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Harrowing, Jean N.

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Culture, context and community: ethical considerations for global nursing research

J.N. Harrowing¹ RN, PhD, J. Mill² RN, PhD, J. Spiers² RN, PhD, J. Kulig³ RN, DNSc & W. Kipp⁴ MD, MPH, PhD

¹ Assistant Professor, ² Associate Professor, ³ Professor, Faculty of Nursing, ⁴ Professor, School of Public Health, University of Alberta, Edmonton, Alberta, Canada


High-quality research is essential for the generation of scientific nursing knowledge and the achievement of the Millennium Development Goals. However, the 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 paper was to examine the ethical principles and considerations that guide health research conducted in international settings using the example of a qualitative study of Ugandan nurses and nurse-midwives by a Canadian researcher.

The 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. The 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.

Keywords: Capacity Building, Developing Countries, Nursing, Qualitative Methods, Research Ethics

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 & 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 et al. 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 paper, we 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, we 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 treat illness. Finally, we 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 the first author’s 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 6-month programme to improve their skills and knowledge around counselling, 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 programme in June 2006 and concluded 2 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, we expected 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 their participation in the programme enabled them to address many challenges that interfered with their ability to provide quality care to people with HIV. They envisioned new possibilities for themselves as holistic and collaborative carers, with a greater capacity to positively influence service delivery and patient outcomes. They also came to understand the power of education to motivate and prepare 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 without jeopardizing the privacy, dignity and safety of the participants? How might the project be designed to build capacity among the 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), protects the rights of vulnerable populations (Smith 2008) and emphasizes 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 an 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 & 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 et al. 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 et al. 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 a 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 programme. 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, the first author 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
Although these conditions may be found in the researcher’s own pants (Joint United Nations Programme on HIV/AIDS 2000). To prevent the 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 was drawn. Any intervention that proves successful needs to be affordable and sustainable for community members.

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 a 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 that the informed consent be viewed as a dynamic, ongoing process (CIHR et al. 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 the first author made an initial trip to Uganda to ask the potential participants themselves about their interest and willingness to engage in the project with her.

An observation during the first author’s 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 the first author was confident that the consent process and the research participants’ rights were understood clearly. This experience reinforced the 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-styled 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 the 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 was 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 he or she should be aware of the health and other needs of the population so that a sensitive and appropriate study can be designed (Ketefian 2000). Also, 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 a fundamental disagreement in such an evaluation (Olsen 2003). The participants in this study consistently indicated the positive
impact of the education programme on their personal, professional and social lives and demonstrated their motivation to advocate for their peers and clients by promoting access to the programme for all nurses. They described in detail their new conceptualization of the nursing practice and the 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. The participants did not identify any unsatisfactory or troubling outcomes of the education programme 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 the researcher’s ongoing contact with them and support for their plans for interventions, research and continuing education as evidence that she was interested in and committed to building their capacity for enhanced practice. They indicated that through reflection and discussion with her and each other about their practice and the effects of the education programme, they gained a new understanding of the skills and knowledge that could be used to promote health and well-being in their communities; they considered this to be the researcher’s 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 the 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 (van de Mortel 2008; Smith & Ellingson 2002). Given the sensitive nature of the questions, along with the cultural and other differences between the researcher and the 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 the access to the education programme and the participants may have resulted in attempts to make a good impression on the researcher by providing only positive feedback. Strategies employed to counteract such effects included prolonged engagement, clear commitment by the researcher to assist the participants to develop their own projects and advance their own practice, the use of process consent, periodic discussions with the participants about my interpretation of the findings, and sensitivity to political and cultural issues. As the relationship developed, the concerns about SDB diminished. The participants freely disclosed personal issues and experiences that gradually opened their world to the researcher. 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 developed plans for extending the educational opportunities to their colleagues. Eventually, some of them began to generate their own research questions and asked 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 to. 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 the 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 her. Conversation with the administrator about the research process and findings during the course of data collection and analysis was strictly avoided. The researcher’s understanding and interpretation of the data were discussed with the participants at several points to keep them informed, ensure accuracy and develop the 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 efforts to seek, hear and incorporate their feedback, and the candour of the participants was enhanced as they became accustomed to the researcher’s 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. The dissemination of those findings may cause some embarrassment or humiliation for the participants. The researcher is faced with a dilemma: publish the findings to facilitate a 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 a betrayal of trust. This is a most complex and distressing situation for all concerned and requires a careful and thorough discussion to clarify misunderstandings and
expose agendas. A paper in which the first author described the resource shortages and difficult conditions under which Ugandan nurses worked was interpreted as a criticism of the hospital’s health-care services by the nurse administrator. After discussion of the reasons behind the use of critical qualitative methodology and the intended audience (primarily non-LMIC readers), she indicated a clearer understanding of the aim. Some of the details that she found particularly discomfiting were omitted and the language made more tentative to indicate that the comments were based on observations of a small number of worksites. Thus, we were able to come to a resolution that allowed the first author to pursue the 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, focusing instead on individual rights. Dresden et al. recommended the 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 the 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, is 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 the 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, the senior administrative staff of the hospital as well as leaders of the nursing and medical programmes. Finally, the participants were engaged in conversations about the 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 the 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 earlier, 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 towards paternalism that 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. The first author worked with several of the nurses to develop small research and community development proposals based on needs they identified. Creating opportunities for the expansion of nurses’ capacity to participate in research activities has been identified as an essential strategy to enhance the effectiveness of health policy and improve the quality of care in LMIC (Edwards et al. 2009).

Conclusion
The 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 inte-
grates 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 behoves 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 an illness in order to eliminate inequities between the haves and the have-nots. The 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, what is 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 people 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 mitigated 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 & Whiteside (2006) implore us to recognize the significance of the African concept of ubuntu as we work together to reduce the impact of the 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 the members of society, in particular the vulnerable and marginalized, to improve health and promote justice for the benefit of everyone.

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Author contributions
J.N. Harrowing conducted the research study, and prepared and revised the study based on feedback from the supervisory committee. J. Mill is the doctoral supervisor; she facilitated the research process, assisted with the conceptualization of the project, consulted on the style and content of the paper, and provided feedback on the paper. J. Spiers, J. Kulig and W. Kipp were supervisory committee members; they assisted with conceptualization of the project and provided feedback on the manuscript.

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