenged regions such as sub-Saharan Africa. The aim of the paper was to describe the manifestation and impact of moral distress as it was experienced by study participants.

The experience of moral distress among nurses in Uganda differed somewhat from the experience of nurses in high-income countries. Constraints imposed by the lack of resources and infrastructure may result in the omission of care for patients. Moral distress appears to manifest within a relational and contextual environment and participants focused on the impact for patients, communities, and the nursing profession as a whole, rather than on their own personal suffering. The opportunity for continuing education led to the group's exploration of strategies to transform personal attitudes and practice as well as to enhance the presentation of the profession to the public.

### **Critical Ethnography, Cultural Safety, and International Nursing Research**

Carspecken's (1996) critical qualitative methodology provides a strategy to examine the human experience and its relationship to power and truth. Cultural safety is a concept that has been applied to nursing education and practice and refers to interactions that acknowledge and respect the unique cultural background of patients. It recognizes power inequities between caregivers who belong to dominant cultures and patients who may belong to oppressed groups. Culture is interpreted from a critical constructivist perspective as a fluid relational process that is enacted contextually. The purpose of this paper was to examine the congruence between and among Carspecken's methodology, cultural safety, and the conduct of nursing research in LMIC by nurses from high-income countries. It is argued that if cultural safety is important and relevant to education and practice, then it might be appropriate to address it in research endeavours.

Carspecken (1996) does not specifically identify or address the concept of cultural safety, nor does he address many culture-related issues that might be of concern to nurse researchers. However, he does recommend that researchers reflect on personal biases and values, and become aware of the inequities and power imbalances situated within communication modalities. To conduct research within the bounds of accepted ethical standards, nurses must ensure that study participants are not endangered by culturally unsafe practices in the process of the research project.

### References

- Barnett, T., & Whiteside, A. (2006). *AIDS in the twenty-first century: Disease and globalization* (2nd ed.). New York: Palgrave Macmillan.
- Brouwer, C. N. M., Lok, C. L., Wolffers, I., & Sebagalls, S. (2000). Psychosocial and economic aspects of HIV/AIDS and counselling of caretakers of HIV-infected children in Uganda. *AIDS Care, 12*(5), 535-540.
- Buchan, J., & Calman, L. (2005). *The global shortage of registered nurses: An overview of issues and actions*. Geneva, Switzerland: International Council of Nurses.
- Carspecken, P. F. (1996). *Critical ethnography in educational research: A theoretical and practical guide*. New York: Routledge.
- Castelnuovo, B., Babigumira, J., Lamorde, M., Muwanga, A., Kambugu, A., & Colebunders, R. (2009). Improvement of the patient flow in a large urban clinic with high HIV seroprevalence in Kampala, Uganda. *International Journal of STD and AIDS, 20*(2), 123-124.
- Chang, L. W., Alamo, S., Guma, S., Christopher, J., Suntoke, T., Omasete, R., et al. (2009). Two-year virologic outcomes of an alternative AIDS care model: Evaluation of a peer health worker and nurse-staffed community-based program in Uganda. *Journal Of Acquired Immune Deficiency Syndromes, 50*(3), 276-282.
- Chen, L., Evans, T., Anand, S., Boufford, J. I., Brown, H., & Chowdhury, M. (2004). Human resources for health: Overcoming the crisis. *Lancet, 364*, 1984-1990.
- Clarke-Jones, J. (2004). Moving forces. *Nursing Standard, 18*(30), 12-14.
- Cook, K. E. (2005). Using critical ethnography to explore issues in health promotion. *Qualitative Health Research, 15*(1), 129-138.
- Dey, C. (2002). The use of critical ethnography as an active research methodology. *Accounting, Auditing & Accountability Journal, 15*(1), 106-121.
- Farmer, P. E. (1999). *Infections and inequalities: The modern plague*. Berkeley, CA: University of California Press.

- Foley, D., & Valenzuela, A. (2005). Critical ethnography. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (3rd ed., pp. 217-234). Thousand Oaks, CA: Sage.
- Fournier, B., Kipp, W., Mill, J., & Walusimbi, M. (2007). Nursing care of AIDS patients in Uganda. *Journal of Transcultural Nursing, 18*(3), 257-264.
- Fournier, B., Mill, J., Kipp, W., & Walusimbi, M. (2007). Discovering voice: A participatory action research study with nurses in Uganda. *International Journal of Qualitative Methods, 6*(2), 1-13. Retrieved February 18, 2008, from [http://www.ualberta.ca/~iiqm/backissues/6\\_2/fournier.pdf](http://www.ualberta.ca/~iiqm/backissues/6_2/fournier.pdf)
- Garbus, L., & Marseille, E. (2003). *HIV/AIDS in Uganda*. San Francisco: AIDS Policy Research Center, University of California.
- Hammersley, M. (1992). *What's wrong with ethnography?* London: Routledge.
- Hladik, W., Musinguzi, J., Kirungi, W., Opio, A., Stover, J., Kaharuzza, F., et al. (2008). The estimated burden of HIV/AIDS in Uganda, 2005-2010. *AIDS, 22*(4), 503-510.
- International Council of Nurses (2000). *Reducing the impact of HIV/AIDS on nursing and midwifery personnel*. Geneva, Switzerland: Author.
- Kaleeba, N., Kalibala, S., Kaseje, M., Ssebhanja, P., Anderson, S., van Praag, E., et al. (1997). Participatory evaluation of counselling, medical and social services of The AIDS Support Organization (TASO) in Uganda. *AIDS Care, 9*(1), 13-26.
- Katabira, E., Mubiru, F., & van Praag, E. (1998). Care for people living with HIV/AIDS. *World Health, 6*, 16-17.
- Kincheloe, J. L., & McLaren, P. (2005). Rethinking critical theory and qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (3rd ed., pp. 303-342). Thousand Oaks, CA: Sage.
- MacLachlan, E., Neema, S., Luyirika, E., Ssali, F., Juncker, M., Rwabukwali, C., et al. (2009). Women, economic hardship and the path of survival: HIV/AIDS risk behavior among women receiving HIV/AIDS treatment in Uganda. *AIDS Care, 21*(3), 355-367.

- Madison, D. S. (2005). *Critical ethnography: Method, ethics, and performance*. Thousand Oaks, CA: Sage.
- Morrow, R., & Brown, D. D. (1994). *Critical theory and methodology* (Vol. 3). Thousand Oaks, CA: Sage.
- Okero, F. A., Aceng, E., Madraa, E., Namagala, E., & Serutoke, J. (2003). *Scaling up antiretroviral therapy: Experience in Uganda*. Geneva, Switzerland: World Health Organization.
- Parish, C. (2005). Africa: The case for more nurses. *Nursing Standard*, 19(41), 14-16.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Smith, D. E. (2002). Institutional ethnography. In T. May (Ed.), *Qualitative research in action* (pp. 17-52). London: Sage.
- Stallknecht, K. (1998). Nurses are the key to effective HIV/AIDS prevention and care. *International Nursing Review*, 45(6), 173-174.
- The AIDS Support Organisation (2003). *Courses on offer and related course fees*. Retrieved July 20, 2009, from <http://www.tasouganda.org/course.php>
- Thomas, J. (1993). *Doing critical ethnography*. Newbury Park, CA: Sage.
- UNAIDS (2003). *Stepping back from the edge: The pursuit of antiretroviral therapy in Botswana, South Africa and Uganda*. Geneva, Switzerland: Author.
- UNAIDS (2004). *UNAIDS at country level: Progress report*. Geneva, Switzerland: Author.
- UNAIDS (2008a). *2008 report on the global AIDS epidemic*. Geneva, Switzerland: Author.
- UNAIDS (2008b). *Epidemiological fact sheet on HIV and AIDS, Uganda: 2008 update*. Geneva, Switzerland: World Health Organization.
- UNAIDS (2008c). *Epidemiological fact sheets on HIV/AIDS and sexually transmitted infections, 2008 update: Uganda*. Geneva, Switzerland: Author.

- Uys, L. R. (2005). HIV/AIDS nursing research in the African context. *Journal of the Association of Nurses in AIDS Care*, 16(3), 1-2.
- Van Damme, W., Kober, K., & Laga, M. (2006). The real challenges for scaling up ART in sub-Saharan Africa. *AIDS*, 20(5), 653-656.
- Wallerstein, N., & Duran, B. (2003). The conceptual, historical, and practice roots of community based participatory research and related participatory traditions. In M. Minkler & N. Wallerstein (Eds.), *Community-based participatory research for health* (pp. 27-52). San Francisco: Jossey-Bass.
- Walusimbi, M., & Okonsky, J. G. (2004). Knowledge and attitude of nurses caring for patients with HIV/AIDS in Uganda. *Applied Nursing Research*, 17(2), 92-99.
- Wawer, M. J., Gray, R. H., Sewankambo, N. K., Serwadda, D., Xianbin, L., Laeyendecker, O., et al. (2005). Rates of HIV-1 transmission per coital act, by stage of HIV-1 infection, in Rakai, Uganda. *Journal of Infectious Diseases*, 191, 1403-1409.
- World Health Organization (2006a). *Strengthening nursing and midwifery*. Fifty-ninth World Health Assembly. Retrieved July 20, 2009, from [http://apps.who.int/gb/ebwha/pdf\\_files/WHA59/A59\\_R27-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/WHA59/A59_R27-en.pdf)
- World Health Organization (2006b). *Working together for health: The world health report 2006*. Geneva, Switzerland: Author.
- World Health Organization (2008). *Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector: Progress report 2008*. Geneva, Switzerland: Author.
- World Health Organization (2009). *World health statistics 2009*. Geneva, Switzerland: Author.

## II. The Impact of HIV Education on the Lives of Ugandan Nurses and Nurse-Midwives<sup>†</sup>

In the context of the devastating HIV/AIDS pandemic in sub-Saharan Africa, nurses and nurse-midwives face overwhelming challenges. Stigma and discrimination (Holzemer et al., 2007; Mill, 2003; Mwinituo & Mill, 2006; Okafor & Holder, 2004), inadequate knowledge (Walusimbi & Okonsky, 2004), frustration and stress related to heavy workloads (Fournier, Kipp, Mill, & Walusimbi, 2007; Mavhandu-Mudzusi, Netshandama, & Davhana-Maselesele, 2007), negative attitudes (Mbanya et al., 2001), and lack of access to basic protective supplies combine to render nursing staff vulnerable to infection (International Council of Nurses, 2000; Stallknecht, 1998) and severely constrained in their attempts to provide competent, safe care. Furthermore, African nurses (the vast majority of whom are women) continue in their caregiving roles outside of the workplace, offering countless services to family and community members. If the trajectory of the AIDS pandemic is to be reversed, it is essential that the voice and wisdom of nurses be heard and included in the design and implementation of effective prevention, care and treatment strategies.

The purpose of this article is to discuss the impact of a project that provided continuing professional education about HIV and AIDS interventions to nurses and nurse-midwives in a national referral and teaching hospital in Kampala, Uganda. Through a focused ethnographic approach, participants shared the journey of their unanticipated transition to new understandings of nursing, its image, and its practice, as well as the process of individual and collective empowerment over a two-year period. In addition, they discussed the difficulties of bringing new perspectives, enthusiasm, and ideas to a workplace that did not always welcome innovation. Their words resound in the relative silence of the

---

<sup>†</sup> A version of this chapter has been published as: Harrowing, J.N. (2009). The impact of HIV education on the lives of Ugandan nurses and nurse-midwives. *Advances in Nursing Science*, 32(2), E94-E104.

literature regarding the obstacles that face nurses “on the ground” as they struggle to cope with the HIV pandemic in Africa.

### **Background**

The Republic of Uganda is situated in East Africa and has a population of 28.8 million people (UNAIDS, 2006). Life expectancy at birth is 48 years for men and 51 years for women in a country with an estimated one million HIV-infected people (UNAIDS, 2006). More than 900,000 Ugandans have died from the disease since the epidemic began 25 years ago (World Health Organization [WHO], 2005). Virtually every family has experienced loss because of AIDS, and every health care provider has treated countless patients with the illness. Despite evidence of an overall decline in new infections, the number of Ugandans already infected and progressing to AIDS is increasing (Okero, Aceng, Madraa, Namagala, & Serutoke, 2003). However, as the demand for health services has increased, there has been a concomitant reduction in numbers of available health care providers (Bärnighausen, Bloom, & Humair, 2007; Hall, 2004). As in other African countries, about 20% of Ugandan health care workers have already died from AIDS (Clarke-Jones, 2004). It is critical that strategies be implemented to achieve the universal antiretroviral therapy (ART) coverage that is required to slow the pandemic, yet without interventions to increase the number and capacity of health care workers, that goal will be almost impossible to achieve (2007; Uebel, Nash, & Avalos, 2007; UNAIDS, 2003; Walusimbi & Okonsky, 2004).

Employment and social conditions are not conducive to good mental or physical health for Ugandan nurses and nurse-midwives. Their workload is staggering: the country recently reported a nurse-population ratio of 6:10,000 (WHO, 2006), with 1-2 nurses per 100 patients reported in some units of its largest tertiary care facility (Clarke-Jones, 2004). The health of female nurses is disproportionately affected by HIV, given their frequent exposures to the virus as a result of their gender and high-risk work environments. Women account for 59% of all those infected with HIV in sub-Saharan Africa (The Global Coalition on Women and AIDS, 2006) and are considered to be particularly vulnerable to infection, compared with men, for a number of physiological, social, and cultural

reasons (Fournier, 2004; Mill & Anarfi, 2002; UNAIDS, 2004; Vitols, du Plessis, & Ng'andu, 2007; Yeboah, 2007; Zungu-Dirwayi, Shisana, Louw, & Dana, 2007). Many customary and statutory laws discriminate against Ugandan women in areas of marriage, divorce, and property rights (Garbus & Marseille, 2003), diminishing further their capacity to protect themselves against the effects of HIV infection. Failure to attend to the many challenges that face African nurses will undoubtedly result in ongoing devastation of the continent by the deadly virus (Parish, 2005; Yeboah, 2007).

### **Research Study**

In an effort to enhance the knowledge and skills required to provide nursing care for persons with HIV disease, funding was obtained in 2005 by the hospital's senior nursing administrator to allow 25 staff nurses and nurse-midwives (hereafter referred to as nurses) to participate in a six-month educational program. Provided by The AIDS Support Organisation (TASO) of Uganda (TASO, 2003), the highly regarded Counsellors' Course comprised five modules covering topics such as basic physiology and pathology of HIV and its effects on the body and mind; the HIV testing process; communication, counselling, and health promotion skills; common sexually transmitted infections; contraception and family planning; positive living following the diagnosis of HIV infection; prevention and treatment of the infection; and dealing with specific groups or populations (e.g., adolescents, children, adults). Each module was covered in five to ten days of case study, role-playing, group assignments and discussion, storytelling, and other interactive strategies. Two eight-week counselling practice components were completed between the classroom modules. Participants were assessed on their clinical performance, case study reports, and a final examination. Immediately following their successful completion of the program in June 2006, the nurses were invited to enroll in the current study to explore their perceptions of the education's impact.

### ***Purpose***

The purpose of the study was to investigate aspects of the lives of a group of Ugandan nurses in such a way that social injustices and inequities and power

differentials might be identified and analyzed. The following question formed the lens through which this examination occurred: *What is the impact of an HIV/AIDS education program on the lives of a group of Ugandan nurses and nurse-midwives?* Education is a precious commodity in Uganda, particularly for women, and I anticipated that participants' narratives around these experiences might reveal and represent patterns of oppression, marginalization, and vulnerability on several different levels. In order to achieve the research goal, I planned to probe not only the immediate and direct effect of education on the professional practice of nurses, but also to explore possible sequelae in the personal, social, and political lives of the women. For example, I was curious about the effect on the nurses' understanding of their role as caregivers, advocates, and community members. I wondered about their relationships and interactions with colleagues and supervisors in the workplace, and the impact on nurses' ability to influence decisions and policy that affect care and treatment of clients. Were their perceptions of vulnerability altered as a result of increased visibility and contact with HIV-infected persons in a country where stigma is a barrier to care and social contact? Did participation in continuing education provoke questions about or enhance awareness of their power to make changes to any aspect of society? Did the health care system accommodate any shifts in the nurses' perceptions or practices? If so, how? There was no intention to evaluate the education program itself; it has been described and evaluated elsewhere (Kaleeba et al., 1997; Kalibala & Kaleeba, 1989). Rather, the intent was to learn about its relevance and impact from the perspective of those nurses who participated.

### **Methods**

The questions that guided the study are ones that challenge social practices and knowledge and require systematic uncovering and analysis of multiple layers and dimensions. Consequently, I chose to use the critical ethnographic methodology as outlined by Carspecken (1996). This approach was chosen in order to gain understanding, within a defined duration of time, about how the participants interacted with and interpreted the social and political forces that influenced their lives as women, registered nurses and midwives, and community

members in a low-income country. Guided by a belief that science is subtly biased in favour of privileged groups, the critical ethnographer endeavors to disrupt commonly held assumptions and reveal underlying operations of power and control (Cook, 2005; Madison, 2005). The five stages of the research process described by Carspecken are designed to allow the researcher to study social action and to explore the significance of, and the interactions among, the subjective experiences of the participants, the locale in which those interactions occur, and the larger system in which the participants are situated.

The research study was reviewed and approved by three ethical review boards, one at a Canadian university and two in Uganda. In order to avoid any perceptions of coercion from the hospital's nurse administrator, I shared no information with her about any aspect of the research process once it was underway. Written informed consent was obtained from each participant at our initial contact and was reconfirmed at subsequent data collection points.

Data were gathered primarily through individual semi-structured interviews with participants. In addition, I observed counselling sessions between participants and clients; participants engaged in their regular duties at the work site; and meetings of the participants. An interview guide was developed at the outset of the project and revised over time to reflect themes that began to emerge from the data. Interviews lasted 60-100 minutes and were audiotaped with the consent of the participant; extensive notes were taken during and after the interview for one person who preferred not to be recorded. Tapes and field notes were transcribed and entered into a qualitative data management software program (NVivo7); thematic coding occurred simultaneously with data collection. I also sought opportunities to engage in and learn about community activities (e.g., attending cultural events and church services, traveling on public transportation, learning the local language, reading local newspapers and magazines, and sharing meals in private homes). Rigor was enhanced through the choice of appropriate methodology; frequent consultation and debriefing with experienced qualitative researchers throughout the process; maintenance of detailed field notes and memos; prolonged engagement and persistent

observation; and ensuring the concurrent collection and analysis of data (Morse, Barrett, Mayan, Olson, & Spiers, 2002).

As a researcher from a high-income country with only an outsider's understanding of the culture of Uganda, I was obligated to ensure that the research question and study design were relevant to and respectful of the participants and indeed the people of the country. Therefore, the study proposal was developed in collaboration with the nurse administrator who initiated the implementation of the education program for the nurses. She was interested in learning about its impact on the nurses in the Ugandan context—a context in which everyone is affected by HIV, working conditions are poor, stigma remains a problem, and there is pressure on nurses to emigrate to other countries where the quality of life is perceived to be better and surplus earnings can be sent home to support destitute family members.

### ***Participants***

All but one of the 25 nurses selected by the nurse administrator for the educational program participated in the research study; one nurse was on extended medical leave and was therefore unavailable. Participants included senior nursing staff with 15 to 35 years of experience; many were in management or supervisory positions and were within 10 years of retirement (mandatory at age 60). All were women who represented a cross-section of nursing specialties, including emergency, pediatrics, obstetrics, intensive care, oncology, radiation therapy, public health, education, and out-patient clinics. All of them held diplomas in nursing, two had baccalaureate degrees, and one was working on a master's degree. Many were dually trained as midwives, while others had completed various post-basic certificates. Of the 24 participants, 10 were interviewed once; 13 were interviewed a second time and one was interviewed three times. Fourteen nurses were observed for 100 hours in their worksites and/or in counselling sessions with clients.

Prior to ethical review, I visited Uganda to begin the groundwork for recruitment and data collection. Twelve potential participants were available to meet with me to learn about the proposed study. All of them were deeply honored

to have been chosen to attend the education program and were very enthusiastic about the research. Following ethical approval, three more site visits were made. The first one began immediately after the TASO program was completed and consisted of ten weeks of intensive data collection. The second, a year later, lasted four weeks, during which preliminary findings were shared and more interviews were conducted. Finally, 12 months after the second, a third trip of one week allowed for general follow-up as well as the sharing of findings with participants.

### **Findings**

Study participants toiled under conditions that a nurse from a high-income country would find extremely difficult, yet the discussion of such challenges in this article may be a source of discomfort to Ugandan healthcare administrators. Nevertheless, it is important to provide a general sense of the context in which frontline nurses struggled to raise awareness and create momentum for change. Supplies and equipment such as gloves were rationed despite the increased risk of disease transmission and injuries to staff members and patients. Some managers found themselves using storage closets as offices, where a broken gurney might serve as a desk; boxes of syringes and medications were stacked against walls and under furniture; and the nurse occasionally would be greeted in the morning by a flood as a result of damaged water pipes in the ceiling. Units with 18 beds often admitted 80 or more patients, by making use of mats on the floor, with two nurses on duty to provide care. Frequent maintenance problems, such as blocked toilets, challenged the hospital's ability to respond. In one unit, nasogastric tubing was creatively adapted for use with the single oxygen tank that was intended to serve all patients in need. Items such as toilet paper and drugs sometimes had to be provided by patients. Family members bathed, dressed, fed, and comforted the patients. Staff members often were unable to get to work on time as public transportation was limited, expensive, and subject to frequent disruption. Some workers came directly from another job to work a shift at the hospital, and often arrived late, fatigued, and hungry. Many care providers, from physicians to porters, worked on a volunteer basis as there were no employment opportunities; these workers were compensated with a cup of tea. It was under

these circumstances that study participants laboured to lead, support, and nurture staff and provide quality services to patients and their families, all the while trying to personally sustain the motivation and positive attitude necessary to remain committed to their work.

Overall, participants expressed great satisfaction with the content and process of the TASO program. It addressed topics and skills they felt to be essential, although a few areas for improvement were identified; many of the nurses indicated that more emphasis on the counselling of children and adolescents would have been useful. Generally, however, the knowledge and confidence gained and the opportunities to practice and receive feedback on their counselling skills exceeded the nurses' expectations. The nurses recognized that the TASO educators modeled the behaviours and attitudes they were trying to instill in the learners who were very impressed with the quality and commitment of their mentors. The nurses were most grateful for the "golden chance" to attend the course, as the cost of tuition prohibited most of them from taking it as private students.

Participation in the TASO program had a major impact on the nurses' lives. They described the effects in terms of their professional practice as well as their personal, political, and social lives. Many initially undertook the education with some hesitation, as they were uncertain about the final benefits and anxious about the expectation that they would have to demonstrate their skills. The group members, not all of whom were known to each other at the outset, quickly formed a cohesive collective and began providing support and encouragement to each other. As the weeks went by, participants found themselves gaining interest and seeing new opportunities to put the skills to good use, both in the short term and later in their careers.

My conversations with the participants revolved around a theme that focused on a revisioning of their potential as individuals, nurses, and members of a collective struggling within a structured and resource-poor system. They described experiences and awareness that reflected a new understanding of what it meant, or could mean, to be a nurse. They revealed a growing sense of

empowerment, applied both to themselves and to their clients and colleagues. Finally, they recounted their impressions of the changing image of nurses in society and their role in and contribution to that evolution. Threaded throughout their narratives, however, was an intimate awareness of the constraints of the environment.

### ***Reconceptualizing the Practice of Nursing***

The most obvious impact of the TASO program was the enormous shift it sparked in the way the participants conceptualized nursing practice. As Laura\* exclaimed, “*The thing is when you do counselling, then you start talking the real nursing!*” Trained during the 1970s, their basic nursing programs prepared them as “advisors and sympathizers” and dispensers of instructions and medications. The TASO approach required them to listen with empathy and encourage clients to identify and choose workable solutions for themselves. Although participants reported that prior to the course they had not placed much importance on, or deliberately practiced, therapeutic communication behaviours (e.g., attentiveness, open body posture), they consistently demonstrated such skills in my presence. Clients were encouraged to articulate their feelings and thoughts, as well as their ideas about the solutions that would work best for them, while the nurses listened carefully and supported or challenged as required. Grace spoke for many of the participants when she explained how the TASO education enabled her to engage in helping relationships with her clients:

*If I'm able to listen then I'm able to respect and give the services where this client expects me to do my best for her or him for that matter. It has improved my approaches to my clients; it has given me more room to realize they have their rights. They have their rights that I should respect, they have—they easily come with their own predetermined mind of what they would want to be done. So it is up to me to see whether this can be done and how I can put it back to them.*

---

\* Participants chose or were assigned pseudonyms.

The nurses found that they were humbled through the experience of engaging in dialogue with clients. Ruth reflected, *“With the clients, I seem to understand them more. I seem to understand their conditions in the ward. I see the suffering in there, in them, and compassion in my heart is great.”* Lorna gained awareness about the importance of listening without judging: *“I’m trying my best to listen this time. And not to judge, to judge the problem before I listen, it’s important not to judge because you never know, anybody can get a problem without knowing.”* Paula recognized a new perspective about her own involvement with the client: *“I feel it is a privilege if I can help them because you can reduce the complications which might infringe on someone. . . . With the counselling [the nurse] can change [her] attitude.”* Participants reported that the outcomes for clients were far more satisfying for both parties, as the proposed interventions were more likely to be successful if the nurse listened carefully and engaged the client in generating feasible solutions. Furthermore, clients returned more readily for follow-up visits, which allowed the nurses to monitor progress, provide support, and anticipate problems. Paula suggested, *“Usually here in Uganda, clients when told to come back they do because they feel you are a part of them. They have that feeling that you are a part of them, you’ve assisted them here and there.”* Evelyn agreed, saying that *“They feel I should be their counsellor, not anybody else.”* Maintaining an ongoing relationship was seen as a beneficial outcome of good counselling skills that enhanced the overall health status of the client.

Eunice was convinced that her new ability to facilitate the patient’s comprehension of his or her health condition and treatment options resulted in better healing. She felt it was necessary for the individual to trust that problems could be overcome before symptom relief could occur. She credited the counselling training for her new awareness of the mind-body connection and its role in health maintenance. Jane concurred, and added that:

*This training has helped us to remove stigma from these patients who have HIV/AIDS. Perhaps when we are handling them we handle them like any other patient, unlike these nurses who have not trained in HIV who will*

*even fear them, they would not wish to touch them, you see? But for us they are like any other patient. We go and sit with them; we talk to them so they feel they are part of us. You see? So they heal very fast.*

Evelyn felt that an important part of her role as counsellor was to help people find hope, to understand that with appropriate treatment they could live well. Anne noted the value of asking open-ended questions that would allow “*the story [to] flow out better.*” In this way, she could validate the patient’s experiences while learning information that would improve clinical care. All the nurses commented on their renewed understanding of the fundamental importance of patience, empathy, and confidentiality in the counselling process. Angela confirmed that:

*Now I have to listen and hear from what the client tells me and then build out from what he has told me. I don’t give instructions to them but we just talk and we give them options. . . And it has also helped me in confidentiality. Much as we are supposed to keep confidentiality as nurses, I did not value it so much at the time but right now I value it. . . It is not our duty to disclose, just educate and talk to the person and keep that confidentiality.*

Observations made at the outset of the study of the nurses’ counselling interventions with clients revealed their clear but limited focus on HIV and its diagnosis, treatment, and prevention. These interactions tended to be formal and structured and usually took place in a vacant office or room in the workplace setting. A year later, the nurses’ activities had expanded significantly to include individual and group counselling with all age groups. The nurses recounted casual and spontaneous sessions in a variety of settings regarding such concerns as palliative care, grief, substance abuse, marital issues, parent-child relationships, suicide risk, infertility, and sexuality. The nurses were pleased to observe that their efforts to facilitate problem-solving strategies with a client were often rewarded by requests for counselling from other individuals who had been referred by the index client. The nurses viewed this outcome as validation of their genuine interest in and commitment to providing excellent services, as well as a

useful approach to improving the health of families and communities. They were not concerned that they had limited or no formal education in some of the specific issues raised by clients; rather, they felt that the process of listening, supporting, and encouraging was their primary role. In addition, the participants pointed out that there were scarce or no resources for the clients, so anything they could provide was likely better than nothing.

Another aspect of practice that was influenced by the newly acquired communication and facilitation skills concerned the nurses' leadership and management abilities. Prior to the TASO education, nurses who had supervisory responsibilities often referred staff members with personal or workplace problems to more senior administrators. During the year following the program, Anne found that as the manager of a nursing unit: *"I can handle the staff now more than I used to handle, too. I used to transfer the responsibility to others. Now I don't."* Sandra agreed, noting that she made a greater effort to understand the staff member's perspective before reaching conclusions. She also considered a range of possible alternatives for conflict resolution: *"The options, I make use of them such that our relationship in the ward with my staff has improved a great deal."* Wallis aspired to lead her colleagues to a holistic approach to nursing that she called *"ideal nursing. Really caring for the patient all around."* The participants expressed a heightened sense of satisfaction, pride, autonomy, and confidence as they acknowledged their new capabilities to empower their colleagues.

### ***Gaining and Sharing Power***

In describing the challenges that face Ugandan nurses, participants indicated that their ability to effect significant changes in the health care system was negligible, despite recognition of their own expertise and the enhancements that could be made. Several participants described attempts to raise and resolve issues, only to receive responses perceived to be unjust or negative (e.g., being overlooked for promotion or being transferred to a less-appealing work assignment). Submission of reports that outlined dismal conditions or proposals that suggested improvements seldom achieved their goals. Discrimination on the basis of tribal background was reported to be a common phenomenon both within

and without the institution. Participants agreed that they had limited capacity to alter the forces that shaped the patient care environment and drove health care practices.

Interestingly, participants' completion of the TASO program segued into a growing awareness of a subtle change in their power and status. The simple fact of their selection for the program and their partial release from usual duties marked them as members of a unique group. The increasing frequency of requests from staff and colleagues to teach the new skills and knowledge contributed to their status. Their participation in my research project aroused curiosity, and being sought out by clients made them the object of attention. Such acknowledgment strengthened the participants' sense that they had something worthwhile to contribute.

More important to the participants than status, however, was a perception of an enhanced capacity to empower themselves and others. They realized that their new skills and knowledge offered an avenue to greater financial security and improved job opportunities. They began to speculate about the potential of their group to collectively lobby for primary health care initiatives that would directly impact the health of their communities and improve sustainability of services. The participants found that incorporation of the TASO principles into their counselling practice resulted in the empowerment of clients who were then able to assume greater responsibility for their own health concerns. To the nurses, this was initially a foreign and uncomfortable experience, as it meant relinquishing a degree of control. As soon as they recognized the benefits for clients, however, the participants' apprehension changed to a sense of pride and accomplishment as they acknowledged their contributions to clients' improved wellbeing.

At the personal level, the nurses found that the TASO education led to new ways of communicating with their own families. They found that a solid knowledge base and improved communication skills enabled them to talk about sensitive issues with their children and partners in a more effective way. Lorna observed: *"They are very happy, my kids. . . they feel Mummy can also do something and when you talk to them they seem to think that maybe I understand*

*more since that training.*” When recounting her new, gentler approach with her offspring, Evelyn compared it to her previous strategy this way: *“Before I sort of used force, which I don’t do now.”* Jane described joking with an extended family member who wanted to come and live with her, telling her: *“All those who stay with me, I always test them.”* To her surprise, the young woman indicated that she wanted to be tested and to initiate treatment if it was indicated. This response emboldened Jane to raise the subject with other family members, who often disclosed their worries and lack of information. Jane appreciated the opportunity to provide support and direction to her family, although like all of the nurses, she was careful to refer family members to other counsellors in order to ensure confidentiality and objectivity.

Those participants who had been reluctant to be tested for HIV were challenged to reconsider their decisions. A number had not been tested yet, or had been tested but had never returned for the results. Following the counselling education, many of those nurses believed that they could no longer work to convince clients to know their status if they themselves refused to go through the same process. As Evelyn said, after learning her test results, *“So I felt very good and that stigma in me also went out.”*

The nurses were amazed to notice their own improved physical and spiritual health as a result of learning and applying the principles of counselling to their own personal situations. Ruth commented that:

*Even when I face difficulties at home or at my place of work, I tend to counsel myself that it will pass. . . . I could get headaches and I think that was stress. You know, stress, too much stress. I don’t now—once in a while, once in a while. Yes, it helped me physically.*

She went on to say that counselling helped her to grow spiritually:

*Now that you become a patient person, I think those are the things that the spirit of God can teach you. Yeah, you become patient, you’re enduring the time of the suffering, and you know that it will—they don’t stay there forever. And the fact that even if a problem is there you don’t have to put yourself inside it.*

From a pragmatic perspective, the nurses saw their new skills as an important career opportunity. With mandatory retirement looming for most of them, and in the absence of government pension plans, they all faced the problem of financial security for themselves and their families once they were required to leave their current employment. With a credential that was recognized and respected by private and non-governmental organizations and knowledge and skills that were in high demand, the nurses viewed their futures with much greater confidence.

Although barriers to prevention interventions were easily identified, participants consistently assessed and worked with the assets of their target populations. For example, mothers often were found to be very interested in and committed to learning how to protect their children from HIV infection. The nurses took the opportunity, when responding to these women, to determine the possibility of engaging their sexual partners in discussions about HIV prevention and treatment. If the men declined the invitation to address these issues, the nurses ensured that the women were aware of approaches they could take to enhance their own safety and that of their children. Women were also counselled extensively about income-generating activities in which they might become involved should they find themselves solely responsible for providing for the family. Referrals were often made to the International Federation of Women Lawyers, where women were able to access legal services for little or no cost.

Following completion of the TASO program, participants formed a Nurse Counsellors Association in order to maintain contact with one another, promote volunteer community service and research projects, collect evidence about the work they were doing and its impact, and facilitate ongoing professional development. The group scheduled monthly meetings, elected an executive, and collected membership fees. The nurses felt that it was essential to provide ongoing support to one another as they encountered challenges while practicing their new skills. They also took the opportunity to celebrate their triumphs and successes. The nurses recognized the need to monitor and describe the impact of their work on the health of the community. They felt that it was important to

promote more widespread education of nurses in counselling skills. Furthermore, they believed that they had the ability to influence other organizations concerned with nursing issues, such as the national nursing association and the professional registration and licensing council. There was the perception that the nursing voice in Uganda was fragmented, but that collectively, the profession could create an agenda that would enable it to advocate for change at the policy level thereby improving the health care system's capacity to accommodate the needs of the population.

### ***Challenging the Image and Role of Nursing***

Participants expressed great concern about the public perception of nurses. Virtually all agreed that they are often regarded as rude and uncaring by members of the public. They attributed this opinion in large part to fatigue brought on by the overwhelming workload which prevented nurses from offering holistic individualized care to each and every client. In addition, the hospital is a tertiary care centre at which people often arrived in advanced stages of illness or disease, and often there was little that could be done. The nurses, as front line workers, found that they often took the brunt of the anger, confusion, and distress experienced by distraught family members. If a midwife was the only health care provider present at the moment when a woman died in childbirth, she was likely to be the one who witnessed the family's emotional response. Participants were quite distressed by the low regard with which they were viewed but were uncertain about what could be done to improve it, given the constraints of the health care system.

However, as participants grew into their new roles as caring counsellors, they began to see their newly framed relationships with clients as an important step toward improving their image in the minds of the public. They found that when they took the time to hear concerns, they were able to engage with the client and family to provide more sensitive care, and the clients responded more positively. According to Jackie, the resulting partnership between nurse and client "*gives the clients more room to draw closer to the health workers.*" By enabling the clients to participate in the decision-making process, the nurses found that the

clients were grateful and freely expressed their appreciation. This in turn enhanced the satisfaction and pride the nurses felt about their work.

Outside of their work lives, the nurses discovered that their capacity for contributing to the wellbeing of their communities was greatly enhanced by their awareness of new approaches to health promotion and illness prevention. Although most of the nurses had limited professional experience outside of the hospital environment, one of their course assignments necessitated that they work with clients in the community. Through witnessing the daily realities of a client's life, the nurses were better able to understand their role as supporter and facilitator. It became clear to them that involving the client in developing realistic and appropriate strategies for better health often resulted in greater success and satisfaction for the client.

In contrast to the lack of respect and autonomy the nurses experienced in the work place, they found that their expertise was much sought after in the neighbourhoods and social settings that comprised their daily lives. Whether they were visiting extended family in the remote villages of their childhood, attending continuing education courses, or walking home after a day's work, they were often stopped and asked for information or advice. The nurses welcomed such encounters, and went to great lengths to satisfy the needs of the inquirers. Grace described how she often found herself interacting with people she met in the community:

*At times I may just be in a taxi, because for us here in our country our people tend to talk at times about their problems loudly, so I easily find myself having time to allay their anxiety. . . . At times one would have given me a lift and then since they feel I'm a nurse by profession, I'm working in [hospital] which is an international referral hospital, they always consult me here and there.*

The nurses provided many more examples of spontaneous counselling, education, or advocacy sessions that occurred in the marketplace, at their children's school, or on the veranda in the evening. As Evelyn commented, "You know we health educators don't stop!" Collectively, the nurses expressed a sense

of deep satisfaction in their ability to contribute to the wellbeing of their communities, and did not view their interactions with neighbours as intrusive or burdensome.

### *Systemic Challenges*

Although the educational experience was universally regarded as a very positive one, participants described a number of systemic barriers and the consequent personal costs. Workloads were chronically taxing and resources scarce. To make time for counselling, participants either worked beyond their scheduled shifts or they delegated their usual responsibilities to colleagues. As salaried employees, participants' overtime hours were not compensated financially.

Recruiting clients for counselling was not always easy. Participants felt that some hospital departments were reluctant to refer clients to them, so effort had to be expended to seek people in need of counselling. Participants were sensitive to the potential for clients to fall through the cracks of the system as a result of being expected to move from site to site on the immense hospital campus to attend the various clinics and laboratories to which they were referred. Participants who worked in areas where HIV testing services were unavailable were uncomfortable asking clients to present for counselling, only to be sent off for testing with the expectation that they wait for results and then return for post-test counselling. Participants, at some inconvenience to themselves, often went to other departments in the hospital where testing services were more readily accessible in order to ease the process for clients. Private space for counselling was usually at a premium; when it was found, it was often in high demand by other practitioners, so sessions were frequently interrupted.

Participants expressed the frustration that often accompanied their lack of success in advocating for basic and essential resources for clients and staff. They were convinced that patient care and staff retention would be enhanced by small incentives such as provision of meals and basic drugs for patients and a transportation allowance for staff. Despite the efforts of the participants to have their concerns and proposals considered as urgent priorities, they felt that their

appeals fell on deaf ears at the senior administrative level. They noted the relative luxury with which private patients were accommodated on the quiet and well-appointed upper floor of the facility, and questioned why patients on the lower floors, who were financially destitute, received minimal care. Participants were distressed at this inequity but believed that there was little they could do to effect change in what they viewed as the corrupt practices of the bureaucrats and politicians who could afford to purchase special services.

### **Discussion**

The findings of this study are significant on two levels. Not only did the TASO program have a direct and positive influence on the day-to-day professional practice of the participants, but it also served as a powerful inspiration for their new perspectives, awareness, and understanding of nursing and health care in Uganda. Participants' descriptions of the challenges of their work illuminated the inequities, injustices, and power differentials that infuse the daily lives of nurses, thus providing us a picture of the complex interplay of forces that perpetuate the oppression of female health care providers in the context of the AIDS pandemic.

Many authors have described the obstacles faced by nurses and other health care providers in sub-Saharan Africa as they try to cope with the HIV pandemic on that continent (Marchal, De Brouwere, & Kegels, 2005; Vitols et al., 2007; Walusimbi & Okonsky, 2004). Using education to enhance the competence of the nurses in this study to deliver more effective care addressed some of these challenges. Indeed, the findings of this study provided additional evidence that expanding the professional skills of care providers contributes to the implementation of innovative and useful interventions. In their articulation of the impact of the educational program, participants described an unanticipated renewal of their passion for nursing. The course stimulated a remarkable re-visioning of the possibilities and potential that might be created and enacted by nurses on behalf of themselves and their patients, families, and communities. The nurses' assessment of the impact of the TASO program on all aspects of their lives was overwhelmingly positive. Their comments regarding the high standard

of the program and its instructors are congruent with those found in the literature and heard from other practitioners and clients. Not only did the participants acquire new knowledge and skills, but they also gained confidence in their capacity to improve client care as well as insight into their ability to influence the health care system. The positive changes they observed in their practice as well as in their personal lives renewed their hope and motivation to continue to face the challenges inherent in their daily existence.

The participants' observations that they were poorly viewed by some members of society are well supported in the literature (Jewkes, Abrahams, & Mvo, 1998; Ojo, Wambui, Mutea, & Chelagat, 2002; Smit, 2005). Marchal and colleagues (2005) noted that health care providers' negative attitudes and inadequate knowledge combined to increase reluctance to offer quality care to people with HIV. At the same time, lack of public respect for the profession renders a career in health care professions less appealing to potential candidates, further reducing the capacity of the system to recruit and retain staff. The participants believed that the public's perception of them would be favourably improved by their new ability to form relationships, communicate effectively, and provide more holistic care. There is an important, reciprocal relationship between feeling respected and the quality of client care nurses deliver (Faulkner & Laschinger, 2008); the nurses in this study were empowered by their ability to earn respect from clients who appreciated and benefited from their interventions. Furthermore, the participants were often invited by colleagues to provide instruction and mentorship in their own efforts to learn more about HIV care. The growing acknowledgement by participants of their role in the shaping of perceptions about nursing practice and scope and their insights into the advantages and benefits of their new skills and attitudes were important steps toward the creation of positive changes on behalf of all nurses and health care providers. It will be critical to sustain the momentum, however, by providing ongoing support to these nurses and by extending similar opportunities to their colleagues.

A recent report concluded that the failure of American HIV care providers to offer prevention counselling to their HIV-positive clients could be attributed to the perceived potential of such interventions to harm the client-provider relationship (Grodensky et al., 2007). In contrast, the Ugandan nurses were confident that they could successfully address sensitive topics without jeopardizing the therapeutic relationship. It may be that the credibility of the counsellors was enhanced by their demonstration of commitment and dedication in a context characterized by increasing societal tolerance of open discussion on the topic of HIV. Study participants were frequently observed raising such topics as sexuality and sexual practices, use of contraception, and effective communication techniques with people of all ages without embarrassment or self-consciousness, and the messages appeared to be received in the same manner. Indeed, such topics were often discussed casually with me by individuals on the street, by taxi drivers, and by university students. People seemed genuinely interested in learning all they could about the topic, and nurses were viewed as informed and trustworthy.

The participants began to see themselves as potential change agents—as a collective, they felt they had some power to influence administration and policy. There is a wide discrepancy between macro factors, such as workplace policies, involvement in decision-making and gender-based roles, and the capacity of nurses and their leaders to influence those factors. Despite the constraints on their ability to engage in such activities, there are many reasons to aggressively promote the participation of nurses in leadership roles that will further the health care agenda (Ojo et al., 2002). According to Ehlers (2000), nurses must engage in political debate to ensure that clients receive the care their conditions warrant, and that the nurses themselves receive the benefits to which they are entitled. Participants in this study were in the initial stages of discussing possible approaches and strategies within the Nurse Counsellors Association. Some had already submitted reports to senior management that they hoped would stimulate further discussion, and others were seeking connections with nurses on the national regulatory board in anticipation of opening talks at that level. Another

participant and I developed and submitted to potential funders a small research proposal that reflected the groups' belief that community interventions were essential in order to effect change in the pandemic.

The nurses' primary recommendation was that funding be sought to enable all nurses to complete the TASO program, as each participant firmly believed that all health care practitioners should receive this education. Indeed, the nurses developed and submitted to senior administration a funding proposal to support a 'Train the Trainer' initiative in which they themselves would learn to provide the Counsellors Course; however, no response has been received to date.

Furthermore, the nurses agreed that TASO education or its equivalent should be a component of the basic curriculum for every nurse. They voiced the opinion that a novice practitioner's ability to practice competently could be greatly enhanced by the program. Indeed, as has been demonstrated in this study, the effects of the education were far-reaching and significant. The nurses recognized that the ripple initiated by their increased capacity to provide better care could potentially influence the health care system. The nurses were excited and motivated to be part of what they anticipated would be positive change for themselves, their clients, and the country as a whole. It is significant that the nurses acknowledged that it was the process of participating in this research study that led them to the realization that they could aspire to greater influence over their practice through political action. One of the participants had recently been hired as a research assistant for a large international study led by Edwards (Edwards et al., 2007), and her colleagues were anxious to learn about and become involved in the project.

The findings of this study are important because little research has been conducted to determine the value or impact of education on the ability of nurses to effect change in the delivery of health care to people with HIV in developing or low-income countries. Williams and colleagues (2006) described the importance of comprehensive HIV education for nurses in China to change not only their knowledge level about the disease, but also their attitude toward caring for people with the virus. Nurses in Ghana believed that a program to educate members of the profession about HIV counselling would be beneficial in overcoming the

stigma associated with HIV testing and treatment (Mill, 2003). My findings support the usefulness of an intensive program for addressing the affective, emotional, and cognitive domains of learning, resulting in new perspectives about many aspects of nursing and health care.

### **Limitations And Future Research**

The findings from this qualitative study are limited by the fact that a small, relatively homogenous group of nurses working in one particular institution comprised the participants. The assumptions that guided the nurse administrator's selection of candidates for the education program may have been inaccurate or inappropriate and therefore may have influenced any or all phases of the research process. In addition, the nurses experienced only one specific format and curriculum designed to enhance their knowledge and skills. Furthermore, the perspectives of clients and the nurses' co-workers might have contributed additional dimensions to the data.

Future research efforts might focus on nurses in different settings, such as clinic, smaller hospital, community, or rural locations. Should funding be found to present a Train the Trainer program, it would be of great interest to investigate the outcomes. Opportunities might be found to explore the progress of the participants in this study with regard to their involvement at the systems level.

### **Conclusion**

The extent to which nurses are prepared and enabled to work to full capacity will largely determine a country's ability to effectively cope with the HIV crisis. The initiative of a nurse administrator in Uganda to promote such an opportunity resulted in a transformative outcome for the nurses involved. Beyond the simple acquisition of new knowledge and skills, the nurses gained confidence and vision. They began the TASO program as a collection of disillusioned and uncertain individuals who held out little hope of changing the trajectory of the AIDS pandemic in Uganda. They emerged as a team of collaborative and empowered health care professionals who believed in their ability to influence not only clients, but also organizations and the health care system itself. If nursing practice is truly "activated by knowledge" as proposed by Purkis and Bjornsdottir

(2006, p. 251), then the participants in this study provide an excellent example of the energy, synergy, and momentum that are created when practitioners grasp an opportunity to learn and apply new knowledge. The project described in this article is only one small-scale initiative—but a contribution nonetheless to empowering a group of nurses to champion the cause of overcoming the devastation of HIV in Uganda.

## References

- Bärnighausen, T., Bloom, D. E., & Humair, S. (2007). Human resources for treating HIV/AIDS: Needs, capacities, and gaps. *AIDS Patient Care and STDs*, 21(11), 799-812.
- Carspecken, P. F. (1996). *Critical ethnography in educational research: A theoretical and practical guide*. New York: Routledge.
- Clarke-Jones, J. (2004). Moving forces. *Nursing Standard*, 18(30), 12-14.
- Cook, K. E. (2005). Using critical ethnography to explore issues in health promotion. *Qualitative Health Research*, 15(1), 129-138.
- Edwards, N., Kahwa, E., Kaseje, D., Mill, J., Webber, J., & Roelofs, S. (2007). Strengthening health care systems for HIV and AIDS in sub-Saharan Africa and the Caribbean: A programme of research. *Caribbean Journal of Nursing and Midwifery*, 2, 29-36.
- Ehlers, V. J. (2000). Nursing and politics: A South African perspective. *International Nursing Review*, 47(2), 74-82.
- Faulkner, J., & Laschinger, H. (2008). The effects of structural and psychological empowerment on perceived respect in acute care nurses. *Journal of Nursing Management*, 16(2), 214-221.
- Fournier, B. (2004). *The role of Ugandan nurses in the care of individuals with HIV illness*. Unpublished master's thesis, University of Alberta, Edmonton, Alberta.
- Fournier, B., Kipp, W., Mill, J., & Walusimbi, M. (2007). Nursing care of AIDS patients in Uganda. *Journal of Transcultural Nursing*, 18(3), 257-264.
- Garbus, L., & Marseille, E. (2003). *HIV/AIDS in Uganda*. San Francisco: AIDS Policy Research Center, University of California.
- Grodensky, C. A., Golin, C. E., Boland, M. S., Patel, S. N., Quinlivan, E. B., & Price, M. (2007). Translating concern into action: HIV care providers' views on counseling patients about HIV prevention in the clinical setting. *AIDS and Behavior*, 12(3), 404-411.
- Hall, E. J. (2004). Nursing attrition and the work environment in South African health facilities. *Curationis*, 27(4), 28-36.

- Holzemer, W. L., Uys, L. R., Makoa, L. N., Stewart, A., Phetlhu, R., Dlamini, P. S., et al. (2007). A conceptual model of HIV/AIDS stigma from five African countries. *Journal of Advanced Nursing*, 58(6), 541-551.
- International Council of Nurses (2000). *Reducing the impact of HIV/AIDS on nursing and midwifery personnel*. Geneva, Switzerland: Author.
- Jewkes, R., Abrahams, N., & Mvo, Z. (1998). Why do nurses abuse patients? Reflections from South African obstetric services. *Social Science & Medicine*, 47(11), 1781-1795.
- Kaleeba, N., Kalibala, S., Kaseje, M., Ssebhanja, P., Anderson, S., van Praag, E., et al. (1997). Participatory evaluation of counselling, medical and social services of The AIDS Support Organization (TASO) in Uganda. *AIDS Care*, 9(1), 13-26.
- Kalibala, S., & Kaleeba, N. (1989). AIDS and community-based care in Uganda: The AIDS Support Organization, TASO. *AIDS Care*, 1(2), 173-175.
- Madison, D. S. (2005). *Critical ethnography: Method, ethics, and performance*. Thousand Oaks, CA: Sage.
- Marchal, B., De Brouwere, V., & Kegels, G. (2005). HIV/AIDS and the health workforce crisis: What are the next steps? *Tropical Medicine and International Health*, 10(4), 300-304.
- Mavhandu-Mudzusi, A. H., Netshandama, V. O., & Davhana-Maselesele, M. (2007). Nurses' experiences of delivering voluntary counseling and testing services for people with HIV/AIDS in the Vhembe District, Limpopo Province, South Africa. *Nursing and Health Sciences*, 9(4), 254-262.
- Mbanya, D. N., Zebaze, R., Kengne, A. P., Minkoulou, E. M., Awah, P., & Beure (2001). Knowledge, attitudes and practices of nursing staff in a rural hospital of Cameroon: How much does the health care provider know about the human immunodeficiency virus/acquired immune deficiency syndrome? *International Nursing Review*, 48(4), 241-249.
- Mill, J. E. (2003). Shrouded in secrecy: Breaking the news of HIV infection to Ghanaian women. *Journal of Transcultural Nursing*, 14(1), 6-16.

- Mill, J. E., & Anarfi, J. K. (2002). HIV risk environment for Ghanaian women: Challenges to prevention. *Social Science & Medicine*, 54(3), 325-337.
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2), Article 2. Retrieved May 25, 2009, from [http://www.ualberta.ca/~iiqm/backissues/1\\_2Final/html/morse.html](http://www.ualberta.ca/~iiqm/backissues/1_2Final/html/morse.html)
- Mwinituo, P. P., & Mill, J. E. (2006). Stigma associated with Ghanaian caregivers of AIDS patients. *Western Journal of Nursing Research*, 28(4), 369-382.
- Ojo, A. A., Wambui, T., Mutea, N., & Chelagat, D. (2002). Presenting oneself as a nurse: A social and professional reality construction. *Africa Journal of Nursing & Midwifery*, 4(2), 40-45.
- Okafor, C. B., & Holder, B. (2004). HIV/AIDS related stigma in sub-Saharan Africa: Context and consequences. *International Journal of Global Health*, 3(1), 20-34.
- Okero, F. A., Aceng, E., Madraa, E., Namagala, E., & Serutoke, J. (2003). *Scaling up antiretroviral therapy: Experience in Uganda*. Geneva, Switzerland: World Health Organization.
- Parish, C. (2005). Africa: The case for more nurses. *Nursing Standard*, 19(41), 14-16.
- Purkis, M. E., & Bjornsdottir, K. (2006). Intelligent nursing: Accounting for knowledge as action in practice. *Nursing Philosophy*, 7(4), 247-256.
- Smit, R. (2005). HIV/AIDS and the workplace: Perceptions of nurses in a public hospital in South Africa. *Journal of Advanced Nursing*, 51(1), 22-29.
- Stallknecht, K. (1998). Nurses are the key to effective HIV/AIDS prevention and care. *International Nursing Review*, 45(6), 173-174.
- The AIDS Support Organisation (2003). *Courses on offer and related course fees*. Retrieved July 20, 2009, from <http://www.tasouganda.org/course.php>
- The Global Coalition on Women and AIDS (2006). *Keeping the promise: An agenda for action on women and AIDS*. Geneva, Switzerland: UNAIDS.

- Uebel, K. E., Nash, J., & Avalos, A. (2007). Caring for the caregivers: Models of HIV/AIDS care and treatment provision for health care workers in southern Africa. *Journal of Infectious Diseases*, 196(S3), S500-S504.
- UNAIDS (2003). *Stepping back from the edge: The pursuit of antiretroviral therapy in Botswana, South Africa and Uganda*. Geneva, Switzerland: Author.
- UNAIDS (2004). *UNAIDS at country level: Progress report*. Geneva, Switzerland: Author.
- UNAIDS (2006). *Country situation analysis: Uganda*. New York: Author.
- Vitols, M. P., du Plessis, E., & Ng'andu, O. (2007). Mitigating the plight of HIV-infected and -affected nurses in Zambia. *International Nursing Review*, 54(375-382).
- Walusimbi, M., & Okonsky, J. G. (2004). Knowledge and attitude of nurses caring for patients with HIV/AIDS in Uganda. *Applied Nursing Research*, 17(2), 92-99.
- Williams, A. B., Wang, H., Burgess, J., Wu, C., Gong, Y., & Li, Y. (2006). Effectiveness of an HIV/AIDS educational programme for Chinese nurses. *Journal of Advanced Nursing*, 53(6), 710-720.
- World Health Organization (2005). *Summary country profile for HIV/AIDS treatment scale-up: Uganda*. Geneva, Switzerland: Author.
- World Health Organization (2006). *Working together for health: The world health report 2006*. Geneva, Switzerland: Author.
- Yeboah, I. E. (2007). HIV/AIDS and the construction of Sub-Saharan Africa: Heuristic lessons from the social sciences for policy. *Social Science & Medicine*, 64(5), 1128-1150.
- Zungu-Dirwayi, N., Shisana, O., Louw, J., & Dana, P. (2007). Social determinants for HIV prevalence among South African educators. *AIDS Care*, 19(10), 1296 - 1303.

### **III. Culture, Context, and Community: Ethical Considerations for Global Nursing Research<sup>‡</sup>**

We live in a world of complex interactions that affect the well-being and health of the populations of all countries, regardless of national or individual wealth. Barnett and Whiteside (2006, p. 374) noted that “health and well-being are not individual concerns: they are global issues.” Indeed, good health for all populations is an accepted international goal, and much progress has been made in recent years (Labonte, Schrecker, & Gupta, 2005). However, the emergence of the HIV/AIDS pandemic three decades ago has presented us with an unprecedented challenge to our ability to maintain forward momentum in the health promotion arena.

Finding solutions to the tremendous burden of disease in developing countries will require significant investment in externally sponsored research. It is crucial that we address the development and implementation of ethical guidelines for the conduct of such research. Not only must these guidelines protect the research participants from exploitation and exclusion and ensure the fair distribution of the benefits of the process, they must also actively promote the capacity of the participants to engage in social transformation. In addition, the rigour of the study is promoted when the researcher articulates the ethical process followed. It is not adequate or appropriate to blindly apply western principles of ethics without thoughtful consideration of the context in which participants live and function.

In this article I will discuss some of the challenges that face nurses as they participate in the process of health research in a world progressively more affected by the forces of globalization. In particular, I will focus on ethical concerns related to the conduct of research in low- and middle-income countries (LMIC) by non-resident nurses, using the HIV/AIDS pandemic in sub-Saharan Africa as the backdrop against which health care providers struggle to prevent and

---

<sup>‡</sup> A version of this chapter has been accepted for publication as: Harrowing, J.N., Mill, J., Spiers, J., Kulig, J., & Kipp, W. Culture, context, and community: Ethical considerations for global nursing research. *International Nursing Review*.

treat illness. Finally, I will describe strategies and approaches that may be used to conduct global nursing research in an ethically sound manner.

### **Background**

The need for careful attention to ethical issues emerged during my preparation for a study of the impact of education for Ugandan registered nurses and nurse-midwives (hereafter collectively referred to as nurses) who provided care to persons living with HIV and AIDS. Twenty-five nurses employed by a tertiary care hospital were selected by the senior nursing administrator to participate in a six-month program to improve their skills and knowledge around counseling, testing, and caring for people at risk of, or living with, HIV. Using qualitative critical methodology, the research project commenced upon the nurses' completion of the education program in June 2006 and concluded two years later. Data were collected over a total of 18 weeks in the field through semi-structured interviews, focus groups, and participant observation. By exploring the nurses' perceptions of the impact of the education on their lives, I hoped to identify social, political, cultural, and environmental factors that influenced their capacity to contribute to the resolution of the AIDS crisis in Uganda.

Briefly, the nurses reported that participation in the program enabled them to address many challenges that interfered with their ability to provide quality care to people with HIV illness. They envisioned new possibilities for themselves as holistic and collaborative caregivers with greater capacity to positively influence service delivery and patient outcomes. They also came to understand the power of education to motivate and prepare themselves for leadership and advocacy roles with respect to policy development and other forms of political action. Full details of the study are provided elsewhere (Harrowing, 2009); in this article I will focus on ethical issues and concerns associated with the research project.

As a privileged researcher from a high-income country, I was faced with a number of questions concerning the implementation of a project in a cultural milieu that differed greatly from my own. Was adherence to the standard pillars of autonomy, nonmaleficence, beneficence, and justice appropriate and sufficient in

this case? What role should participants play in the design and conduct of the research to make it relevant and useful to them? In choosing a critical methodology, how might sensitive issues around power and inequity be approached without jeopardizing the privacy, dignity, and safety of participants? How might the project be designed to build capacity among participants? To ensure an ethically defensible balance among the responsibilities of nurse researchers to reveal strong evidence that supports the improvement of health care for individuals and families (Schultz, 2004), protect the rights of vulnerable populations (Smith, 2008), and emphasize the development of agency among study participants (Buresh & Gordon, 2006), these and other questions need to be considered. Nursing knowledge and skills have the potential to ameliorate the factors that contribute to the burden of illness that disproportionately affects people who live in LMIC (Austin, 2004). A variety of challenges must be overcome, however, for nurses to engage safely and appropriately in the creation and implementation of new nursing knowledge in a global context.

### **Nursing and the Global Context**

Yach and Bettcher (1998) suggested that in an increasingly interdependent world, the moral imperative of addressing global health issues brings mutual benefits in a demonstration of the convergence of altruism and self-interest. Austin (2001, p.1), noting that all inhabitants of the planet are interconnected, suggested that we need to reconsider a basic ethical question: “How should we live together?” This question along with the subsequent one, “How should I act?” (Austin, 2008, p. 19), set the context for careful examination of the purpose and process of any proposed global health project. The intent to conduct research in an international setting brings with it the obligation to explore the nurse researcher’s responsibility to articulate the complex relationship between such research and issues of ethics and social justice.

Nursing is central to the health care system of every nation. Ideally, nurses understand the intimate relationship between disease and the social determinants of health, and are knowledgeable about strategies that may lead to the reduction of inequities for the vulnerable populations of the world. Indeed, nurses are expected

to be aware of global health concerns, such as violations of human rights and world hunger, and share an ethical responsibility to work individually and collectively to bring about social change (Canadian Nurses Association, 2008). The International Council of Nurses (ICN) promotes and encourages international collaboration for the conduct and use of research to support innovative nursing interventions and capacity building by its member associations. It also assumes a leadership role in the establishment of ethical guidelines to support such research (ICN, 2007). As nurses reflect upon and discuss with the broader community their experiences in the conduct of global research, that ethical framework will be refined and enhanced. Such a process will enable nurses to protect research participants and promote their voice. In addition, the body of evidence that informs excellent nursing practice will be expanded and strengthened.

#### **Non-Resident Researchers in International Contexts**

Agreement is virtually universal that high-quality research is needed in LMIC to achieve the Millennium Development Goals (Macklin, 2001; Nuffield Council on Bioethics, 2005) and address the 10/90 research gap (Global Forum for Health Research, 2004). Scientific knowledge is relevant to all people; according to Brundtland (2002, p. 5), the challenge is to “spread that knowledge and make it more integral to the way people lead their lives.” However, ethical issues associated with global health research, specifically those that arise when researchers from high-income countries propose to conduct projects in LMIC, are abundant and complex (Ketefian, 2000; McElmurry, Misner, & Buseh, 2003). Macklin (2001) concurred, saying that research in developing countries raises different, often more serious, problems than research carried out in industrialized nations. Bhutta (2002) suggested that the focus of ethicists from high-income countries on regulatory issues rather than the underlying factors that perpetuate inequities in health and human rights impedes the initiation of research that would address the concerns of LMIC. Hayes (2004) questioned the feasibility of “transplanting” researchers from one country to another, and wondered if the interpretation and intention of the research would change in the process. Other authors cautioned that researchers from wealthy nations must be careful not to

recreate procedures and ethical standards in contexts where they might not be appropriate (Olsen, 2003). The use of ethical principles is not in dispute; rather, it is their application that is of concern. Research protocols must address and respect the values and priorities of the community in which they are to be applied (Kaufert, Glass, & Freeman, 2004).

The research must be relevant to and consistent with the cultural environment in which it is to occur. The aim should be to find ways to close the gap between the community's health needs and the capacity of its social institutions to meet those needs (London, 2005), should that be considered important to the community. Thus, local input is required and may take the form of review committees and extended interaction with community leaders, health care providers, and advocacy agencies. Ensuring ownership in such a way that non-resident researchers function in a technical and advisory capacity while nationals manage the process contributes to truly cooperative research that will have a greater influence on policy development and implementation (Edwards et al., 2007).

An important principle to consider is that of distributive justice. Based on the value that all individuals have equal worth and should therefore receive fair treatment (Keatings & Smith, 2000), it is particularly salient in the African context of limited health resources and human rights violations (Dhai & Noble, 2005). All persons should have equal access to resources; in fact, the College and Association of Registered Nurses of Alberta (2005, p. 11) suggested that "those who are most disadvantaged may even deserve a greater share of resources." Evans et al. (2005) asserted that pro-equity research is imperative to supply the necessary knowledge and tools to better understand health inequities and implement effective interventions, including those aimed at policy reform, for the reduction of inequities. Olsen (2003, p. 126) extended this notion by suggesting that in the context of research, justice refers not only to the fair treatment of participants and communities, but also to the "fair distribution of both the benefits and burdens of research at individual and community levels." Additionally, Dresden et al. (2003) recommended that communities should be involved in the

design and evaluation of the research in order to promote justice for the larger society. The notion of justice is broad and complex, and requires careful deliberation by the researcher to ensure that wise decisions are made in the development of a research study.

The purpose of the current project was to learn how an opportunity for education might lead to new understanding of nurses' capacity to influence the system and their practice culture. In order to achieve these objectives, it was essential that the entire research process be relevant and acceptable to the participants. Indeed, the project was initiated at the request of the individual responsible for proposing and facilitating the access of nurses to the education program. Because the funds used to create the professional development opportunity were hard-won, it was important to know if the effort involved was worthwhile and if attempts should be made to repeat it. Thus, the research was designed to meet a need relevant to the community from which it originated, and made use of the interest, commitment, and resources offered by a Canadian nurse. Furthermore, as a doctoral student I was funded primarily by the Canadian Institutes of Health Research (CIHR), a federal agency whose mandate includes supporting the participation of Canadian scientists in global health research (CIHR, 2008). Hence, the responsibility to work collaboratively and with adequate resources to create an environment in which social change might occur was satisfied. The findings of the study would potentially reveal opportunities to promote the professional practice of Ugandan nurses and the health of Ugandan citizens.

### ***Western Bioethics***

Ethical principles are derived from moral theory and provide health care providers a framework to guide ethical decision-making (Keatings & Smith, 2000). Although a tetrad of principles (autonomy, beneficence, nonmaleficence, and justice) guides the conduct of research in high-income countries, there is debate about its applicability to the conduct of research in LMIC. Ketefian (2000) suggested that the principles should apply when nurses are engaged in global research, but that modifications may need to be made to ensure congruence with

local regulations, customs, and norms. Austin (2008, p. 17) argued that emphasis on individualism and autonomy ignores the fact that “ethics is fundamentally about our collective life.” Hewitt (2007) noted that the principle-based ethical approach fails to provide a contextual framework in which the qualitative researcher interacts with participants who might be perceived as vulnerable due to their lack of autonomy and liberty. London (2005) concurred, stating that the relationship between research and the issue of social justice is not adequately addressed through the application of nonmaleficence and beneficence standards. Other authors have also recognized the need to examine the limitations associated with the imposition of an approach that is perceived to be heavily influenced by western values and assumptions (Dresden et al., 2003; Olsen, 2003). What follows is a discussion of some of the issues that must be considered during the process of developing a research protocol for use in LMIC.

### ***Vulnerability and Exploitation***

Numerous organizations (e.g., Council for International Organizations of Medical Sciences, the World Medical Association, and the Council of Europe’s Steering Committee on Bioethics) have attempted to address ethical issues related to the protection of participants involved in health research in LMIC. Most of these guidelines focus on the conduct of clinical trials (Nuffield Council on Bioethics, 2005; Olsen, 2003). Although the Nuffield Council on Bioethics (2005) recently noted the importance of also including efforts to examine improved strategies for delivery of health care products and services, its report was not specific to nursing. The report of the International Centre for Nursing Ethics (Olsen, 2003) is helpful in that it identifies relevant ethical issues and offers useful guidance to nurse researchers who work in international settings.

Olsen (2003) noted that two factors contribute to increased potential for ethical difficulties in the conduct of global research: the degree of cultural difference between the involved countries, and the potential for exploitation. Conditions such as limited economic and research capacity and infrastructure as well as uncertainty around the ability of individuals to provide informed consent as a result of social class or customs, combine to create an environment of

vulnerability for research participants (Joint United Nations Programme on HIV/AIDS, 2000). Although these conditions may be found in the researcher's own country, it may be more difficult to identify or address them in the context of an unfamiliar culture. Furthermore, although the qualitative methodologies often favoured by nurses do not usually carry the risk of physical harm, there is greater danger of social or psychological damage (Oberle & Storch, 2004). In addition, providing informed consent may be difficult in the case of qualitative research, as the direction the study will take cannot always be predicted (Hewitt, 2007).

Language barriers, high illiteracy rates, and lack of formal education may result in difficulty obtaining a meaningful informed consent and may require creative and flexible approaches (Schultz, 2004). Thus it is recommended the informed consent be viewed as a dynamic, ongoing process (CIHR, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2005), in which the researcher frequently seeks permission to proceed over the course of the study (Oberle & Storch, 2004). The process for the current study began well before ethical approval when I made an initial trip to Uganda to ask the potential participants themselves about their interest and willingness to engage in the project with me. An observation during my early interactions with the Ugandan participants was that the concepts of consent and confidentiality were perplexing to them. They did not understand why the process was so formal and required their signatures on official-looking documents. Considerable explanation was necessary before I was confident that the consent process and research participants' rights were understood clearly. This experience reinforced my decision to review and renew consent prior to each interaction. It is essential to recognize the potential for intimidation by the demands for control and governance by western-style ethics committees, and to explore avenues to diminish such procedures while maintaining safeguards to protect participants and the larger communities from which they come. It may be possible and acceptable, for example, to find other approaches of documenting informed consent that do not involve signatures on forms. Such strategies would

need careful consideration to make certain that other problems do not arise as a result.

To prevent exploitation of potential participants, the researcher must be able to articulate the direct benefit that may result from the generation of new knowledge for the population from which the sample is drawn. Any intervention that proves successful needs to be affordable and sustainable for community members. The researcher must be familiar with or willing to learn about the region in which the research will be conducted, and should be aware of the health and other needs of the population so that a sensitive and appropriate study can be designed (Ketefian, 2000). As well, the researcher must become aware of local norms and values when assessing the risks and benefits in anticipation of the possibility that there might be fundamental disagreement in such an evaluation (Olsen, 2003). The participants in this study consistently indicated the positive impact of the education program on their personal, professional, and social lives and demonstrated their motivation to advocate for their peers and clients by promoting access to the program for all nurses. They described in detail their new conceptualization of nursing practice and satisfaction with their new ways of interacting with clients and family members. They discussed intentions to use their new knowledge and skill to improve the lives of clients and communities. Participants did not identify any unsatisfactory or troubling outcomes of the education program or the research process. Furthermore, the participants viewed the research process itself as a learning experience. Although a few referred to unvoiced initial concerns about “being researched” with no follow-up or benefit to themselves or their situation, all expressed satisfaction and a sense of empowerment as a result of the whole experience. They viewed my ongoing contact with them and support for their plans for interventions, research, and continuing education as evidence that I was interested in and committed to building their capacity for enhanced practice. They indicated that through reflection and discussion with me and each other about their practice and the effects of the education program, they gained new understanding of skills and knowledge that could be used to promote health and wellbeing in their

communities; they considered this to be my gift to them. If the goal of research is to generate new knowledge for all who participate along with strategies for using that knowledge to benefit the community, then this project enjoyed a modest degree of success.

Questions might be raised about the possibility of social desirability bias (SDB) in the responses provided by participants. The tendency of respondents to present a favourable image of themselves on questionnaires and other self-report tools and strategies in social research and its effect on validity have been noted by a number of authors (Smith & Ellingson, 2002; van de Mortel, 2008). Given the sensitive nature of my questions, along with the cultural and other differences between researcher and participants, there was certainly potential for SDB to affect the findings of this study. In addition, the power differential between the nurse administrator who facilitated access to the education program and the participants may have resulted in attempts to make a good impression on me by providing only positive feedback. Strategies employed to counteract such effects included prolonged engagement, clear commitment on my part to assist the participants to develop their own projects and advance their own practice, use of process consent, periodic discussions with participants about my interpretation of the findings, and sensitivity to political and cultural issues. As our relationship developed, my concerns about SDB diminished. Participants freely disclosed personal issues and experiences that gradually opened their world to me. They patiently answered questions, provided insight, and suggested further avenues to pursue. They formed an interest group among themselves to offer support to each other and develop plans for extending the educational opportunities to their colleagues. Eventually, some of them began to generate their own research questions and ask for assistance regarding the design of small studies. Others initiated discussion about strategies to advocate for change at the institution, nursing association, and policy levels. Although these initiatives were preliminary, it was evident that the participants in this study felt some ownership of the issue and were inspired to take the opportunity to co-create further knowledge in aid of their communities and profession.

Another ethical issue centres on the potential for the identification of participants through the dissemination of findings. Participants may be at risk for negative repercussions from individuals in positions of power, a situation that can arise despite the researcher's best efforts to anonymize the data. A study in which the researcher deliberately seeks out injustices and inequities only multiplies the threats to which participants may be exposed. Of particular note in the current project was the fact that the nurse administrator who implemented the educational opportunity for the staff nurses under her supervision was fully aware of the participation of those nurses in the research study. Because the researcher's foremost responsibility was to the participants, concerns about completeness of the research had to be secondary to the need to mitigate the potential harm to the individuals who risked much to engage with me. Conversation with the administrator about the research process and findings during the course of data collection and analysis was strictly avoided. My understanding and interpretation of the data were discussed with the participants at several points to keep them informed, ensure accuracy, and develop our relationship and rapport. A number of objectives were met as a consequence: the strategy strengthened the rigour of the study; potential power imbalances were reduced through my efforts to seek, hear, and incorporate their feedback; and the candor of the participants was enhanced as they became accustomed to my presence over time.

Some findings in a study such as this one may be interpreted by the researcher as evidence of power imbalances that needs to be shared with a wider audience. Dissemination of those findings may cause some embarrassment or humiliation for the participants. The researcher is faced with a dilemma: publish findings to facilitate greater understanding of the realities of a particular context in an audience that may be unaware of such details, or suppress the release of the information to avoid what might be interpreted as betrayal of trust. This is a most complex and distressing situation for all concerned, and requires careful and thorough discussion to clarify misunderstandings and expose agendas. A manuscript in which I described the resource shortages and difficult conditions under which Ugandan nurses worked was interpreted as criticism of the hospital's

health care services by the nurse administrator. After we discussed the reasons behind my use of critical qualitative methodology and the intended audience (primarily non-LMIC readers), she indicated clearer understanding of my aim. I omitted some of the details that she found particularly discomfiting and made my language more tentative, to indicate that my comments were based on observations of a small number of worksites. Thus, we were able to come to a resolution that allowed me to pursue my goal of provoking debate and dialogue while protecting her dignity in a respectful manner.

### ***Community Considerations***

Another issue concerning consent was raised by Dresden et al. (2003) and reflects the lack of congruence between research ethics guidelines that are based on western principles and the cultural context of LMIC where the research is to be conducted. Such guidelines do not adequately consider the role and influence of the community, focussing instead on individual rights. Dresden et al. recommended adoption of a communitarian ethical framework for global research. In this framework, the individual is seen as inseparable from the community to which he or she belongs. Also considered are the traditions, culture, history, interpersonal relations, power differentials, and other aspects of community living as both influences on, and influenced by, the individual. Similar recommendations have been made regarding research involving Indigenous populations in Canada and Australia (Kaufert et al., 2004; Manderson & Hoban, 2006). Such an approach is one that begins with the awareness that a person's choices and way of being make as much difference to one's neighbour as they do to oneself (Callahan, 1994). In parts of Africa, this concept is known as ubuntu—I am because we are (Barnett & Whiteside, 2006)—and reflects the integral importance of the collective over the individual. Although this concern for community may seem to be diametrically opposed to concern for individual well-being within the context of research activities, Dresden et al. suggested that the non-resident researcher should focus on the principles of beneficence, justice, and autonomy from a community, rather than an individual, perspective. In this manner, the community as well as the individual are protected from harm.

Olsen (2003) clarified that along with respect for persons (as opposed to respect for autonomy), researchers should include the principle of respect for community, recognizing that individualism may be inappropriate in environments where the concept of individual rights is not of primary concern. Dresden et al. (2003) also suggested that concern for potential harm to the community as a result of the research process should be a priority for the communitarian researcher. Assessing and balancing the risks and benefits require consultation with community leaders and stakeholders. In the current study, the research proposal was reviewed and approved by ethics review boards at not only a Canadian university, but at both the university and the hospital in Uganda as well, signifying their belief that the research was relevant, the design appropriate, and the process respectful. It was also discussed with and approved by senior administrative staff of the hospital as well as leaders of the nursing and medical programs. Finally, I engaged the participants in conversations about potential harm that could arise from the conduct of the project, but none was identified.

### ***Doing Good***

Olsen (2003, p. 126) added a fifth guiding principle, contextual caring, which entreats researchers to consider “what good can and may be done for another to whom one feels responsible beyond the obligatory dictates of what must and must not be done.” This principle is an interesting one, tied as it is to the emotional aspects of moral goodness and the personal values of the researcher, because it is consistent with the basic philosophy of care that is integral to professional nursing practice. A design that emphasizes a relational approach rather than an individual-oriented one is considered to be more realistic in international or cross-cultural research (Olsen, 2003). The participant becomes a collaborator in the project and therefore is invested in achieving the goals. This strategy facilitates adherence to the principle of contextual caring described above, encourages a sustained relationship between researcher and participant, and ensures that the participant will not be treated as an object (CIHR et al., 2005). In addition, the tendency toward paternalism which often accompanies research based in western ethical traditions is mitigated in a milieu of

collaboration. The current study emphasized the involvement of the participants in its design and implementation, and in the interpretation of the findings. I worked with several of the nurses to develop small research and community development proposals based on needs they identified. Creating opportunities for expansion of nurses' capacity to participate in research activities has been identified as an essential strategy to enhance effectiveness of health policy and improve quality of care in LMIC (Edwards, Webber, Mill, Kahwa, & Roelofs, 2009).

### **Conclusion**

Improvement of the health of the citizens of the planet, as well as that of the settings where nurses work, is the primary aim of global nursing research. Within the context of an increasingly borderless world, an ethical framework that integrates awareness of and respect for the cultural values, traditions, and health care system realities of the country or region of interest is imperative for researchers. Morally committed as nurses are to the alleviation of suffering and the promotion of health and social justice, it behooves us to adopt an approach that incorporates these values into the foundation of any research study. Our vision must go beyond the ethnocentric idea that widespread sickness and disease in the developing world threaten the prosperity and security enjoyed by the developed world, and seek to address the root causes of illness in order to eliminate inequities between the haves and the have-nots. Reliance on western biomedical ethics reflects a narrow paternalistic perspective that is inconsistent with acceptance and understanding of that broader aim. For example, although autonomy is considered to be the primary principle of western-based ethical traditions, it can be argued that distributive justice is of greater importance when considering the implications of conducting research in developing countries. Indeed, preferable and appropriate for the conduct of nursing research in global settings is adherence to the principles of respect for persons and communities, justice, contextual caring, and beneficence. It is noteworthy that the 2009 draft of the second edition of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (CIHR et al., 2005; see also

<http://pre.ethics.gc.ca/eng/policy-politique/initiatives/draft-preliminaire/>) specifically addresses issues of community engagement when conducting research with the Indigenous peoples of Canada. As institutional ethics review boards and funding bodies implement policies that support such an approach, opportunities to engage in culturally safe and appropriate research will become more accessible.

The HIV/AIDS pandemic has illustrated in stark detail the susceptibility of LMIC to exploitation and abuse. However, those dangers can be meliorated by research that is based on a belief that a community's basic social structures should ensure opportunities for access to resources, control over person and environment, protection of basic human rights, and participation in the political process. This approach requires a collaborative approach where the lines between researcher and community are blurred, where participants have a say in the implementation of the project, and where the primary beneficiary is the community and its members. In short, a communitarian, relational philosophy that acknowledges the irreducibility of the community and the importance of contextual influences on each individual offers an appropriate framework for the conduct of ethical nursing research. Barnett and Whiteside (2006) implore us to recognize the significance of the African concept of *ubuntu* as we work together to reduce the impact of HIV illness on all members of the human community. It is critical that nurses incorporate this notion into their research endeavours in order to meet their moral obligations to all members of society, in particular the vulnerable and marginalized, to improve health and promote justice for the benefit of everyone.

### References

- Austin, W. (2001). Nursing ethics in an era of globalization. *Advances in Nursing Science*, 24(2), 1-18.
- Austin, W. (2004). Global health challenges, human rights, and nursing ethics. In J. L. Storch, P. Rodney & R. Starzonski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (pp. 339-356). Toronto, ON: Pearson.
- Austin, W. (2008). Ethics in a time of contagion: A relational perspective. *Canadian Journal of Nursing Research*, 40(4), 10-24.
- Barnett, T., & Whiteside, A. (2006). *AIDS in the twenty-first century: Disease and globalization* (2nd ed.). New York: Palgrave Macmillan.
- Bhutta, Z. A. (2002). Ethics in international health research: A perspective from the developing world. *Bulletin of the World Health Organization*, 80, 114-120.
- Brundtland, G. H. (2002). The future of the world's health. In C. E. Koop, C. E. Pearson & M. R. Schwarz (Eds.), *Critical issues in global health* (pp. 3-11). San Francisco: Jossey-Bass.
- Buresh, B., & Gordon, S. (2006). *From silence to voice: What nurses know and must communicate to the public* (2nd ed.). Ithaca, NY: Cornell University Press.
- Callahan, D. (1994). Bioethics: Private choice and common good. *Hastings Center Report*, 24(3), 28-31.
- Canadian Institutes of Health Research (2008). *CIHR and global health research (GHR)*. Retrieved January 10, 2009, from <http://www.cihr-irsc.gc.ca/e/31562.html>
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada (2005). *Tri-council policy statement: Ethical conduct for research involving humans*. Ottawa, ON: Interagency Secretariat on Research Ethics.

- Canadian Nurses Association (2008). *Code of ethics for registered nurses*. Ottawa, ON: Author.
- College and Association of Registered Nurses of Alberta (2005). *Ethical decision-making for registered nurses in Alberta: Guidelines and recommendations*. Edmonton, AB: Author.
- Dhai, A., & Noble, R. (2005). Ethical issues in HIV. *Best Practice & Research Clinical Obstetrics and Gynaecology*, 19(2), 255-267.
- Dresden, E., McElmurry, B. J., & McCreary, L. L. (2003). Approaching ethical reasoning in nursing research through a communitarian perspective. *Journal of Professional Nursing*, 19(5), 295-304.
- Edwards, N., Kahwa, E., Kaseje, D., Mill, J., Webber, J., & Roelofs, S. (2007). Strengthening health care systems for HIV and AIDS in sub-Saharan Africa and the Caribbean: A programme of research. *Caribbean Journal of Nursing and Midwifery*, 2, 29-36.
- Edwards, N., Webber, J., Mill, J. E., Kahwa, E., & Roelofs, S. (2009). Building capacity for nurse-led research. *International Nursing Review*, 56, 88-94.
- Evans, T., Irwin, A., & Vega, J. (2005). Health research, poverty and equity. In S. Matlin (Ed.), *Global forum update on research for health 2005* (pp. 130-133). London: Pro-Brook Publishing.
- Global Forum for Health Research (2004). *The 10/90 report on health research 2003-2004*. Geneva, Switzerland: Author.
- Harrowing, J. N. (2009). The impact of HIV education on the lives of Ugandan nurses and nurse-midwives. *Advances in Nursing Science*, 32(2), E94-E108.
- Hayes, P. (2004). An international perspective on research. *Clinical Nursing Research*, 13(4), 267-270.
- Hewitt, J. (2007). Ethical components of researcher-researched relationships in qualitative interviewing. *Qualitative Health Research*, 17(8), 1149-1159.
- International Council of Nurses (2007). *Position statement: Nursing research*. Geneva, Switzerland: Author.

- Joint United Nations Programme on HIV/AIDS (2000). *Ethical considerations in HIV preventive vaccine research: UNAIDS guidance document*. Geneva, Switzerland: Author.
- Kaufert, J. M., Glass, K. C., & Freeman, W. L. (2004). *Background paper on issues of group, community or First Nation consent in health research*. Winnipeg, MB: Centre for Aboriginal Health Research, University of Manitoba.
- Keatings, M., & Smith, O. N. B. (2000). *Ethical and legal issues in Canadian nursing* (2nd ed.). Toronto, ON: W.B. Saunders.
- Ketefian, S. (2000). Ethical considerations in international nursing. *Journal of Professional Nursing, 16*(5), 257.
- Labonte, R., Schrecker, T., & Gupta, A. S. (2005). *Health for some: Death, disease and disparity in a globalizing era*. Toronto, ON: Centre for Social Justice.
- London, A. J. (2005). Justice and the human development approach to international research. *Hastings Center Report, 35*(1), 24-37.
- Macklin, R. (2001). After Helsinki: Unresolved issues in international research. *Kennedy Institute of Ethics Journal, 11*(1), 17-36.
- Manderson, L., & Hoban, E. (2006). Cervical cancer services for indigenous women: Advocacy, community-based research and policy change in Australia. *Women & Health, 43*(4), 69 - 88.
- McElmurry, B. J., Misner, S. J., & Buseh, A. G. (2003). Minority international research training program: Global collaboration in nursing research. *Journal of Professional Nursing, 19*(1), 22-31.
- Nuffield Council on Bioethics (2005). *The ethics of research related to healthcare in developing countries: A follow-up discussion paper*. London: Author.
- Oberle, K., & Storch, J. L. (2004). Nursing ethics and research. In J. L. Storch, P. Rodney & R. Starzonski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (pp. 357-377). Toronto, ON: Pearson.

- Olsen, D. P. (2003). Ethical considerations in international nursing research: A report from the International Centre for Nursing Ethics. *Nursing Ethics*, *10*(2), 122-137.
- Schultz, A. A. (2004). Role of research in reconstructing global healthcare for the 21st century. *Nursing Administration Quarterly*, *28*(2), 133-143.
- Smith, D. B., & Ellingson, J. E. (2002). Substance versus style: A new look at social desirability in motivating contexts. *Journal of Applied Psychology*, *87*(2), 211-219.
- Smith, L. J. (2008). How ethical is ethical research? Recruiting marginalized, vulnerable groups into health services research. *Journal of Advanced Nursing*, *62*(2), 248-257.
- van de Mortel, T. (2008). Faking it: Social desirability response bias in self-report research. *Australian Journal of Advanced Nursing*, *25*(4), 40-48.
- Yach, D., & Bettcher, D. (1998). The globalization of public health, II: The convergence of self-interest and altruism. *American Journal of Public Health*, *88*(5), 738-743.

#### **IV. Moral Distress Among Ugandan Nurses Providing HIV Care: A Critical Ethnography<sup>§</sup>**

Virtually every person in Uganda is affected by HIV—either a family member is infected, ill, or has died of AIDS, or the individual him/herself is infected. Nurses and nurse-midwives (hereafter referred to as nurses) are confronted daily by the overwhelming and complex needs of the sick. Constrained by insufficient staffing levels, inadequate organizational policy frameworks, few opportunities for continuing education, and a critical lack of essential supplies such as gloves, medications, and sterile equipment, nurses struggle to provide care that is congruent with their professional and ethical standards. Nurses experience moral distress as a consequence of being unable to attain those standards.

The purpose of this article is to discuss the context and manifestation of moral distress as it emerged during a qualitative study that was conducted with 24 Ugandan nurses to explore the impact of HIV education on their lives. We describe the coping strategies employed by the participants and argue that the phenomenon is shaped and defined by the social, economic, and cultural milieu in which it is experienced.

#### **Background**

There is widespread consensus that moral distress forms a significant part of the fabric of nursing practice. Defined initially by Jameton (1984) as the painful emotions experienced by nurses in situations when they are cognizant of the morally appropriate actions to take but find themselves limited by institutional barriers, the term was subsequently applied to biomedical problems that were “intermittently occurring and dramatic” (Corley, 2002, p. 637). However, Austin et al. (2005) pointed out that the daily practice of nurses abounds with ethical issues that are difficult to define and articulate. Furthermore, internal constraints such as fear or doubt as well as external ones may prevent the chosen action. A range of uncomfortable feelings as well as physical, cognitive, and behavioural

---

<sup>§</sup> A version of this chapter has been revised and re-submitted for publication as: Harrowing, J.N., & Mill, J. Moral distress among Ugandan nurses providing HIV care: A critical ethnography. *International Journal of Nursing Studies*.

symptoms may indicate the presence of moral distress in an affected individual. The Canadian Nurses Association (2008, p. 6) defines moral or ethical distress as situations where:

nurses know or believe they know the right thing to do, but for various reasons (including fear or circumstances beyond their control) do not or cannot take the right action or prevent a particular harm. When values and commitments are compromised in this way, nurses' identity and integrity as moral agents are affected and they feel moral distress.

The experience of moral distress has been reported in nurses working in a range of acute, long-term care, and community settings and clinical areas (see Table 1). The sequelae of moral distress include a variety of biopsychosocial effects (Gutierrez, 2005), diminished job satisfaction (Rice, Rady, Hamrick, Verheijde, & Pendergast, 2008), avoidance of the context or setting in which the distress occurred (Hanna, 2005), use of alcohol and drugs (Hanna, 2005), decreased capacity for caring (Nathaniel, 2006), symptoms of burnout and leaving the profession of nursing altogether (Aiken, Clarke, Sloane, Sochalski, & Silber, 2002; Meltzer & Huckabay, 2004; Tiedje, 2000). Many of these authors alluded to a connection between moral distress and the challenges associated with nurse retention in the workforce.

<b>Author(s)</b>	<b>Clinical Setting/Population</b>
Gutierrez, 2005 Meltzer & Huckabay, 2004 Sundin-Huard & Fahy, 1999	Critical care
Aiken et al., 2002 Corley, Minick, Elswick, & Jacobs, 2005 Rice et al., 2008	Medical/surgical care
Pijl Zieber et al., 2008	Long-term care
Salmond & Ropis, 2005	Home care
Cohen & Erickson, 2006	Oncology
Tiedje, 2000	Perinatal care
Nathaniel, 2006	Not specified
Hanna, 2005	Care of women with elective abortions

**Table 4-1.** Examples of 'Moral Distress' in the Nursing Literature.

Discussion of barriers to good nursing practice in low- and middle-income countries (LMIC) focuses on challenges created by the HIV pandemic. In 2007, 68% of the world's new infections occurred in sub-Saharan Africa (UNAIDS, 2007) where AIDS continues to be the primary cause of death. On the frontlines of health care delivery, African nurses face many daunting challenges. There is a lack of access to basic supplies, such as gloves and syringes, resulting in exposure to serious health risks (International Council of Nurses, 2000; Stallknecht, 1998). Other obstacles for health care providers include stigma and discrimination (Holzemer et al., 2007; Mwinituo & Mill, 2006; Okafor & Holder, 2004), inadequate knowledge (Walusimbi & Okonsky, 2004), frustration and stress related to heavy workloads (Mavhandu-Mudzusi, Netshandama, & Davhana-Maselesele, 2007; Turan, Bukusi, Cohen, Sande, & Miller, 2008), and negative attitudes (Mbanya et al., 2001). Few authors acknowledge a specific association between such barriers and moral distress, however. As noted by Fournier et al. (2007) and Hanna (2004), the phenomenon has been widely observed and described in North American settings yet little is known about it in the context of other cultures, ethnicities, educational levels, and sociopolitical environments. In particular, there appears to be a complete lack of research reported in the scholarly literature that explores moral distress among nurses in sub-Saharan Africa.

In this paper, we draw on results of a qualitative study conducted in Uganda in 2006-2008 that examined the impact of a 6-month HIV education program on 24 registered nurses. Following completion of the program, study participants were invited to share their professional and personal experiences related to care of people infected or affected by HIV. Briefly, the nurses reported that participation in the program enabled them to address many challenges that interfered with their ability to provide quality care to people with HIV illness. They envisioned new possibilities for themselves as holistic and collaborative caregivers with greater capacity to positively influence service delivery and patient outcomes. They also came to understand the power of education to motivate and prepare themselves for leadership and advocacy roles with respect to

policy development and other forms of political action. Full details of the study are provided elsewhere (Harrowing, 2009); in this article we focus on moral distress, which emerged as a dominant theme in the data.

### **Purpose**

The overall purpose of the study was to address the question: *What is the impact of an AIDS education program on the lives of a group of Ugandan nurses and nurse-midwives?* In addition to gaining greater awareness of the effect of education on the professional practice of nurses, it was deemed important to explore possible sequelae in the personal and social lives of the women. Specific research goals were: (1) to better understand the implications of an educational intervention on various aspects (including professional, personal, and social) of the lives of Ugandan nurses; (2) to identify injustices and power inequities that affect the lives of the nurses and strategies that might be implemented to address these concerns; and (3) to engage the nurses in capacity-building innovations that would ultimately enable them to enhance their care of individuals, families, and communities who are affected by HIV and AIDS. The purpose of this article is to discuss the phenomenon of moral distress as it was described and defined by participants as an aspect of their nursing practice and context.

### **Method**

The research was undertaken using a critical focused ethnographic methodology as outlined by Carspecken (1996). This approach was chosen in order to gain understanding, within a limited duration of time, about how the participants interpreted their experiences and made choices that influenced their behaviours within the context of their lives as nurses in a LMIC. Guided by a belief that science is subtly biased in favour of privileged groups, the critical ethnographer endeavors to disrupt commonly held assumptions and reveal underlying operations of power and control (Cook, 2005; Madison, 2005). We anticipated that opportunities for Ugandan nurses to develop professional knowledge and skills, engage in a full scope of practice activities, and influence HIV policy formulation might be circumscribed by social, political, economic, gender, and cultural factors that would be important to probe and expose in the

process of conducting the research. Participants' experiences of being selected for an educational program presented an ideal circumstance in which such factors could be explored.

Three trips were made to Uganda for data collection over a two-year period, for a total of 18 weeks spent in the country. Data were gathered through individual semi-structured interviews with the nurses as well as participant observation during counseling sessions between the nurses and clients, regular duties at the work site, and meetings of the nurses. An interview guide was developed at the outset of the project and revised over time to reflect themes that began to emerge from the data. Interviews lasted 60-100 minutes and were audiotaped with the consent of the participant; extensive notes were taken during and after the interview for one who preferred not to be taped. Tapes and field notes were transcribed and entered into a qualitative data management software program (NVivo7); thematic coding occurred simultaneously with data collection. The first author also sought opportunities to engage in and learn about community activities (such as attending cultural events and church services, traveling on public transportation, taking lessons in the local language, reading local newspapers and magazines, and sharing meals in private homes). Iterative verification strategies to ensure rigor, including frequent consultation and debriefing with experienced qualitative researchers, maintenance of detailed field notes and memos, prolonged engagement and persistent observation, and the concurrent collection and analysis of data (Morse, Barrett, Mayan, Olson, & Spiers, 2002), were incorporated throughout the research process.

### ***Ethics***

Approval for the study was acquired from the relevant academic and health care institutions in the first author's home country and in Uganda. Informed consent was obtained upon initial contact with the participants and reconfirmed with each subsequent encounter. Participants' clients granted permission for the first author to attend counseling sessions after the purpose of her presence was explained to them and their questions and concerns addressed.

### ***Participants***

The senior nursing administrator for the hospital selected 25 registered nurse employees for the educational program; 24 of them consented to participate in the study. All were female and represented a broad cross-section of nursing practice, including most areas of acute care as well as community health. Many were dually trained as midwives, and all had 15-35 years of nursing experience. A number were in management or supervisory positions and were within 10 years of retirement (mandatory at age 60). All held diplomas in nursing, two had baccalaureate degrees, and one was working on a master's degree. Each participant was interviewed at least once; one or two follow-up interviews were held with 14 participants to further clarify or expand on the information and ideas presented at the first meeting. Fourteen were observed in their worksites and/or in counselling sessions with clients, for a total of 100 hours of observation.

### **Findings**

Participants shared numerous observations about the many factors that shaped the trajectory of their nursing practice over the years of their careers. It was interesting to see the shifts that occurred over two years of data collection in their attitudes and interpretations about power and responsibility with regard to choices and actions. Early conversations were replete with examples of frustration and hopelessness at participants' perceived inability to initiate change in the system. Two years later, during the first author's final trip to Uganda, there was a much stronger sense of optimism and hopefulness, blended with a pragmatism grounded in a realistic awareness that change would come slowly, if at all. Participants discussed the idealistic foundations of their choices to become nurses, the slow erosion of their hopes for themselves and the profession as a whole as forces conspired to erect overwhelming barriers to care. Eventually there was the growing realization that their encounter with education could inspire new awareness of their abilities and power to evoke change.

### ***Called to Serve***

The participants framed their experiences within the context of the meaning of nursing practice and its importance in their lives. To them, nursing

was a passion and a way of being in the world. They identified themselves as nurses in all aspects of their lives, sharing their knowledge and skill with family, friends, and communities. Many stated that they were “called by God to serve” and were responding to a deep need to care for people and alleviate suffering. Some recalled positive encounters with nurses as a result of childhood illness or injury that affected their decision to join the profession. Others aspired to the status and prestige conferred on nurses in their villages. As a child, Sandra\* had observed that nurses in her community were consulted and “involved in every aspect of life,” a powerful role not normally enjoyed by women, and she intended to earn such respect for herself by emulating her older sisters and becoming a nurse. For those whose families were unable to pay university tuition fees, nursing was a more affordable option. Regardless of the reason for their choices, participants were committed members of the nursing profession and were proud of their many years of service. In contrast, the participants commented on their perspectives of the characteristics and motivations of contemporary nursing students, noting that for some, nursing was not their first choice of careers, but a default based on secondary school grades. Those students who failed to meet the entrance requirements of medical or law schools were offered seats in the two-year nursing diploma program, and thus did not always display the passion for nursing that the study participants themselves felt.

The participants had seen many changes in health care and nursing over their years of nursing practice. Unlike that of the early days of their careers, the existing environment was notable for its lack of adequate funding, staff, supplies and equipment. Participants cited as examples the lack of linen for the beds, food, medications, gloves and other protective gear. Patients were asked to bring or acquire most of these items; when they could not afford them, they did without. It was not uncommon for the nurses to purchase, from their own personal resources, medications or food for the patients. Nursing units with 25 beds often admitted 80-100 patients and were staffed by one or two nurses. The demand for services

---

\* Participants chose or were assigned a pseudonym

greatly exceeded the available resources; consequently the nurses were unable to offer the quality of care they wished to provide.

The participants recognized that HIV illness and its associated costs related to prevention, treatment, and care interventions placed a huge burden on the health care system. They acknowledged the social and political factors that created the situation, and felt that they had a responsibility to compensate for deficiencies in health care delivery. It was “not an option to leave the patient to die,” according to Sandra, despite the limitations on the nurses’ capacity to provide adequate services. In their assumption of this responsibility, the nurses experienced a set of powerful emotions that caused them to examine closely their understanding of and commitment to the profession. Consequently, they had to choose a response to the situation that would enable them to carry on functioning in their daily lives.

### ***Hurting and Haunting***

“Suffering” was the term used by almost all of the participants to describe the universal experience of being unable to provide the quality of nursing care they believed their patients deserved. They acknowledged that the patients suffered, as did they themselves. Sadie witnessed and shared in the distress experienced by a colleague in the intensive care unit who, while working alone, received two critically ill patients. Forced to choose which one he would attend to, he could only watch in despair as the other one died. Ruth noted that when a nurse cannot provide for a patient’s basic needs, “she gets hurt” and feels she has “done nothing.” She recalled on one occasion feeling that she should give up nursing when she checked on a particular patient, only to find that he was dead. She perceived her lack of awareness of his deterioration as negligence and believed that it contributed to the man’s death.

Participants described the sense of inadequacy and helplessness that resulted from their inability to provide an acceptable level of care to their patients. Paula was “haunted” by persistent thoughts of the people she could not assist. Ruth observed that failing to meet the patient’s needs would result in retribution from two sources: “[the patient] accusing you, the conscience is accusing you.”

Christine recalled how she “used to feel so bad. . . . When I left duty I still felt that maybe [if I had] remained behind, that patient [might not have] died.” Lorna recounted that frequently at the end of the day:

you start reflecting back what you have done through the day and you see somewhere you haven’t given and you feel bad. . . . [you] didn’t really listen to . . . give what this person was . . . asking and instead of answering--the proper thing--you do something else. So tired, too much work, not enough nurses!

Most participants agreed that they were extremely frustrated by the obstacles and limitations they faced. They described the sense of hopelessness that permeated their practice prior to the education program. Ruth identified a terrible sense of loss in response to the knowledge that the lives of patients and their families were profoundly, and sometimes negatively, affected by her actions. She recognized that her nursing care had changed over the years and her satisfaction with its quality had declined; she experienced significant guilt as a result. Christine observed that “we are not doing as much nursing as we used to do” as a consequence of the lack of resources.

### ***Losing the Essence***

Participants noted the impact of systemic challenges on the image and functioning of the nursing profession overall. Leanne declared that “nurses in Uganda are traumatized” by the efforts required to deliver quality care. Eunice believed that not only was burnout a risk for individual nurses, but that the profession itself was “crippled” by the constraints that interfered with a positive public perception of nurses’ work.

Participants spoke at length about the general public’s poor understanding of the role of nurses and the challenges they faced. They perceived that they were unfairly blamed for the poor quality of services delivered under circumstances beyond their control. Most participants observed that the public’s interpretation of nurses’ behaviours failed to acknowledge the difficult constraints under which they worked. Because nurses worked on the front lines and had continuous contact with patients, they tended to receive the blame for unfortunate outcomes.

Yet nurses were seldom in a position to defend themselves, nor did their leaders attempt to raise awareness among the population. This situation resulted in significant distress for the participants. They desired the public to understand that they were nurses because, as Ruth put it, “I loved to do the work. . . . I had compassion and a sense in my heart towards people.” Their commitment to their patients and profession remained strong, and they struggled to address the need to raise awareness in the general population.

Lorna suggested that nurses were caught in a vicious cycle: the lack of resources led to fatigue and despair, which in turn contributed to a growing negative attitude toward their work and their patients. Nurses then became less conscientious about meeting professional standards, and often failed to appear at the workplace for their scheduled shifts, thus aggravating an already critical situation. Jackie agreed, noting that as nurses’ exhaustion intensified and stamina declined, the prevailing attitude might change to a “Who cares?” approach. Eunice concurred: “When you get used to doing things substandard it can become a habit I think. You then lose the essence of doing it fully right.”

### ***Counting for Something***

Despite the emotional toll of chronic inability to meet personal and professional practice standards, participants focused on their good intentions and the contributions they were able to make. Perseverance was a common theme. Jackie quietly declared: “I have been called to serve, and I will serve. It’s not that we don’t want to do it, but the situation is a-b-c-d. And so we go on like that, day in and day out.” Sandra acknowledged the challenges, but was not prepared to admit defeat: “It is a difficult situation but I don’t think that we should give up. . . . There’s nobody who is going to have it easier than me.” The nurses made judicious use of the supplies and equipment to which they had access, and at times performed care even when it put their own health at risk, according to Ruth: “They do their work but they can also be sick—I mean they can also be affected if they don’t have the [protective equipment]. . . . But you find they are trying.” Christine agreed: “I’ve learned to make the best use of what I have.”

The participants gained satisfaction from any successes, no matter how small. Ruth asserted that: “Even if out of 100 . . . you save maybe three or four. That counts for something.” There was great satisfaction in maintaining contact with clients whom the participants had counseled during the practicum components of the education program, as they were able to see firsthand the improvement in the clients’ health and wellbeing that resulted from the nurses’ interventions. A number of participants noted that they achieved a degree of comfort by praying for their patients, particularly those for whom they could do little. In this way, they believed that they were able to contribute something to everyone. Jackie summed up the nurses’ approach when she said, “You do your best and you leave the Lord to do the rest.”

Funding realities were accepted, and choices debated and eliminated: “You are told the government cannot afford to give you what you really want. Should you walk away from those patients in the halls?” Sandra affirmed that this was not a viable choice. Instead she promoted engagement in political action by nurses to raise awareness of the critical situation (“You have to make your voice loud”), while striving to provide the best possible care in the meantime. She and her colleagues were convinced that “the way forward remains . . . education.” Participants as a group identified the need to make available to their colleagues similar opportunities for education and engaged in negotiations with hospital administration to implement their ideas. They believed that it was only through professional development activities for nurses and awareness raising campaigns for the public and the decision-makers that improvements would be made. Furthermore, they began to see a role for themselves in bringing about those changes.

The participants perceived the need to choose effective strategies for coping with the suffering they had to endure as a result of providing sub-standard services. None felt that terminating their employment was a viable option, as the chances of finding other employment were minimal at best and all participants depended heavily on the income to support family and extended family members. Sandra spoke for all when she said, “I wouldn’t think of [giving up].” Ruth noted

that if you did what you could do under the circumstances, then “you feel contented.” Christine concurred, saying that “sometimes I also fail, but I say I did the best, I did what I could do. I can do nothing more . . . so I’m not going to cry over that.” Eunice shared her strategy of “closing the door” and delegating work to other staff when she was overwhelmed and needed time to recover. Lorna suggested that nurses must choose their attitude in order to successfully deal with the dilemmas they experienced. Likewise, Jackie was determined to “move on with the right attitude” and believed that “you really do so through a lot of strength, physical and psychological strength.” Using this strategy, she found she was able to sleep well at night.

### **Discussion**

The narratives of suffering, loss, pain, and trauma paint a compelling picture of the profound complexities and layers of moral distress in the biographies of the participants. It was a cumulative experience that permeated all aspects of the nurses’ lives as well as their attitudes toward and ability to provide care for their patients. In her comprehensive review of the literature on moral distress among clinicians, Hanna (2004) noted four themes: conflict associated with early insights; truth telling; anguish or interior suffering; and role morality. The first theme was associated with the distress that resulted from involvement in treatments considered, in the clinical judgment of expert nurses, to be futile (such as trying to keep very young and low-birth-weight babies alive in an intensive care setting, for example). This type of issue did not concern the participants in this study; in a resource-challenged environment, the use of complex technology to maintain vital functions was generally not a treatment option.

The second theme concerned the withholding of truth, perhaps news of a grim prognosis, from patients. Interestingly, participants expressed no issues about their previous professional approach to information-sharing with clients. Their role as nurses was to reiterate the pronouncement of the physician and not to offer their interpretation of the diagnosis or prognosis. However, upon completion of the education program, many participants found themselves communicating much more openly and honestly with clients and family members

around sensitive topics such as terminal illness and the consequences of certain sexual activities. The participants felt more comfortable discussing the implications and facilitating the client's problem-solving process, providing explanation where necessary. From an ethical standpoint, they felt that it was their responsibility to provide information to clients that would allow thoughtful decision making. Rather than experiencing distress as a result of truth-withholding, the participants shared a sense of freedom upon learning strategies for approaching difficult topics in a therapeutic manner.

Participants related many examples of anguish and suffering as they described the impact of their inability to provide the care they so wanted to give. This inability was largely related to inadequate resources coupled with overwhelming demand. The suffering was long-standing and manifested as physical, spiritual, and psychological symptoms, congruent with the findings of other authors who have explored this phenomenon (Fournier et al., 2007; McCarthy & Deady, 2008; Pijl Zieber et al., 2008). Most of the participants had practiced nursing long enough that they remembered the pre-HIV days when the demands on the health care system were much less overwhelming and resources were relatively more available. Although suffering was clearly described as a consequence of the participants' inability to enact nursing care as they wished to, it was not the focus of their experience. Rather, discussions about distress emphasized negative public perception of nurses and their roles, and the desire to replace such perception with more positive understandings of the profession along with insight into the issues that resulted in the level of service available to clients. This view of the situation indicates the importance of the collective over the individual in the minds of participants; the notion that what damages one nurse has far-reaching implications for the profession as a whole.

Role morality refers to the strategies used by nurses to accomplish the goals of nursing and speaks to the possibility of disconnecting personal from professional self (Hanna, 2004). Numerous authors (e.g., Cignacco, 2002; Doka, Rushton, & Thorstenson, 1994) have described the suppressed moral distress and emotional blunting that occurs when nurses execute professional duties that

contradict their beliefs about ethical nursing practice. Austin et al. (2005, p. 34) noted that the difficulty is not deciding the right thing to do; the nurse's "greatest difficulty occurs when the choice for the good is quite clear, but implementation of the morally acceptable action is thwarted. The chosen action may be prevented by internal constraints or external ones." Similarly, Pendry (2007) observed that definitions that focus on external constraints fail to acknowledge constraints associated with the nurses' belief system. In this study, there was clear indication that personal *was* professional, that environmental influences on the quality of nursing care in the institution extended to the personal lives of participants. However, in the community, participants saw themselves at greater liberty to offer care without the constraints associated with the workplace. They took great satisfaction from counseling neighbours, raising awareness during encounters in the markets and taxis, and volunteering their services in churches and schools. The nurses' offering of self, knowledge, and skills offset lack of material resources. The positive response from the recipients of such services alleviated some of the suffering and permitted participants to enjoy some measure of fulfillment from their work. Thus, the creative application of new knowledge and skills permitted the participants to practice according to meaningful values, thereby enabling them to maintain personal and professional integrity despite the challenges inherent in the environment.

Criticism has been aimed at the discourse about moral distress by Paley (2004) who argued that focusing on nurses implies that no other occupational groups are likely to suffer, and that nurses are inherently powerless to reverse the process and effects of moral distress. Likewise, Aita (2006) challenged researchers to seek cases of nurses who have experienced moral distress and who have dealt with it in a positive manner. The focus in much of the literature on factors that thwart nurses' preferred actions fails to account for those factors that protect the moral integrity of the nurses and mitigate the effects of distress-causing obstacles. Some authors discussed burnout and other consequences of moral distress as if they result from the nurse's failure to have the personal resiliency necessary for work-related demands (Rodney, Brown, & Liaschenko,

2004). Indeed, the participants in this study experienced profound and fundamental challenges that might be expected to result in moral paralysis, yet many elements of a remarkable resilience and perseverance of the participants were observed. Varcoe et al. (2003) suggested that rather than focussing on the individual, we need to view moral distress within the context of a network of individuals acting in relation to one another. Such a framework contributes to our understanding of the impact of constraints on the relationship between nurse and client, rather than on the nurse's personal experience of suffering. The acute awareness of the "crippling" effects of public perception on the morale and agency of the nursing profession supports a relational approach to the consideration of moral distress.

Although their distress cannot be downplayed or denied, participants' commitment to patients, families, and communities demonstrated that there may be strategies that would allow nurses to overcome the debilitating effects of environmental constraints on their practice. Financial necessity dictated that Ugandan nurses maintain employment at almost any cost; however, it was noteworthy that study participants articulated their ability to select their attitudes in response to the conditions under which they worked. Their experience and qualifications meant that they could have secured work in other countries, yet they indicated little interest in leaving family members behind (a phenomenon that may be partly related to the age of participants; all were nearing the end of their careers and were chosen for the education program based on the assumption that they would be less likely to leave the country in search of international employment). Virtually all participants indicated the importance of service in their understanding of their roles as nurses—service that included off-duty care to neighbours and extended family. Their informal contributions in the community helped to compensate for the frustrations encountered in the institution.

Varcoe et al. (2003, p. 966) discussed nurses' passive acceptance of resource shortages and the "ideology of scarcity," as did the participants in this study. However, completion of the education program and expansion of their own practice enabled the nurses to begin considering other avenues for achieving their

goals. They realized that although they might have little direct impact on the availability of supplies and equipment, improved access to education offered another route to making positive changes in their ability to provide good care. Development of a trusting relationship with clients began to take on more importance, and implementation of their new skills provided dramatic and immediate feedback about their ability to provide care using the resources at their disposal. This was a powerful discovery for participants and altered their thoughts about the potential to activate change. They began to discuss strategies for collective approaches to addressing the issues facing them. They rapidly decided that creation of a critical mass of advocates and activists would offer an outlet for frustrations if, as a group, they and their colleagues could identify and address issues of concern to all. Participants recognized that the process would not effect immediate change, but that over time and with continuous effort, a positive impact might be felt.

The findings from this study are limited by the fact that the interpretation of 24 relatively homogenous voices cannot be expected to be applicable to all nurses and nurse-midwives in Uganda. Furthermore, the assumptions that guided the senior administrator's selection of participants for the education program may have affected the research process. In addition, perspectives were not obtained from the participants' co-workers and clients; such data would likely provide a more comprehensive picture of the phenomenon. Future research needs to be done in order to better understand the complexity of factors that contribute to and alleviate the experience of moral distress among nurses in LMIC, particularly in view of the fact that the original intent of this study did not focus on that phenomenon.

### **Conclusion**

Moral distress among nurses is a phenomenon that has received increasing attention in the past decade. It is often associated with nurse recruitment and retention issues as well as general health concerns for this group of health care providers, and thus is of critical interest to the profession. Although much of the discussion emanates from high-income countries, it is apparent that nurses in

LMIC also experience moral distress, albeit in a slightly different way. Whereas nurses in high-income countries tend to anguish over the commission of procedures (for example, prolongation of life-extending therapies beyond what nurses feel is reasonable or contributing to quality of life), nurses in Uganda suffered from the omission of care because of a lack of resources such that basic care often cannot be provided. Furthermore, nurses may differ in their access to options for addressing moral distress. In LMIC, financial imperative and limited employment opportunities offered few choices to health care providers who wished to avoid or escape negative situations. Instead, such workers benefited from choosing attitudes and responses to circumstances that they found difficult to tolerate in order to maintain integrity and the ability to function appropriately.

It is important to note that moral distress affects more than just the individual who faces a discrete and isolated ethical dilemma. Rather, it manifests within a relational and contextual environment comprising complex structural and interpersonal conditions. Although participants in this study expressed their personal experiences of suffering, the emphasis was always on the impact on clients, communities, and the nursing profession as a whole. As the nurses implemented and refined their new skills, their initial awareness of the inertia associated with large institutions and the sociopolitical milieu in which they were situated was replaced with exploration of strategies to initiate change. They began to see themselves as capable of initiating change through collective effort and constructive resistance to the status quo. Their education became a catalyst for transformation of not only their own attitudes and practices, but also for the presentation of the profession to the public. Future research must focus on investigation of elements of practice and setting that support nurses in their efforts to enact their collective professional values. By fostering a moral community for nursing practice, nurses will enhance not only their capacity for autonomous and ethical practice, but also for the creation of an environment in which the essence of nursing is regained and sustained to the benefit of clients and communities.

### References

- Aiken, L. H., Clarke, S. P., Sloane, D. M., Sochalski, J., & Silber, J. H. (2002). Hospital nurse staffing and patient mortality, nurse burnout, and job dissatisfaction. *JAMA*, 288(16), 1987-1993.
- Aita, V. (2006). Commentary [Nathaniel, A.K. (2006). Moral reckoning in nursing. *Western Journal of Nursing Research*, 28(4), 419-438]. *Western Journal of Nursing Research*, 28(4), 439-441.
- Austin, W., Lemermeier, G., Goldberg, L., Bergum, V., & Johnson, M. S. (2005). Moral distress in healthcare practice: The situation of nurses. *HEC Forum*, 17(1), 33-48.
- Canadian Nurses Association (2008). *Code of ethics for registered nurses*. Ottawa, ON: Author.
- Carspecken, P. F. (1996). *Critical ethnography in educational research: A theoretical and practical guide*. New York: Routledge.
- Cignacco, E. (2002). Between professional duty and ethical confusion: Midwives and selective termination of pregnancy. *Nursing Ethics*, 9(2), 179-191.
- Cohen, J. S., & Erickson, J. M. (2006). Ethical dilemmas and moral distress in oncology nursing practice. *Clinical Journal of Oncology Nursing*, 10(6), 775-780.
- Cook, K. E. (2005). Using critical ethnography to explore issues in health promotion. *Qualitative Health Research*, 15(1), 129-138.
- Corley, M. C. (2002). Nurse moral distress: A proposed theory and research agenda. *Nursing Ethics*, 9(6), 636-650.
- Corley, M. C., Minick, P., Elswick, R. K., & Jacobs, M. (2005). Nurse moral distress and ethical work environment. *Nursing Ethics*, 12(4), 381.
- Doka, K., Rushton, C. H., & Thorstenson, T. A. (1994). Caregiver distress: If it is so ethical, why does it feel so bad? *AACN Clinical Issues in Critical Care Nursing*, 5(3), 346-352.
- Fournier, B., Kipp, W., Mill, J., & Walusimbi, M. (2007). Nursing care of AIDS patients in Uganda. *Journal of Transcultural Nursing*, 18(3), 257-264.

- Gutierrez, K. M. (2005). Critical care nurses' perceptions of and responses to moral distress. *Dimensions of Critical Care Nursing*, 24(5), 229-241.
- Hanna, D. R. (2004). Moral distress: The state of the science. *Research & Theory for Nursing Practice*, 18(1), 73-93.
- Hanna, D. R. (2005). The lived experience of moral distress: Nurses who assisted with elective abortions. *Research and Theory for Nursing Practice*, 19(1), 95.
- Harrowing, J. N. (2009). The impact of HIV education on the lives of Ugandan nurses and nurse-midwives. *Advances in Nursing Science*, 32(2), E94-E108.
- Holzemer, W. L., Uys, L. R., Makoae, L. N., Stewart, A., Phetlhu, R., Dlamini, P. S., et al. (2007). A conceptual model of HIV/AIDS stigma from five African countries. *Journal of Advanced Nursing*, 58(6), 541-551.
- International Council of Nurses (2000). *Reducing the impact of HIV/AIDS on nursing and midwifery personnel*. Geneva, Switzerland: Author.
- Jameton, A. (1984). *Nursing practice: The ethical issues*. Englewood Cliffs, NJ: Prentice Hall.
- Madison, D. S. (2005). *Critical ethnography: Method, ethics, and performance*. Thousand Oaks, CA: Sage.
- Mavhandu-Mudzusi, A. H., Netshandama, V. O., & Davhana-Maselesele, M. (2007). Nurses' experiences of delivering voluntary counseling and testing services for people with HIV/AIDS in the Vhembe District, Limpopo Province, South Africa. *Nursing and Health Sciences*, 9(4), 254-262.
- Mbanya, D. N., Zebaze, R., Kengne, A. P., Minkoulou, E. M., Awah, P., & Beure (2001). Knowledge, attitudes and practices of nursing staff in a rural hospital of Cameroon: How much does the health care provider know about the human immunodeficiency virus/acquired immune deficiency syndrome? *International Nursing Review*, 48(4), 241-249.
- McCarthy, J., & Deady, R. (2008). Moral distress reconsidered. *Nursing Ethics*, 15(2), 254-262.

- Meltzer, L. S., & Huckabay, L. M. (2004). Critical care nurses' perceptions of futile care and its effect on burnout. *American Journal of Critical Care, 13*(3), 202-208.
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods, 1*(2), Article 2. Retrieved May 25, 2009, from [http://www.ualberta.ca/~iiqm/backissues/1\\_2Final/html/morse.html](http://www.ualberta.ca/~iiqm/backissues/1_2Final/html/morse.html)
- Mwinituo, P. P., & Mill, J. E. (2006). Stigma associated with Ghanaian caregivers of AIDS patients. *Western Journal of Nursing Research, 28*(4), 369-382.
- Nathaniel, A. K. (2006). Moral reckoning in nursing. *Western Journal of Nursing Research, 28*(4), 419-438.
- Okafor, C. B., & Holder, B. (2004). HIV/AIDS related stigma in sub-Saharan Africa: Context and consequences. *International Journal of Global Health, 3*(1), 20-34.
- Paley, J. (2004). Commentary: The discourse of moral suffering. *Journal of Advanced Nursing, 47*(4), 364-365.
- Pendry, P. S. (2007). Moral distress: Recognizing it to retain nurses. *Nursing Economic\$, 25*(4), 217-221.
- Pijl Zieber, E., Hagen, B., Armstrong-Esther, C., Hall, B., Akins, L., & Stingl, M. (2008). Moral distress: An emerging problem for nurses in long-term care? *Quality in Ageing, 9*(2), 39-48.
- Rice, E. M., Rady, M. Y., Hamrick, A., Verheijde, J. L., & Pendergast, D. K. (2008). Determinants of moral distress in medical and surgical nurses at an adult acute tertiary care hospital. *Journal of Nursing Management, 16*(3), 360-373.
- Rodney, P., Brown, H., & Liaschenko, J. (2004). Moral agency: Relational connections and trust. In J. L. Storch, P. Rodney & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (pp. 154-180). Toronto, ON: Pearson Prentice Hall.

- Salmond, S., & Ropis, P. E. (2005). Job stress and general well-being: A comparative study of medical-surgical and home care nurses. *Medsurg Nursing, 14*(5), 301-309.
- Stallknecht, K. (1998). Nurses are the key to effective HIV/AIDS prevention and care. *International Nursing Review, 45*(6), 173-174.
- Sundin-Huard, D., & Fahy, K. (1999). Moral distress, advocacy and burnout: Theorising the relationships. *International Journal of Nursing Practice, 5*(1), 8-13.
- Tiedje, L. B. (2000). Moral distress in perinatal nursing. *Journal of Perinatal & Neonatal Nursing, 14*(2), 36-43.
- Turan, J. M., Bukusi, E. A., Cohen, C. R., Sande, J., & Miller, S. (2008). Effects of HIV/AIDS on maternity care providers in Kenya. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 37*(5), 588-595.
- UNAIDS (2007). *AIDS epidemic update: 2007*. Geneva, Switzerland: Author.
- Varcoe, C., Rodney, P., & McCormick, J. (2003). Health care relationships in context: An analysis of three ethnographies. *Qualitative Health Research, 13*(7), 957-973.
- Walusimbi, M., & Okonsky, J. G. (2004). Knowledge and attitude of nurses caring for patients with HIV/AIDS in Uganda. *Applied Nursing Research, 17*(2), 92-99.

## V. Critical Ethnography, Cultural Safety, and International Nursing Research\*\*

Critical ethnography is a qualitative research methodology that enables the researcher to not only study and understand society, but also to critique and potentially change that society through his or her work. It is a methodology that is well suited to health research, given the contemporary perspective of health as a sociopolitical phenomenon influenced by issues of power and dominance (Cook, 2005). Use of a critical qualitative research method that emphasizes holistic human experience and its relationship to power and truth offers the opportunity to closely examine health challenges from the perspective of those who live with them daily. However, when researchers conduct studies in contexts and cultures with which they are unfamiliar, questions may arise about the ability to give authentic voice to participants without objectifying their knowledge or putting them at risk for unanticipated or unpleasant repercussions.

As a Canadian nurse researcher engaged in a study about the impact of HIV education on Ugandan nurses, I was concerned about the effects of my status as an outsider who is relatively inexperienced in international health research and my naiveté about the research setting on these issues. I was particularly interested in the concept of cultural safety and its potential role in the conduct of research in the Ugandan setting. Cultural safety, briefly, refers to

fostering an understanding of the relationship between minority status and health status as a way of changing nurses' attitudes from those which continue to support current dominant practices and systems of health care to those which are more supportive of the health of minority groups.

(Smye & Browne, 2002, p. 47)

Does the concept of cultural safety apply to the conduct of nursing research? If so, is there congruence between critical ethnographic methodology and cultural safety? In this article, I describe the methodological framework used in the study

---

\*\* A version of this chapter has been submitted for publication as: Harrowing, J.N., Mill, J., Spiers, J., Kulig, J., & Kipp, W. Critical ethnography, cultural safety, and international nursing research. *International Journal of Qualitative Methodology*.

and explore differences and similarities of selected elements to the notion of cultural safety in nursing. I then discuss the application of this concept to nursing research, citing illustrative examples from my study.

### **Background**

This research project focused on the impact of a 6-month education program about HIV care on the lives of 24 Ugandan nurses and nurse-midwives (hereafter referred to as nurses). I had been approached by the senior nursing administrator of a large referral hospital to conduct a study of the outcome of her efforts to secure a professional development opportunity for the nursing staff. We agreed that I would explore the effects of completing this intensive and comprehensive learning activity on all aspects of participants' lives, including the professional, social, and personal. Details of the study findings have been published elsewhere (Harrowing, 2009).

As I prepared to conduct the study, I learned that nursing in Africa is not a highly valued or respected profession (Buchan & Calman, 2005), and nurses face many challenges in their attempts to provide adequate care for people who are HIV-infected (Chen et al., 2004). The workload for Ugandan nurses and midwives is staggering (Buchan & Calman, 2005), and financial compensation is poor (Clarke-Jones, 2004). Nurses in Africa frequently are the victims of violence because of their position at the forefront of direct care delivery (Buchan & Calman, 2005). Furthermore, the health of nurses and midwives in Africa, the majority of whom are women, is disproportionately affected by the virus, given the multiple opportunities for exposure as a result of their sex and gender roles as well as the high-risk work environments. Women and girls account for approximately 60% of all those infected with HIV in eastern and southern Africa (UNAIDS, 2008). Women are considered to be particularly vulnerable to infection as a result of their lower educational attainment, higher unemployment, and weaker negotiating skills within relationships (Fournier, Kipp, Mill, & Walusimbi, 2007; UNAIDS, 2008). In addition, many customary and statutory laws discriminate against Ugandan women in areas of marriage, divorce, and property rights (Garbus & Marseille, 2003). Based on this evidence, I anticipated

that participants might reveal their perceptions of political and social structures and patterns of interaction that contributed to the inability of nurses to achieve their full potential with regard to providing care to persons with HIV disease.

Because I sought to reveal and understand issues of power, politics, and justice, I chose to use Carspecken's (1996) critical methodology in a focused examination and exploration of these topics. Given that this type of inquiry may place participants at risk, I was sensitive to the need to promote a safe environment in which they would feel confident and comfortable describing their experiences. General aspects of some ethical concerns related to the global health research process that were identified during this study have been discussed elsewhere (Harrowing, Mill, Spiers, Kulig, & Kipp, in press); in this article I focus on the concept and practice of cultural safety and its relevance to the use of Carspecken's approach in the conduct of nursing research in international settings.

### **Critical Ethnography**

Qualitative research is directed at the discovery of meaning, rather than cause and effect, and typically focuses on process and context. The study is usually conducted in a natural setting and analysis is inductive, with the researcher paying particular attention to discourse and behaviour of participants. In addition, the researcher is the data collection instrument and makes no attempt to avoid, in fact generally is dependent upon, relationships with the participants in an attempt to gain the emic, or insider, perspective (Rubin & Rubin, 2005). Ethnography is a qualitative approach in which the researcher explores aspects and meanings of a group's culture, including values, behaviours, and beliefs. The critical ethnographer examines that culture through the lens of power, prestige, privilege, and authority (Creswell, 2007) in response to an ethical responsibility to address unfairness or injustices and attempts to achieve positive social change (Brown & Dobrin, 2004; Carspecken, 1996; Hammersley, 1992; Madison, 2005).

A focused critical ethnographic approach was applied to better understand the factors that shape the experiences of Ugandan nurses as they provide HIV care in resource-challenged settings. Despite the increasing popularity of critical

ethnography as a research methodology, there is limited description of it in the literature. Carspecken (1996) offers an approach to critical ethnography in educational settings that has been noted as useful for nurse researchers. However, most of the published research using Carspecken's method has been conducted in Australia by nurses from that country or other high-income countries (as defined by The World Bank, 2009) in clinical settings such as renal dialysis and intensive care that utilize complex technologies, or in health promotion practice (Cook, 2005; Hardcastle, Usher, & Holmes, 2006; Smyth & Holmes, 2005). There is no reported research in which nurses from high-income countries conducted studies using this approach in low- and middle-income countries (LMIC) with colleagues who face severe resource constraints. Furthermore, nurse researchers have not articulated linkages between cultural safety and critical ethnography in the conduct of research in LMIC.

Qualitative research using Carspecken's (1996) method comprises a five-stage process (see Table 1) which is intended to facilitate the study and explanation of social action that takes place in particular social sites. Some or all of the stages may be used, depending on the type and intent of the study. As in other qualitative methods, analysis begins when data collection begins, and the process becomes iterative. Data are collected in stages one and three. First, monological data based on thick descriptions of passive observations of people's interactions and routines are compiled in order to provide a baseline under natural conditions. Following initial speculation about the meaning of those behaviours using the preliminary reconstructive analysis process of stage two, the researcher actively engages with participants in conversations and group discussions to generate dialogical data in the third stage. The last two stages involve systems analysis, first at the level of similar social sites, and then at the level of social-theoretical models. It is the fifth stage that invites creative approaches by the researcher, providing opportunities for existing system theories to be altered or refined, according to Carspecken (1996, p. 195). Because this particular study was a focused ethnography, I elected to omit the last stage of Carspecken's process.

Stage	Core Activities and Aims
Preliminary	Create list of research questions and specific items for study; examine researcher value orientations
1	Compile primary record of monological data through intensive observation only; develop notes about the research site; maintain journal
2	Preliminary reconstructive analysis of primary record; speculate about meanings of interactions observed in first stage
3	Dialogical data generation through semistructured interviews and group discussions with participants
4	Discover relationship between social site of interest and other sites that bear some relation to it
5	Explain findings by reference to the broader system; link findings to political structures of society

**Table 5-1.** Carspecken’s Stages for Critical Qualitative Research (Carspecken, 1996).

### **Cultural Safety**

Cultural safety is concerned with the provision of health care services in a manner that is respectful of and sensitive to the unique cultural background of the recipients of those services. As Dion Stout and Downey (2006, p. 327) so eloquently stated, “cultural safety finds expression in caring spaces that are equality seeking and rights oriented” and contributes to health for Indigenous peoples. Originating in the work of Maori nurse educators in the 1980s in response to the harmful effects of colonization on the health of Indigenous peoples in New Zealand, cultural safety was defined by the Nursing Council of that country in terms of the awareness and practice of individual nurses and midwives (Nursing Council of New Zealand, 2005). Ideally, the recipient of nursing services evaluated the effectiveness and quality of the care, and was empowered to contribute to improving outcomes.

Cultural safety education was introduced into nursing curricula in New Zealand in an attempt to change nurses’ attitudes and behaviours, from indiscriminate support of dominant health care practices toward affirmation of the cultural identity of each client (McGrath & Phillips, 2008). Following the specific application of cultural safety to the health care of the Maori people of New

Zealand, advocates of the concept have promoted its consideration for use in other contexts and settings. A number of authors have suggested that cultural safety is an essential component of high quality health care delivery in such culturally diverse countries as Canada and Australia (Anderson et al., 2003; Browne, Fiske, & Thomas, 2000; Dion Stout & Downey, 2006; Johnstone & Kanitsaki, 2007; Williams, 1999), and that it should be a standard of practice when caring for any patient (Polaschek, 1998).

### **Intersections Between Critical Ethnography and Cultural Safety**

What then are the connections between and among the underpinnings and process of Carspecken's (1996) critical ethnography, cultural safety, and the conduct of nursing research in LMIC by researchers from high-income countries? The question is an important one because research findings are intended to inform nursing education and practice. If educators and practitioners are articulating the need to bring cultural safety to the foreground of practice, should not researchers be also considering the need for such a lens? Because nurses are increasingly involved with the study and care (or lack thereof) of patients and their diverse backgrounds and settings, it seems reasonable to consider the potential for congruence in foundational principles that might guide, or undermine, the process. Furthermore, nurses share an ethical responsibility to promote justice and to work collectively and individually to bring about social change for all people (Canadian Nurses Association, 2008). Given the evidence that suggests patients do not always receive care that makes them feel safe and respected, it behooves nurses to re-examine their understanding of culture as well as their approaches to caring for people who may feel marginalized by the implementation of standard services. Such effort might well have important implications for nursing care provided to all people, not just members of distinct ethnic or racial backgrounds.

To explore possible answers to the question posed above, critical ethnography and cultural safety are compared and contrasted across three foundational elements: the aims and approaches of each process; embedded perspectives and definitions of culture; and aspects that are relevant to the research process including determination of the research question, recruitment,

consent procedures, attention to language, and consideration of the risk for repercussions against participants. Examples from the current study are used to illustrate the enactment of these elements and the challenges and outcomes I encountered.

### *Aims and Approaches*

The choice of a critical methodology positions the researcher to examine social inequities, with a goal of creating positive social change. Merely increasing knowledge is not the goal of this research; rather, the aim is to move toward political action that can redress the injustices found or constructed during the research process (Kincheloe & McLaren, 2005; Wallerstein & Duran, 2003). Madison (2005, p. 5) observed that the criticalist moves from “what is” to “what could be” in order to contribute to emancipatory knowledge and the discourses of social justice.

Similarly, cultural safety was identified by Maori nurse educators in New Zealand in an attempt to expose and correct inequities in health care service access and delivery to members of the Indigenous culture (Polaschek, 1998). It was considered essential that members of the dominant white culture become aware of the historical, political, and social oppression that manifested in poor health outcomes and negative encounters between the Maori peoples and health care providers in that country. Cultural safety was to be enacted at the level of the individual nurse through his/her increased awareness of and sensitivity to culturally appropriate behaviours and attitudes, as determined by the Maori patients themselves, and knowledge of theories of power relations (Nursing Council of New Zealand, 2005). The voice of Maori nurses also can be perceived as representative of members of other marginalized groups who have been silenced by alienation in one form or another. In bringing awareness of the various forms of oppression imposed by members of a dominant culture, strong congruence with the philosophical stance of critical ethnography is apparent. Furthermore, the aims of the methodology and cultural safety correspond with the ethical responsibilities of nurses to identify and address social change in order to reduce inequities for the vulnerable populations of the world.

A concern arose early in the process of obtaining ethical approval that highlighted my lack of understanding and awareness related to the conduct of research in Uganda. Several weeks went by as I attempted to contact and meet with the people who could assist me through the necessary steps. Many queries about the relevance of conducting a critical qualitative study were voiced during my presentation to the medical school ethics review committee. I began to understand that my assumptions about the committee members' knowledge of and degree of comfort with qualitative methodology were inaccurate. They eventually approved my study protocol, but I was left with the sense that they did not fully support a qualitative approach. Informal conversations later revealed that the relatively small number of researchers in Uganda available to supervise graduate students dictates that research projects be carried out in the most efficient manner possible with minimal use of resources. Qualitative research was deemed to take a long time and use considerable resources, and therefore was not the design of choice. Indeed, I was asked several times by participants why I did not just provide them with a survey instrument and collect data quickly. We had many conversations about the rich contributions of their narratives to outsiders' understanding of the complexities of their experiences.

This encounter with another way of engaging with the world challenged my assumptions about how knowledge is created and shared and forced me to pay attention to perspectives I had not considered. I had been prepared to rationalize the use of a qualitative approach versus a quantitative one based on the reasons widely discussed in the literature, but I had not considered such a pragmatic argument. Reflecting on the process of gaining approval, I was struck by the fact that no one directly articulated the reasoning behind the hesitation to grant approval. Rather, questions were posed and re-worded, as if to guide me gently to the answer. I found this circuitous approach different from the more direct approach I would have expected in a North American committee meeting. Although this situation may not have held implications for the cultural safety of participants, it did highlight my lack of understanding of the local context and my blinders regarding other worldviews. I realized that one cannot ever be completely

prepared for all eventualities; one can only be alert and flexible, ready to notice subtle clues and inquire into participants' expert knowledge and understanding of their lives. Cultural safety is enhanced by awareness of the limitations of one's own thinking and the need to learn about visible and invisible aspects of the culture, including research culture, of others.

### ***Perspectives and Definition of Culture***

Many definitions of and approaches to studying the concept of culture are based on an essentialist viewpoint, which focuses on ethnic and racial differences and reinforces the social practices that institutionalize the dominant approach to health care (Gray & Thomas, 2006). Proponents of the essentialist framework emphasize the presumed shared features of a group that differentiate it from the norm of English-speaking Christians of European descent, thereby constructing a "bicultural situation of Self and Other, Us and Them" (Reimer Kirkham & Anderson, 2002, p. 6) in which difference is interpreted as inferiority. When applied to nursing practice, this viewpoint not only leads to an emphasis on the minutiae of the nurse-client relationship rather than the big picture, it also detracts attention from the connections between systemic oppressions and historical exploitation and colonialism (Gustafson, 2005). Grey and Thomas (2005) noted that nursing's uncritical acceptance of assumptions about culture and cultural competence has resulted in the perpetuation of cultural stereotypes and a false sense of comfort and confidence in our knowledge and ability to care for members of various cultural groups.

A critical constructivist perspective, on the other hand, depicts culture as a fluid, relational process that is contextually enacted, and encourages the exploration of social, historical, political and economic factors in the creation of networks of cultural meaning (Browne & Varcoe, 2006; McGrath & Phillips, 2008). Rather than focusing on cultural Others, examination is required of one's execution and interpretation of behaviours and practices and their contribution to and influence on maintenance of certain norms. A strong argument has been made for the need to transform our understanding of culture from an essentialist perspective to a critical one that focusses on structural inequalities and the

dynamics of the health care relationship between provider and recipient (Gustafson, 2005; Reimer Kirkham & Anderson, 2002). According to Ogilvie, Burgess-Pinto and Caufield (2008), it is the emphasis on the societal origins of oppressive attitudes rather than on the behaviours of the individual nurse that extends the transcultural competence of practitioners to a culturally safe approach. This awareness begins with the nurse's reflection on his/her personal and cultural history, values and beliefs, and continues with the situating of those understandings within a framework of power imbalances, institutional discrimination, and colonizer-colonized relationships. It is in the identification and discussion of inequities that new dimensions of comprehension emerge and can be enacted. Failure to employ a critical cultural perspective will almost certainly result in further marginalization of patients who do not belong to the dominant cultural group.

Carspecken (1996) does not explicitly address the concept or meaning of culture. References to culture tend to focus on "cultural commodities" (p. 200)—artifacts and practices that the researcher is advised to examine for symbolic or cultural meaning and their contribution to the construction of identity. Carspecken discusses the connection between cultural forms and the physical environment and its political and economic antecedents, and encourages the researcher to build abstractions from the data toward the macrosociological theory that best explains the environment. Thus Carspecken's discussion does allude at times to social determinants of health, but tends to remain essentialist throughout most of his book. On the other hand, although ethnography is often described as the outsider's attempt to gain an insider's view of certain cultural realities, Carspecken suggests that one can never attain such a view of another's reality. This viewpoint indicates his awareness of the dynamic nature of culture, that it is more than a list of behaviours and objects. In this, he is supported by Ogilvie et al. (2008) who asserted that the insider-outsider debate represents a false dichotomy, and that researchers and participants may simultaneously occupy various points along the continuum of belongingness. Indeed, in the current project, I was clearly an outsider, due to my status as a Canadian citizen working in Uganda. However, as

a registered nurse working with registered nurses, I shared aspects of the culture associated with the nursing profession. I was able to connect with the participants on the level of our joint interest in nursing concerns, yet at the same time recognized the need to ask questions about aspects of their lives of which I had no knowledge. Similarly, we found other ties such as motherhood and gender roles that afforded additional opportunities for exploring common experiences. In this way, the dance of developing rapport with participants was initiated. This observation is significant because it is indicative of the importance of context and relationship to the making and interpretation of data. The researcher must pay attention to shifting conditions and influences, as well as the potential to misinterpret information or introduce bias. The researcher from a high-income country who works in a LMIC must realize that trust and humility are key components of the process, and should endeavour to create collaborative, respectful relationships with participants. Even in situations where researcher and participant share a common language, the researcher must be sensitive to the possibility of misunderstanding that occurs when local nuances and expressions are unfamiliar. Such awareness is necessary for the conduct of critical methodology, and it is also relevant to the creation of a culturally safe environment for participants and researcher alike, regardless of setting and degree of 'difference' between researcher and participant.

### ***Aspects and Components of the Research Process***

Carspecken's (1996) assertion that critical ethnographers must begin by examining their biases and values in order to articulate the relationship among power, thought, and truth claims is congruent both with the principles of cultural safety and with nursing's code of ethics. Cultural safety is about exposing the antecedents and outcomes of power inequities in order to amplify the voices of those who are marginalized by historical, political, economic and social events. Researchers and practitioners must acknowledge their own beliefs to gain insight into and understanding of the beliefs of others. Although Carspecken (1996) does not address cultural safety in those words, he notes that the researcher must be aware of the potential impact of his/her perspectives on the data making and

interpretation process. Likewise, Polaschek (1998) acknowledged that culturally safe nursing practice is broader than the practice behaviours of the individual nurse; however, there is a component of self-examination by the practitioner in order to better recognize his/her impact on the health care interaction (Nursing Council of New Zealand, 2005). It is up to the individual or community to ascertain the safety of a particular health care approach or intervention, and what is found to be safe in one situation may not be so in another. Therefore it becomes the responsibility of the researcher and the nurse to deliberately create opportunities to ensure safety, rather than make assumptions that may be inaccurate.

Integration of cultural safety into a critical ethnographic nursing study is facilitated by purposeful consideration of the context in which potential participants live. Sampling and recruitment strategies may present particular obstacles. In some settings, it may be important to conduct community consultations prior to contacting individual participants to ensure relevance of the proposed research questions and process and to gain the appropriate consents and access (Ogilvie et al., 2008). In the current study, I worked with the nursing administrator at the Ugandan hospital to determine the research question, and the ethics committee of both the university medical school and the hospital reviewed and approved the protocol. I was assigned a physician to be my Ugandan supervisor. Although this is not typical procedure in the Canadian context, my compliance was expected in Uganda. By doing so, I was able to ensure the relevance of the project, demonstrate respect and collegiality, learn from local experts, and gain the access I required to conduct the study. In addition, the principles of both critical ethnography and cultural safety were appropriately maintained.

The researcher must be explicit about whose voices are being heard and whose are not, and must choose recruitment approaches that neither coerce nor exploit. This may be difficult, as the very act of categorizing people can marginalize them. Anderson et al. (2003, p. 204) cautioned that the researcher must be prepared for the participants to disrupt the “predetermined subject

positions” as they exert agency. Multiple strategies may be required. In the current study, participants were selected by virtue of their involvement in the education program prior to the initiation of data collection; I did not recruit them in the usual sense, other than to explain the project and obtain consent. This process created its own challenges, as the nurse administrator who implemented the program chose the nurses who would be offered the opportunity to join. Because of the lack of anonymity and the potential for coercion, I had to be particularly attentive to the need for strict confidentiality and the process of informed and ongoing consent with participants over the two years of the study.

The consent process itself stimulated further reflection about my assumptions. It was the typical one used in most research studies in North America, in which participants read a carefully prepared form and sign it to indicate their understanding and agreement. I was questioned by the participants in this study regarding the need to sign such an official document; the process did not seem to make sense to them. On further inquiry, they felt that we could trust each other with a verbal explanation and commitment, and did not see the reason for signatures and records. In observance of the approved protocol, I did collect signed forms from participants after careful discussion of the reasons behind the process. In addition, for the remainder of the study, I obtained ongoing consent from participants at each interaction, by reviewing their rights and recording their verbal agreement to continue. For future studies, I would explore the possibility of explaining and recording consent differently to better meet the needs and expectations of participants, while still protecting them adequately. The obligation to create a formal paper trail must be balanced with the duty to avoid imposing discomfort through an unfamiliar and off-putting process.

Careful attention to language and the need for translation and interpretation are critical to ensuring cultural safety. In practice and in research, language prejudice may be indicative of cultural racism (Johnstone & Kanitsaki, 2008; Ogilvie et al., 2008). Interpretation is complex and multilayered, and often involves a third party with the attendant implications for the relationship between researcher and participant. Researchers may not be knowledgeable or skilled in

the use of interpreters, and this situation may negatively affect the quality and accuracy of the data and its meanings. Because inequitable social structures and power relations are often reflected in communication modalities (Carspecken, 1996), it is essential that the researcher be particularly cognizant of the potential threats to cultural safety in the process of data-making. Such threats must be carefully managed in order to prevent harmful outcomes to participants. In the current study, participants all spoke excellent English and appreciated my attempts to learn their local language. Nevertheless, there were times when I had to clarify subtle nuances associated with words and phrases that were used in ways that were vague or unfamiliar to me.

One final concern to be addressed is that of the vulnerability of participants once the study is completed and findings disseminated. Exposure of inequities and power differentials may occur in the confidential setting of the research interview, but when those same issues are released into the public domain, they take on a life of their own and the researcher loses control over their interpretation and use. Participants should be made aware of the potential risks, to the extent that the researcher can anticipate them, at the outset of the study in order to minimize later distress and possible withdrawal of data from the study. Although Carspecken (1996, p. 155) does not address this vulnerability concern specifically, he does advocate the “democratization” of the research process by the taking on of a facilitator role by the researcher. The researcher is then responsible for creating a safe environment in which the participant explores issues using his/her own vocabulary and ideas and power relations are equalized as much as possible. Carspecken also warns the researcher to “be prepared to be threatened” (p. 169) in the process of honouring the experiences and truth claims of participants which may conflict with those of the researcher, particularly if his/her background differs markedly from that of the participants. This approach is compatible with Lather’s (1986) notion of cathartic validity which refers to the extent to which the researcher allows him/herself to change and grow in ways that may challenge oppressive cultural forms. Thus the researcher’s efforts to be open and humble and to enhance the environment for the participant may be seen as

consistent with the principles of cultural safety. The researcher is then in a position to negotiate the interpretation and dissemination of data with the participant in order to diminish the risk of repercussions to the participant.

In the current study, I attempted to develop a strong rapport with participants through prolonged engagement (the project extended over a 24-month period with 18 weeks in the field and ongoing electronic contact when I was not in-country), as well as frequent consultations regarding my understanding of the data and the documentation of findings. During these discussions I was able to ask participants if they had concerns about what might be published following the study, and we were able to negotiate what was said and how it was articulated. Final drafts of manuscripts were shared with those participants who were available, and their feedback was incorporated. Although it is difficult to ensure absolute and complete cultural safety in all situations, it is important for the researcher to make clear and deliberate efforts to demonstrate attention to the process throughout the life of the study.

### **Conclusion**

Globally, nurses are committed to the provision of safe, competent, compassionate, and ethical care to all clients. Identification and application of the concept of cultural safety as a unique aspect of that care has been confined until recently to nursing education and practice in the New Zealand context where it originated. In the last decade, a number of authors have argued for broader application, asserting that cultural safety is an essential component of postcolonial nursing discourse. Extending the definition of “care” to include the treatment of those who consent to engage in research studies, this principle can be interpreted as embracing sensitivity to and awareness of those aspects of the participant’s culture that he/she deems important in the process of conducting that research. However, consideration of cultural safety as an essential aspect of research protocols has not been discussed widely in the nursing literature. In particular, implications for researchers from high-income countries working in the unfamiliar cultural context of LMIC have not been articulated or addressed to date. In this paper, congruence between Carspecken’s (1996) approach to critical

ethnography and cultural safety was explored and linkages established, using the example of a current research project in Uganda conducted by a Canadian investigator. Carspecken does not fully address all of the issues that might be of concern to nurse researchers; therefore care and attention must be directed at ensuring participants are not harmed by the cultural dangers to which they might be exposed in the process of conducting the study.

In order to protect research participants and to represent them fairly, it is essential that researchers deliberately create the “caring spaces” advocated by Dion Stout and Downey (2006, p. 327) in which cultural safety is likely to occur. To do otherwise is to violate the ethical standards upon which research involving human subjects is based. Nevertheless, the complexities of the issue and the contexts in which international health research is conducted demand that further debate and dialogue occur in order to broaden the discussion and examine in greater detail the utility of cultural safety as a component of research design.

### References

- Anderson, J. M., Perry, J., Blue, C., Browne, A., Henderson, A., Basu Khan, K., et al. (2003). "Rewriting" cultural safety within the postcolonial and postnational feminist project: Toward new epistemologies of healing. *Advances in Nursing Science*, 26(3), 196-214.
- Brown, S. G., & Dobrin, S. I. (2004). New writers of the cultural sage. In S. G. Brown & S. I. Dobrin (Eds.), *Ethnography unbound: From theory shock to critical praxis* (pp. 1-10). Albany, NY: State University of New York Press.
- Browne, A. J., Fiske, J.-A., & Thomas, G. (2000). *First Nations women's encounters with mainstream health care services & systems*. Vancouver, BC: British Columbia Centre of Excellence for Women's Health.
- Browne, A. J., & Varcoe, C. (2006). Critical cultural perspectives and health care involving Aboriginal peoples. *Contemporary Nurse*, 22(2), 155-167.
- Buchan, J., & Calman, L. (2005). *The global shortage of registered nurses: An overview of issues and actions*. Geneva, Switzerland: International Council of Nurses.
- Canadian Nurses Association (2008). *Code of ethics for registered nurses*. Ottawa, ON: Author.
- Carspecken, P. F. (1996). *Critical ethnography in educational research: A theoretical and practical guide*. New York: Routledge.
- Chen, L., Evans, T., Anand, S., Boufford, J. I., Brown, H., & Chowdhury, M. (2004). Human resources for health: Overcoming the crisis. *Lancet*, 364, 1984-1990.
- Clarke-Jones, J. (2004). Moving forces. *Nursing Standard*, 18(30), 12-14.
- Cook, K. E. (2005). Using critical ethnography to explore issues in health promotion. *Qualitative Health Research*, 15(1), 129-138.
- Creswell, J. W. (2007). *Qualitative inquiry and research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage.
- Dion Stout, M., & Downey, B. (2006). Nursing, Indigenous peoples and cultural safety: So what? Now what? *Contemporary Nurse*, 22(2), 327-332.

- Fournier, B., Kipp, W., Mill, J., & Walusimbi, M. (2007). Nursing care of AIDS patients in Uganda. *Journal of Transcultural Nursing, 18*(3), 257-264.
- Garbus, L., & Marseille, E. (2003). *HIV/AIDS in Uganda*. San Francisco: AIDS Policy Research Center, University of California.
- Gray, D. P., & Thomas, D. J. (2005). Critical analysis of "culture" in nursing literature: implications for nursing education in the United States. *Annual Review of Nursing Education, 3*, 249-270.
- Gray, D. P., & Thomas, D. J. (2006). Critical reflections on culture in nursing. *Journal of Cultural Diversity, 13*(2), 76-82.
- Gustafson, D. L. (2005). Transcultural nursing theory from a critical cultural perspective. *Advances in Nursing Science, 28*(1), 2-16.
- Hammersley, M. (1992). *What's wrong with ethnography?* London: Routledge.
- Hardcastle, M., Usher, K., & Holmes, C. (2006). Carspecken's five-stage critical qualitative research method: An application to nursing research. *Qualitative Health Research, 16*(1), 151-161.
- Harrowing, J. N. (2009). The impact of HIV education on the lives of Ugandan nurses and nurse-midwives. *Advances in Nursing Science, 32*(2), E94-E108.
- Harrowing, J. N., Mill, J. E., Spiers, J., Kulig, J., & Kipp, W. (in press). Culture, context, and community: Ethical considerations for global nursing research. *International Nursing Review*.
- Johnstone, M.-J., & Kanitsaki, O. (2007). Health care provider and consumer understandings of cultural safety and cultural competency in health care: An Australian study. *Journal of Cultural Diversity, 14*(2), 96-105.
- Johnstone, M.-J., & Kanitsaki, O. (2008). Cultural racism, language prejudice and discrimination in hospital contexts: An Australian study. *Diversity in Health & Social Care, 5*(1), 19-30.
- Kincheloe, J. L., & McLaren, P. (2005). Rethinking critical theory and qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (3rd ed., pp. 303-342). Thousand Oaks, CA: Sage.

- Lather, P. (1986). Research as praxis. *Harvard Educational Review*, 56(3), 257-277.
- Madison, D. S. (2005). *Critical ethnography: Method, ethics, and performance*. Thousand Oaks, CA: Sage.
- McGrath, P., & Phillips, E. (2008). Western notions of informed consent and indigenous cultures: Australian findings at the interface. *Journal of Bioethical Inquiry*, 5(1), 21-31.
- Nursing Council of New Zealand (2005). *Guidelines for cultural safety, the Treaty of Waitangi and Maori health in nursing education and practice*. Wellington, NZ: Author.
- Ogilvie, L. D., Burgess-Pinto, E., & Caufield, C. (2008). Challenges and approaches to newcomer health research. *Journal of Transcultural Nursing*, 19(1), 64-73.
- Polaschek, N. R. (1998). Cultural safety: A new concept in nursing people of different ethnicities. *Journal of Advanced Nursing*, 27(3), 452-457.
- Reimer Kirkham, S., & Anderson, J. M. (2002). Postcolonial nursing scholarship: From epistemology to method. *Advances in Nursing Science*, 25(1), 1-17.
- Rubin, H. J., & Rubin, I. S. (2005). *Qualitative interviewing: The art of hearing data* (2nd ed.). Thousand Oaks, CA: Sage.
- Smye, V., & Browne, A. (2002). 'Cultural safety' and the analysis of health policy affecting aboriginal people. *Nurse Researcher*, 9(3), 42-56.
- Smyth, W., & Holmes, C. (2005). Using Carspecken's critical ethnography in nursing research. *Contemporary Nurse*, 19(1-2), 65-74.
- The World Bank (2009). Country classification. Retrieved July 21, 2009, from <http://go.worldbank.org/K2CKM78CC0>
- UNAIDS (2008). *2008 report on the global AIDS epidemic*. Geneva, Switzerland: Author.
- Wallerstein, N., & Duran, B. (2003). The conceptual, historical, and practice roots of community based participatory research and related participatory traditions. In M. Minkler & N. Wallerstein (Eds.), *Community-based participatory research for health* (pp. 27-52). San Francisco: Jossey-Bass.

Williams, R. (1999). Cultural safety--what does it mean for our work practice?  
*Australian and New Zealand Journal of Public Health*, 23(2), 213-214.

## VI. Conclusion

This study was implemented in an effort to gain greater understanding of the impact of continuing education on nurses' lives. Lifelong learning is considered to be an essential activity for the provision of competent care and adherence to professional standards (International Council of Nurses [ICN], 2001). Certainly, the role of enhanced knowledge in the performance of nursing practice was considered an important focus of this research. However, professional practice is but one aspect of the larger context in which Ugandan nurses work and live. In addition to the overwhelming societal burden of the HIV epidemic, these participants also faced HIV illness at a personal level. Unlike the North American nurse, who may never be personally or professionally affected by the virus, study participants were touched at many levels each and every day, whether at work or at home. There was no way to separate personal from public, social from professional. Hence, I believed it was critical to explore multiple dimensions and perspectives in order to sculpt a rich and textured understanding of the experience of being a nurse in Uganda in such challenging and devastating times. The choice to use a critical focused ethnographic approach enabled me to pay attention to cultural nuances and meanings that not only intensified the complexities but sharpened the images, allowing me glimpses into a world that is both foreign and familiar, horrifying and awe-inspiring.

My most profound impression, upon completion of the study, centred on the strength and resiliency of the nurses who shared their stories with me. The juxtaposition of despair and hope, uncertainty and wisdom, sadness and optimism, inertia and energy was deeply moving and will continue to challenge my way of seeing the world. My understanding of HIV illness, once couched in terms of its physiological effects, has expanded significantly to the point where I now see it as "capable of achieving an impressive symbiosis with *Homo sapiens*, not just as a biological organism but also as a social collectivity" (de Waal, 2005, p. 113). As the epidemic continues to erode social, political, and economic systems in sub-Saharan Africa, the potential for a secondary disaster looms large. With adult life expectancy declining, the implications for loss of human capital in coming

generations are almost beyond one's imagination. The enormous number of AIDS orphans in Africa starkly foreshadows that disturbing aspect of the future landscape. HIV illness represents a massive disruption of the foundational structure of the continent's society and ecology, and its sequelae will continue to play out over the coming decades, if not longer.

As a country that was just beginning its recovery from the conflict and instability of the 1970s, Uganda was especially vulnerable to the catastrophe of HIV when the virus invaded the Rakai district in the early 1980s. Barnett and Whiteside (2006) cited the increased sexual risk-taking that reflected the need to survive during a period of political and economic collapse as one of the major factors that created an environment of susceptibility throughout the country. HIV spread rapidly, and some regions and age cohorts reported infection rates as high as 35% by the early 1990s (Barnett & Whiteside, 2006). Although the government responded aggressively in the early days of the epidemic, there are concerns that the momentum has slowed and attitudes have changed (de Waal, 2005; UNAIDS, 2008). Recent reports suggest that the current economic recession has resulted in a decrease in donor funding to Ugandan organizations that provide antiretroviral therapy (ART) distribution (Bogere, 2009). This is a dangerous state of affairs; given the lag time between infection of the individual and the development of AIDS, any lapse in the effort to address the situation will almost surely lead to calamity.

The scale-up of ART availability and accessibility over the past few years is beginning to show positive results; however, as the demand continues to increase, the capacity of distribution services will be severely tested. The epidemic imposes many challenges, risks, and threats to the health sector in resource-limited countries. An effective health infrastructure is as important as, if not more than, the availability of microbicides to prospects for halting the spread of the virus. The forces and factors that have created and prolonged the epidemic are complex, ubiquitous, and systemic, and will not be mitigated by simple or singular interventions.

It is generally agreed that the expansion and sustainment of treatment access in low- and middle-income countries (LMIC) requires the creation of a healthy and knowledgeable workforce (Samb et al., 2007; UNAIDS, 2008; World Health Organization [WHO], 2006). Provision of health care services is a labour-intensive undertaking, and the health of a nation cannot be advanced without sufficient health human resources. Registered nurses comprise a significant component of the necessary workforce. As frontline workers who have prolonged contact with patients, the ability to work across sectors of the health care system, and practice that is evidence-informed, nurses are considered essential to the success of any attempt to efficiently roll out ART (Buchan & Calman, 2005; Munjanja, Kibuka, & Dovlo, 2005). Thus, the current global shortage of registered nurses is considered a critical situation, one that is likely to worsen in the coming years and that will have a negative impact on health care if it is not addressed aggressively (Buchan & Aiken, 2008).

Strategies that have been proposed to address the nursing shortage in sub-Saharan Africa include increasing the supply and productivity of nurses; providing HIV treatment for nurses who are affected by the illness; improving retention and managing migration; and strengthening leadership and management capacity in nursing (Munjanja et al., 2005). The findings from this study provide evidence that supports several of these activities. Campbell (2006) suggested that continuing education is essential to the development of an effective nursing cadre in Uganda. The ICN (2001) noted that nurses require access to programs that will maintain their competence and support their advancement. Research participants indicated that not only did their involvement in the AIDS Support Organisation (TASO) program enhance their knowledge and ability to provide better care, it also provided increased job satisfaction and a new way of understanding the nursing profession. Their recognition of the value of education was clearly articulated in their frequent assertions that “education is the key.” This belief was lived out daily in their determination to make educational opportunities available for their colleagues and families, and their expressed hopes of someday being able to work on their own post-diploma and baccalaureate-level studies.

Participants' awareness of and interest in collective political action was inspired and fueled by their newfound confidence, which they attributed to the educational program. As they formed a cohesive group of counsellors and engaged in problem solving and professional conversations, an agenda began to develop that demonstrated the commitment of the nurses to health promotion endeavours in their communities. They expressed interest in encouraging the national nursing association to work with the health and other ministries to expand opportunities for nurses to engage in research, leadership, and education activities. They described a surge of optimism and energy that had been absent prior to the TASO program. They were anxious to engage in formal or informal teaching of their colleagues in an effort to raise the standard of care for patients with HIV. In addition, several participants made known their interest in implementing small research projects aimed at integrating HIV care into their communities. Together, we developed and submitted two research proposals while I was doing my fieldwork. Coming from an environment where educational opportunities are often taken for granted, I was impressed by the efforts invested by study participants in absorbing as much knowledge as possible from our interactions and joint projects.

The relatively small financial investment required to support this group of nurses through the educational program has paid dividends well beyond my expectations. Given the participants' hunger to learn and motivation to provide excellent care, it seems reasonable that funding agencies and organizations should be encouraged to offer this type of initiative. The WHO (2006) considers continuing professional education to be directly related to a more competent, responsive, and productive workforce. Patients receive better care and nurses enjoy greater job satisfaction. These outcomes are likely to enhance the retention of nurses in the local workforce and improve the prospects for recruiting new nurses into the system. Senior nurses, who may be less likely to migrate to other countries and who often enjoy high levels of respect and credibility among their peers, are choice candidates to assume leadership roles with regard to promoting professional development of their colleagues.

The issue of AIDS stigma permeates African society and directly affects choices and behaviours around HIV illness, disclosure, and treatment (Holzemer et al., 2007; Mill, 2003; Okafor & Holder, 2004; Uys et al., 2005). Ugandan society is no exception, nor are the nurses who cope with its manifestations daily. Participants in the study described their own reluctance to seek testing for themselves in the period prior to the TASO program, a choice that was attributed to the fear of repercussions from colleagues and family. Almost all of them, however, decided to learn their HIV status following the education. They believed it was important to set a good example for the patients with whom they worked. Participants were more confident of their ability to cope with the infection should they be seropositive, thanks to their new awareness of available resources. This is an important finding with regard to the wellbeing of nurses as individuals, and also for the overall health of the workforce. As a strategy to address the nursing shortage, identification and treatment of nurses who carry the virus is critical; however the challenge lies in having them come forward for testing. This study shows once again that education results in outcomes that benefit nurses at several different levels.

Participants' narratives around the experience of moral distress and suffering offered a unique perspective about the phenomenon that has not been explored in the nursing literature. Although similarities existed between the Ugandan descriptions and reports from the North American and European research, there were significant differences that at first glance might seem surprising. Ugandan nurses spoke passionately about their commitment to their patients as well as their profession, and of their profound regret at not being able to serve either well due to circumstances largely beyond their control. There was a much greater emphasis on the collective impact of systemic challenges and the complex chain of events that resulted in nurses' acts of omission regarding patient care. The focus was less on the individual's symptoms of distress, and more on the broader implications. Finally, the participants emphasized the ways in which their interventions were able to contribute in a positive, albeit small, way. An observer might expect Ugandan nurses to be completely overwhelmed and filled

with a paralyzing despair, given the circumstances, yet these nurses maintained a hopeful, but realistic perspective that enabled them to carry on from one day to the next. Furthermore, participants' engagement in the creation of strong relationships with patients enabled them to preserve moral integrity while mitigating the potential negative effects of a difficult situation.

### **Implications for Nursing**

The findings of this study have significance for nursing research and practice on several levels. First, the conduct of research in LMIC by individuals from high-income countries requires careful attention to and awareness of ethical and cultural concerns. Researchers must be prepared to engage community members in discussions about the relevance of the question and negotiate in good faith the processes and protocols for interacting with participants and reporting findings. When the researcher is unfamiliar with the culture and context in which the study will take place, it is essential to make every effort to demonstrate respect and humility in the approach. An attitude of "gentle curiosity" and willingness to learn are helpful characteristics that will facilitate the formation of effective partnerships, an atmosphere of trust and security, and the collection of quality data. Offering assistance and expertise in return for the participants' investment of time and effort will further strengthen the relationship. Researchers must consider their obligation to promote social justice and correct inequities in the framing and execution of the study. Paramount is the need to protect the safety and wellbeing of participants; this goal can be achieved by reflecting on one's own biases and assumptions, making the effort to understand the beliefs and practices of participants, and taking nothing for granted. Attention to these details will preserve and protect the integrity of both researcher and participant and will promote understanding and appreciation of each other's perspectives.

Although it is highly improbable that the HIV pandemic will be resolved in the near future, multiple interventions at many levels have the potential to mitigate some of the horrendous effects of the virus. The findings from this study demonstrated that education of nurses is one small contribution that may have synergistic and far-reaching effects. A simple and relatively inexpensive

investment not only allowed nurses to provide essential care, but also empowered them to explore collective strategies to extend their capacity for higher level interventions. Change at the individual level may ripple out to colleagues and other community members, creating increased capacity, awareness, and motivation to influence larger systems. Furthermore, the delight of participants at the realization that they could apply basic skills to a wide range of nursing problems and observe successful outcomes for patients was a joyful event in an otherwise sombre situation.

New evidence about the experience and manifestation of moral distress has implications for our understanding of the phenomenon on a global level. There are lessons to be learned from the unique perspectives of these participants regarding the identification, interpretation, and management of the situations that result in such distress. The relational aspects of moral distress and its context, although in need of further study, may offer helpful strategies for meliorating or preventing its occurrence in health care settings. For example, there may be elements of nursing practice or setting that support, rather than obstruct, nurses in the collective enactment of their professional values. These need to be identified and exploited. Moral distress also has been associated with the challenges of recruitment and retention of nurses; the response of Ugandan participants to its role and effects may be instructive for those who plan and manage nursing workforces in high-income countries.

Cultural safety in nursing education and practice has taken on increasing relevance and importance in the literature in recent years, especially as it applies to the care of Indigenous people or newcomers to the researcher's home country (Anderson et al., 2003; Dion Stout & Downey, 2006; Ogilvie, Burgess-Pinto, & Caufield, 2008). Its role in nursing research generally, and in countries to which the researcher is a visitor specifically, has been notably absent from the discussion. Analysis of the congruence between critical methodology and cultural safety demonstrated that research studies conducted in international settings could benefit from the design of protocols that recognize, attend to, and respect the cultural values and beliefs of participants. The critical ethnographer acknowledges

his/her 'outsider' status when conducting research in a culture or setting that is unfamiliar or different from his/her own. Extending that awareness to include purposeful attempts to bring to the foreground aspects of the participants' culture that might influence the research process and outcomes is a logical next step.

It is also important to reflect on those instances in which the researcher must be respectful of norms and traditions and might wish to refrain from being critical in order to avoid undue embarrassment or exposure of participants. For example, although the researcher might feel an urgent need to share details of hospital conditions with the audience, it may well be at great cost to the people who work under those conditions and to the relationship between researcher and participants. It is essential that researchers as well as participants develop a capacity for agency; by recognizing our own contributions to liberate through research, we may find that we "perpetuate the relations of dominance" (Lather, 1991, p. 16). A discussion about cultural safety may facilitate some resolution to this situation and contribute to the wellbeing of participants and researcher alike, as well as the overall quality of the data and its interpretation.

### **Recommendations for Further Research**

This study is relevant to nursing research and practice insofar as it demonstrates that a group of nurses can initiate change when motivated to do so. It also highlights the many possibilities for further research that will contribute to our understanding of nursing's role in addressing the massive challenges arising from the HIV pandemic. Interdisciplinary approaches may offer valuable opportunities to consider complex issues from a range of perspectives and may result in robust findings that have strong potential for application. As well, the use of critical qualitative methodology provides many opportunities to explore and expose historical, political, and social inequities that contribute to the phenomenon of interest. In so doing, the researcher engages in the process of creating knowledge that transforms the enterprise of research as well as the world. Research becomes a political process for creating relationships with the knowers in the community, thereby leading to social change that is in their interests.

Nursing education offers a broad platform for a wide range of research activities. Intervention projects that explore effective ways of disseminating essential knowledge and skills to both experienced and novice nurses would provide important information for expanding nursing services and assigning roles. Given the perceived existence of cultural boundaries around the status and credibility of caregivers when discussing issues of sexuality and health, for example, it would be useful to know the possibilities and limitations associated with variables such as gender, tribal affiliation, and age when addressing HIV issues.

Participants in this study offered many ideas for further investigation of realistic and effective interventions to promote quality care related to prevention and treatment of HIV illness. In particular, building on the prevailing sense of collective responsibility for extended family and neighbours, there are vast opportunities to test strategies for creating networks of caregivers within the community that are culturally appropriate and effective. Nurses are in an excellent position to provide leadership in such efforts and can contribute expertise and coordination skills as well as essential local knowledge to the planning of such projects. Nurses also have intimate awareness of the needs of the community and enjoy positions of respect within their family networks that would facilitate the design and implementation of creative interventions.

Nurses have extensive knowledge of the intersections between the needs of patients and the resources of the health care system, and could offer valuable insights related to the best way to bring the two together efficiently. Unfortunately, they lack significant presence and effective voice within the system. However, providing opportunities for education and collective action may evoke change that contributes to an environment in which nursing knowledge and expertise can be better exploited. Research protocols such as the mentorship and training components offered by Edwards and colleagues (2009) invite and support nurses' involvement in such interventions and almost certainly will facilitate creative approaches to the building of capacity among members of the profession.

### References

- Anderson, J. M., Perry, J., Blue, C., Browne, A., Henderson, A., Basu Khan, K., et al. (2003). "Rewriting" cultural safety within the postcolonial and postnational feminist project: Toward new epistemologies of healing. *Advances in Nursing Science*, 26(3), 196-214.
- Barnett, T., & Whiteside, A. (2006). *AIDS in the twenty-first century: Disease and globalization* (2nd ed.). New York: Palgrave Macmillan.
- Bogere, H. (2009, July 5). AIDS crisis: Patients turned away as drugs dry up. *The Observer*. Retrieved July 29, 2009 from [http://www.observer.ug/index.php?option=com\\_content&view=article&id=4133:aids-crisis&catid=78:topstories&Itemid=59](http://www.observer.ug/index.php?option=com_content&view=article&id=4133:aids-crisis&catid=78:topstories&Itemid=59)
- Buchan, J., & Aiken, L. (2008). Solving nursing shortages: A common priority. *Journal of Clinical Nursing*, 17(24), 3262-3268.
- Buchan, J., & Calman, L. (2005). *The global shortage of registered nurses: An overview of issues and actions*. Geneva, Switzerland: International Council of Nurses.
- Campbell, S. (2006). Addressing nursing shortages in sub-Saharan Africa. *Nursing Standard*, 20(51), 46-50.
- de Waal, A. (2005). The challenge of HIV/AIDS. In B. Wisner, C. Toulmin & R. Chitiga (Eds.), *Towards a new map of Africa* (pp. 113-131). London: Earthscan.
- Dion Stout, M., & Downey, B. (2006). Nursing, Indigenous peoples and cultural safety: So what? Now what? *Contemporary Nurse*, 22(2), 327-332.
- Edwards, N., Webber, J., Mill, J. E., Kahwa, E., & Roelofs, S. (2009). Building capacity for nurse-led research. *International Nursing Review*, 56, 88-94.
- Holzemer, W. L., Uys, L. R., Makoae, L. N., Stewart, A., Phetlhu, R., Dlamini, P. S., et al. (2007). A conceptual model of HIV/AIDS stigma from five African countries. *Journal of Advanced Nursing*, 58(6), 541-551.
- International Council of Nurses (2001). *Position statement: Ethical nurse recruitment*. Retrieved July 22, 2009, from <http://www.icn.ch/psrecruit01.htm>

- Lather, P. (1991). *Getting smart: Feminist research and pedagogy with/in the postmodern*. New York: Routledge.
- Mill, J. E. (2003). Shrouded in secrecy: Breaking the news of HIV infection to Ghanaian women. *Journal of Transcultural Nursing, 14*(1), 6-16.
- Munjanja, O. K., Kibuka, S., & Dovlo, D. (2005). *The nursing workforce in sub-Saharan Africa*. Geneva, Switzerland: International Council of Nurses.
- Ogilvie, L. D., Burgess-Pinto, E., & Caufield, C. (2008). Challenges and approaches to newcomer health research. *Journal of Transcultural Nursing, 19*(1), 64-73.
- Okafor, C. B., & Holder, B. (2004). HIV/AIDS related stigma in sub-Saharan Africa: Context and consequences. *International Journal of Global Health, 3*(1), 20-34.
- Samb, B., Celletti, F., Holloway, J., Van Damme, W., De Cock, K. M., & Dybul, M. (2007). Rapid expansion of the health workforce in response to the HIV epidemic. *The New England Journal of Medicine, 357*(24), 2510-2514.
- UNAIDS (2008). *2008 report on the global AIDS epidemic*. Geneva, Switzerland: Author.
- Uys, L. R., Chirwa, M., Dlamini, P., Greeff, M., Kohi, T., Holzemer, W. L., et al. (2005). "Eating plastic," winning the lotto," "joining the WWW". . . Descriptions of HIV/AIDS in Africa. *Journal of the Association of Nurses in AIDS Care, 16*(3), 11-21.
- World Health Organization (2006). *Working together for health: The world health report 2006*. Geneva, Switzerland: Author.

## Appendix A

### Research Information Sheet

**Title of Research Study:** “The Impact of Educational Training for Nurses Providing AIDS Care in Uganda”

**Principal Researcher:** Jean N. Harrowing, doctoral student  
Faculty of Nursing, University of Alberta, Edmonton, Canada

**Supervisor:** Dr. Judy Mill, Faculty of Nursing, University of Alberta

**Uganda Contact:** Mrs. Mariam Walusimbi, Mulago Hospital, Kampala

**Background:** I am doing this research study as a doctoral student in the Faculty of Nursing at the University of Alberta. The study is about the impact of education for nurses who provide care to people infected or affected by HIV. You are being asked to take part because I believe that you have knowledge about this topic.

**Purpose:** The purpose of this study is to explore the effects of an HIV education program on a group of nurses and midwives who provide care to people in Uganda. By listening to and watching you, I will learn more about how nurses and midwives care for people and attend to the duties and activities of everyday life.

**What Will Happen:** Taking part will involve one or more interviews (likely 2 to 4), each lasting up to 2 hours. I will ask questions about how you do your work. With your consent, I will record our conversations. You may request that the recorder be shut off at any time. I may also observe you or participate with you in your work as well as in your activities outside of work. I will take notes at times about the things that I am observing and feeling.

**Confidentiality:** Any information that is collected from you will remain private. I will not reveal the names of any people interviewed in any verbal or written account of the research. All information will be held confidential or private, unless professional codes of ethics or the law require reporting. The data you provide will be kept for at least seven (7) years. The information will be kept in a secure area (i.e., a locked filing cabinet) in my office at the University of Lethbridge, Canada. Your name or any other identifying information will not be attached to the information you give. Your name will never be used in any public release of the study results. The information gathered for this study may be used again in the future to help us answer other study questions. If so, an ethics board will first review the study to ensure the information is used ethically.

**Possible Benefits:** The benefits that you may receive as a result of taking part in this study include the chance to contribute to our understanding about nursing care of people with HIV disease. The research process may also enable you to reflect on factors that influence your practice.

**Possible Risks:** Other than taking up some of your time, I believe there are no risks to you from your participation in this study. Should you feel distressed as a result of our discussions, I will refer you to a counselor.

**Voluntary Participation:** Taking part is entirely your choice. You are not required to participate in this study. If you decide to participate and then change your mind, you are free to withdraw at any time. Further, you may refuse to answer any questions asked of you during the research. You may refuse to allow me to observe or share in your activities. I will record our discussions, but

you may request that the voice recorder be shut off at any time. Your decision to not answer a question or to withdraw from the study will not affect your job in any way. If at any time you have any questions about this study, please contact me. You may also contact my supervisor, Dr. Judy Mill, at the Faculty of Nursing, University of Alberta. We would be happy to address any questions you may have. Our contact information is included below. In the event you have concerns and would prefer to contact an individual who has no direct involvement with this study, please feel free to contact:

Mrs. Mariam Walusimbi, Mulago Hospital, Kampala, Uganda. Phone 256-41-540440.

Sincerely,

Jean Harrowing

<p>Jean Harrowing, RN, MN, PhD(c)          Doctoral Student          Faculty of Nursing          University of Alberta          Mobile: 0782733652          Email: <a href="mailto:jnharrow@ualberta.ca">jnharrow@ualberta.ca</a></p>	<p>Mrs. Mariam Walusimbi          Mulago Hospital          Kampala, Uganda          Phone: 256-41-540440</p>	<p>Dr. Judy Mill          Faculty of Nursing          University of Alberta          Phone: 780 492 4338          Email: <a href="mailto:judy.mill@ualberta.ca">judy.mill@ualberta.ca</a></p>
---	--	---

## Appendix B

### Consent Form

**Project Title:** “The Impact of Educational Training for Nurses Providing AIDS Care in Uganda”

**Principal Researcher:** Jean N. Harrowing, doctoral student  
Faculty of Nursing, University of Alberta  
email: [jnharrow@ualberta.ca](mailto:jnharrow@ualberta.ca) Mobile: 0782733652

**Supervisor:** Dr. Judy Mill, Faculty of Nursing, University of Alberta  
email: [judy.mill@ualberta.ca](mailto:judy.mill@ualberta.ca) Phone: 780 492 4338

**Uganda Contact Information:** Mrs. Mariam Walusimbi, Mulago Hospital  
Phone: 256-41-540440 Mobile: 0772349699

Please read the questions below and answer the question by placing your initials in the appropriate column on the right:	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 this study?		
Do you understand that you are free to withdraw from the study at any time, without having to give a reason?		
Has the issue of confidentiality been explained to you?		
Do you understand who will have access to the information?		

This study was explained to me by: \_\_\_\_\_.

*I agree to take part in this study.*

Signature of Research Participant	Date
Printed Name	Witness

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

Signature of Principal Researcher	Date
-----------------------------------	------

*The information sheet must be attached to this consent form and a copy given to the research participant.*

## Appendix C

### Interview Guide

1. Please tell me how you came to be a nurse (midwife).
  - a. At what age or time in your life did you decide to pursue this profession?
  - b. What factors influenced your choice?
  - c. What type of program did you choose?
  - d. How satisfied have you been with your choice?
  - e. What would you have done differently, if you could?
  
2. Tell me about your employment as a nurse (midwife).
  - a. What type of jobs/positions have you had?
  - b. What were your expectations about working as a nurse (midwife)?
  - c. Were your expectations met?
  - d. What job brought you the most satisfaction? Why?
  - e. What job brought you the least satisfaction? Why?
  
3. Tell me about a typical day in your work setting.
  - a. How many patients do you see?
  - b. What is the nature of your nursing care?
  - c. What are your responsibilities?
  - d. What policies, standards, legislation, etc. guide your practice?
  - e. At the end of the day, how do you feel about the care that you have provided?
  
4. Tell me about the TASO course you attended.
  - a. What did you hope to learn from the course?
  - b. What about the course challenged you?
  - c. What about the course disappointed you or failed to meet your expectations or needs?
  - d. How will you apply your learning to your practice?
  - e. Is there anything further that you would like to learn?
  
5. What issues or challenges do you face in your current job/position? Please describe.
  - a. What opportunities do you have to overcome those challenges?
  - b. Do your co-workers share your perspective about these issues?
  - c. How do people generally feel about the potential to resolve these issues?

6. What is it like to care for people with HIV in this setting?
  - a. What works well?
  - b. What doesn't work well?
  - c. What do you need to be able to better care for people with HIV?
  - d. What systems/resources are in place to care for people with HIV?
  - e. Do people with HIV receive good care?
  
7. Tell me about your life, outside of your job.
  - a. Household arrangements (e.g., home, income, partner, children, etc.)?
  - b. Extended family relationships?
  - c. Connections and interactions with neighbours, friends?
  - d. Roles (e.g., wife, mother, daughter, etc.)?
  - e. Practices and beliefs (e.g., religious/spiritual, cultural traditions, etc.)?
  - f. Activities and interests?
  - g. Perception of status as a nurse (midwife) at work and outside of work?
  - h. Volunteer activities?
  - i. Other?
  
8. Describe your relationship with co-workers.
  - a. What other disciplines are involved in providing care to people with HIV?
  - b. How do you communicate with these co-workers?
  - c. How is care managed?
  - d. Who is in charge?
  - e. What challenges do you face in working with these colleagues?
  - f. What are the benefits of working with these colleagues?
  - g. How do you know when you have done a good job?
  
9. Tell me about the health care system in Uganda.
  - a. What resources are in place to provide care to people with HIV?
  - b. What challenges does the system face in providing care?
  - c. What are the strengths of the system?
  - d. What is needed to improve the health care system?
  - e. What role is played by each member of the health care system (including traditional practitioners)?