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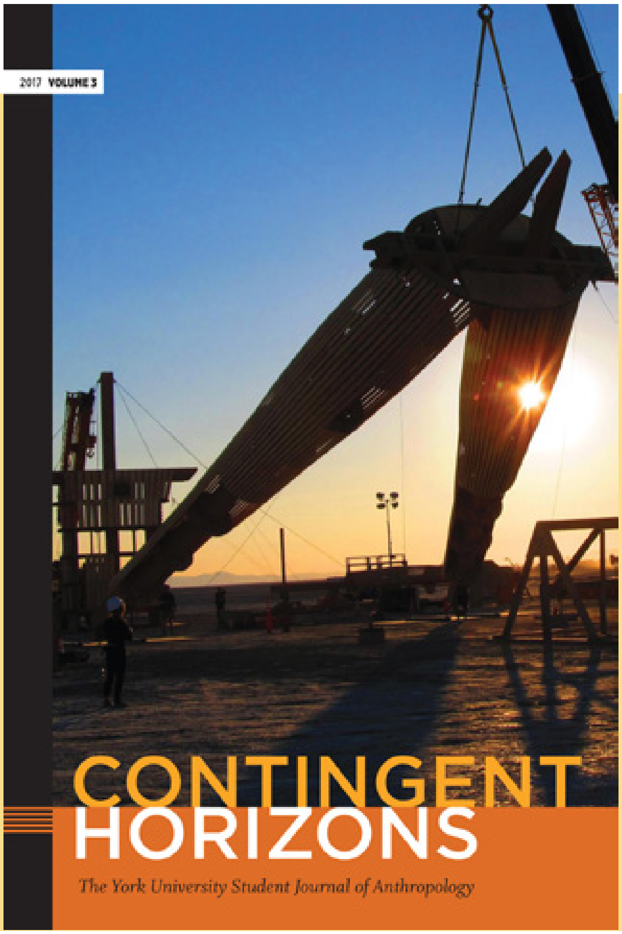
# A Guide for Graduate Students: Barriers to conducting qualitative research among vulnerable groups

Priscilla Medeiros

PhD Candidate | McMaster University, Hamilton, Canada



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# A Guide for Graduate Students

## Barriers to conducting qualitative research among vulnerable groups

**PRISCILLA MEDEIROS**
PHD CANDIDATE | MCMASTER UNIVERSITY, HAMILTON, CANADA

This paper will explore the challenges graduate students may encounter when working with socially vulnerable groups in the field. It is written from the perspective of a current graduate student and draws on her ethnographic experiences in Nairobi Province, Kenya, to provide some modest advice to other researchers. Particular attention is paid to some of the more common challenges students may encounter in the field working with vulnerable groups such as research design, ethical considerations, and participant recruitment and retention. This article concludes with a framework through which to study these groups.

**KEY WORDS** Anthropology, social sciences, vulnerable, vulnerable populations, conceptual model

Social science disciplines including but not limited to anthropology, sociology, health studies, and social work often work with vulnerable groups in an attempt to reduce health disparities. Conducting studies involving vulnerable groups has traditionally been confined to factors such as low socioeconomic status or individuals with poor psychological, physical, or social health (Flaskerud and Winslow 1998). Current approaches to classifying vulnerable groups fail to consider the social dimensions of vulnerability that affect individuals such as stressors like abuse and social exclusion (Nyamathi et al. 2007). Since the 1980s, there has been a growing body of literature in the social sciences on the concept of vulnerability in an attempt to create a conceptual framework for defining this term (Brooks 2003; Nichiata et al. 2008). Anthropology continues to be underrepresented in the literature pertaining to the critical discussion of vulnerable groups (Fluehr-Lobban 2013; Hedican 2016). Why is the concept of vulnerability under-studied in the anthropological literature and what is the future direction of anthropology in relation to this topic?

This paper will explore the challenges graduate students may encounter when working with socially vulnerable groups, and in doing so, will contribute to a more nuanced definition of the concept of vulnerability and provide a framework through which to study these groups. The article does not exhaust all the challenges a student may encounter in the field, but illustrates the more common barriers to conducting research involving vulnerable groups. Some of the examples in this paper draw on my experiences working with women living with HIV and AIDS in Nairobi Province, Kenya, during my master's

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research. I employ Flaskerud and Winslow's (1998) vulnerable populations conceptual model (VPCM) to examine the challenges researchers encounter in the process of data collection and to explore how these challenges affect research design, participant recruitment, and retention. The VPCM assesses the relation between resource availability and relative risk to an individual's health status (Flaskerud and Winslow 1998). Further explanation of this model can be found in the previously cited article. This paper will argue that the challenges encountered by qualitative researchers studying vulnerable groups are overcome by collaborative efforts and ongoing dialogue between researchers and the participants involved in the study.

## Defining vulnerability as a concept in the social sciences

There are many working definitions for the term vulnerability, but the more common frameworks within the social sciences revolve around the intersection of spaces of vulnerability (Delore and Hubert 2000), the concept of vulnerability (Rogers 1997), a theory of reasoned action (Jemmott and Jemmott 1991) and the common sense model of illness danger (Leventhal et al. 1980). These approaches all define vulnerable groups similarly according to their social status, family structure, marital status, and human capital. Defining vulnerable groups as people who are less fortunate fails to address the broader macro level factors that place an individual at an increased level of risk or vulnerability in a given society. According to Sengupta et al.,

> [these frameworks are] too narrow and too broad in scope; too narrow because it does not take into account other factors that lead to vulnerability … and too broad because some individuals … are not vulnerable in certain types of research. (2010:1313)

Alternatively, Flaskerud and Winslow (1998) use VPCM as a population-based framework to explain adverse outcomes like premature mortality, comparative morbidity, and diminished quality of life. This conceptual framework remains relevant to current research related to health because it expands on the knowledge and skills relevant to the care of vulnerable populations.

Flaskerud and Winslow's (1998) model is composed of three concepts: resource availability, relative risk, and health status. *Resource availability* is conceptualized as the availability of socioeconomic and environmental resources (i.e. human capital and social status) for the assessment of vulnerability to health disparities (Nyamathi et al. 2007). A lack of resources, such as social connectedness, unemployment, and the inability to access healthcare services, leads to an increased relative risk (Flaskerud and Winslow 1998). *Relative risk* refers to the vulnerability of different groups to various health disparities resulting from behavioural or lifestyle practices and biological susceptibility (Nyamathi et al. 2007). For example, rising rates of HIV infection among women globally is dependent on attitudes toward sex and sexual health or contraceptive responsibility that will influence an individual's underestimation or overestimation of infection (Akwara et al. 2003). A lack of resources will also increase relative risk.

During my master's fieldwork in Nairobi Province, Kenya, I observed the cultural resistance to sexual education for adolescents. Sex and sexuality issues remain taboo and are only discussed among peers. Cultural silence about sexual health was encouraging sexual curiosity, experimentation, and promiscuity among adolescents, especially men. As a researcher at a religious health facility in rural Kenya, access to basic healthcare is limited and the absence of sexual health education focusing on the various methods of contraception and safe sex activities, and the relative unavailability of contraceptives has led to rising rates of negative health outcomes like sexually transmitted infections. Finally, *health status* of a community correlates to patterns of increased morbidity and premature mortality in various population groups, which is informed by an individual's age and gender (Nyamathi et al. 2007). The existence of interrelationships among resource availability, relative risk, and health status in the VPCM highlights the complexity towards discerning who is vulnerable within each population. Flaskerud and Winslow's (1998) approach to studying vulnerable groups broadens analysis beyond more traditional methods of disease studies such as participant observation and interviewing. The community of study is also involved in the research design to better understand the experiences of vulnerable groups.

## Using a gendered perspective to study vulnerable groups

Inclusion of gender-based analysis in the study of vulnerability is beneficial to understanding the complex needs and sociocultural realities of groups recognized as vulnerable populations, including women and children. Gender-based analysis aims to understand the interrelationships that exist among variables and identifiers such as age, culture, ethnicity, race and sexuality (Prairie Women's Health Center of Excellence 2010). According to a number of scholars applying the health belief model (HBM) (Flaskerud and Winslow 1998; Rawlett 2011; Odhiambo 2012), gender is also an important factor in the study of vulnerable populations. The HBM framework is a psychological model that seeks to explain health behaviors by studying attitudes and beliefs of individuals. This analytical process suggests that gendered experiences of health disparities are different from one individual to another and requires a closer examination of the literature to implement effective strategies. In Nairobi Province, Kenya, I observed the gender roles ascribed to femaleness not only reinforce gender inequality, but also place women at an increased risk for the transmission of sexually transmitted infections. The use of condoms, for instance, was viewed as inappropriate in a marriage because women were expected to practice sexual monogamy.

Documenting growing inequalities using the gender-based analysis approach assists researchers to address the unmet needs of vulnerable groups, especially women (Bayoumi et al. 2011). For example, the Project for an Ontario Women's Health Evidence Based Report (POWER) focuses on a vulnerable population with the gender-based approach to assess women's health status in Ontario (Shiller and Bierman 2009). This study builds on previous women's health research to understand how health disparities are changing for women (Shiller and Bierman 2009). The authors of this report have provided a comprehensive examination of the health inequalities experienced by women in Ontario. It was clear in my own fieldwork that women's health disparities are always health inequalities.

However, the lack of consideration for cultural orientation in this study poses a challenge to assess this topic from a holistic perspective. This is also a practical barrier to performing meaningful research in the social sciences.

## Ethical considerations for studying a vulnerable group

Graduate students in the social sciences face a number of ethical challenges when conducting research with vulnerable groups including providing informed consent, maintaining confidentiality and privacy of collected data, and ensuring research ethics principles are upheld throughout the study. In spite of the development of ethical guidelines and protocols, such as review boards to ensure the protection of participant autonomy during research studies, maintaining ethical guidelines requires constant negotiation with mentors or supervisory committees to resolve any dilemmas encountered during the project.

### Research ethics boards

The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in the United States published the Belmont Report in 1979.[1] This report is still relevant and serves as the basis of scientific codes of conduct in Canada that review boards use to evaluate the integrity of research involving any human participant (Sutton et al. 2003). Ethical principles identified in the report include respect for autonomy, beneficence, non-maleficence, and justice. *Respect for autonomy* refers to the notion that a respondent's participation is voluntary and can be withdrawn at any point during the study (Allen 2002). Participants must be informed of the purpose of the study, potential risks, forms of information dissemination, and data collection processes. *Beneficence* refers to the outcomes respondents perceive will occur resulting from participation in the study (Allen 2002). *Non-maleficence* relates to the efforts of the researcher to minimize participation risks. This includes the avoidance of methodologies, research settings, and data analysis techniques that place respondents at risk for negative psychological and emotional consequences (Allen 2002). *Justice* refers to the responsibility of the researcher to protect the confidentiality, privacy, and integrity of the research process (Allen 2002). These principles have provided a framework for research ethics boards in addition to the Tri-Council (CIHR, NSERC, SSHRC) Policy Statement to create codes of professional ethics that evaluate the integrity of proposed studies.

In the context of HIV and AIDS research, ethics of data collection must also consider the Greater Involvement of People Living with HIV and AIDS (GIPA) principle. The GIPA report was developed in 1994 in an attempt to provide professional codes of ethics that pertain to maintaining the integrity of research conducted among people living with this disease (UNAIDS 2010). Although other guiding principles have been established to protect participants' autonomy, people living with HIV and AIDS endure a number of vulnerabilities such as stigmatization, which are not addressed by current protocols. The GIPA promotes the involvement of people living with HIV and AIDS in the decision-making processes of projects, similar to the methodological approach of participatory action research, in an attempt to address barriers to performing meaningful research with vulnerable groups (UNAIDS 2010). This aim is absent in previous guiding ethical principles like the Health Canada's Ethics Review Board.

Permission from community agencies is needed in some instances to gain access to respondents despite obtaining ethics board approval. Review board guidelines for health and social care research require standardization to account for the ethics in data collection in community-based research (CBR) (Franklin et al. 2012). Current research ethics boards assess the ethical acceptability of a research from the institution's standpoint, which has little to contribute to the people or communities under study. This approach fails to consider GIPA and CBR principles (Flicker et al. 2007). Flicker and colleagues (2007) conducted a content analysis of ethical guidelines for 30 academic institutions across the United States and Canada. Some of the institutions included Harvard School of Public Health, the John Hopkins Bloomberg School of Public Health, the University of British Columbia, and the University of Toronto. Findings from this study, suggest that current protocols are concerned with sample sizes, funding resources, recruitment strategies and privacy of collected data. According to Flicker et al.,

> No regard was given to the potential harm caused by recruiting a large number of individuals or in asking them to participate in a study…None asked about procedures for terminating a study or vetoing publication based on community concerns…none were designed with the intent that CBPR [or community-based research] protocols have flexible timelines because of their process-oriented nature. (2007:486)

To standardize the review of research projects, some studies suggest that research ethics boards require sensitivity training on the principles of community based research (CBR) and that the related documentation be revised to include discussions about the roles of the researcher, perceived community risks and decision-making processes (Flicker et al. 2007; Khanlou and Peter 2004). The CBR approach should be included in the standardization of ethical guidelines that health-related researchers follow while working with vulnerable groups. Awareness of the ethical guidelines for conducting research with human participants assists in the development of informed consent documentation. Obtaining informed consent from respondents presents a particularly significant challenge for researchers conducting studies with vulnerable populations.

Researchers are responsible for obtaining, documenting, and understanding that the respondent's participation is voluntary (Singer and Easton 2006; Chotiga et al. 2010). Obtaining informed consent is a concern when conducting studies that focus on vulnerable populations, especially among those with mental disorders or substance abuse problems. Informed consent is an ongoing process and is maintained by dialogue with respondents (Hutchinson et al. 1994). Levels of low literacy and comprehension pose a challenge for researchers to ensure that respondents are aware of the objectives of the study (Bayoumi and Hwang 2002). Alternative protocols are required such as the inclusion of professional translators and encouraging participants to express any concerns throughout the study, especially related to the perceived benefits and risks associated with involvement in the study. This allows researchers to address individual concerns related to the integrity of the study (Wendler and Grady 2008; Chotiga et al. 2010). According to one study, "the traditional method of seeking informed consent does not allow for consideration of the developmental nature of qualitative inquiry and the need for process consent"

(James and Platzer 1999:74). Current ethical guidelines pertaining to informed consent do not address the potential for harm that may occur to participants throughout the data collection process such as frustration and anxiety. It is the researcher's responsibility to employ the notion of informed consent as a process to protect the autonomy and integrity of participants (James and Platzer 1999).

During my fieldwork experience in Nairobi Province, it became clear to me that the existence of cultural taboos and societal stigmatizations associated with the HIV infection deterred women from informing their sexual partners about my study in the community. Some of the women in my study obtained permission from their partners before consenting to becoming involved in my study but soon afterwards withdrew after reporting their partners' discontent with the disclosure of information about their private lives. Emphasis of voluntary participation and withdrawal from the study were beneficial for the wellbeing of the participants and maintaining my rapport with the community.

Anthropologists and other social scientists can contribute to resolving ethical dilemmas related to working with vulnerable populations. Existing knowledge on anthropologists' experiences working with vulnerable groups can be used to address ethical dilemmas encountered in the fieldwork setting. Despite the existence of protocols to prevent or address ethical barriers, researchers also face a number of practical challenges during the data collection process.

## Practical barriers to conducting work with vulnerable groups

The nature of being a vulnerable participant has been well documented in the literature (Flaskerud and Winslow 1998; Guelder et al. 2012; Seidman 2013). Few academic publications discuss the vulnerabilities researchers, especially graduate students, encounter in the field while collecting data (Gregory et al. 1997; Paterson et al. 1999; McCosker et al. 2001). Researchers involved in qualitative research with vulnerable populations experience a number of practical barriers in the field, including building rapport with potential participants and addressing their own emotions or distress related to the undertaking of sensitive topics.

### Establishing a researcher-participant relationship

A lack of trust between potential participants and researchers resulting from historical experiences of exploitation poses many challenges to data collection processes among vulnerable groups. Dickson-Swift et al. (2007) suggests that reciprocity of disclosure assists researchers in establishing rapport with individuals involved in the study. *Reciprocity* in this context refers to the sharing of narratives between researcher and participants to reduce feelings of mistrust and lessen the hierarchical nature of the research process. Engaging in reciprocal disclosure may lead to participatory action such as the dissemination of findings in the form of a community-based report.

Researchers must be aware of how their identity disclosure has a strong influence on the study's process (Dickson-Swift et al. 2007). Although a researcher should fully disclose their identity in the fieldwork setting, lecture classes and supervisory committees do not often discuss the appropriate timing for disclosure to potential participants. During fieldwork in Nairobi Province, immediate disclosure of my identity as a qualitative researcher was met with fear and avoidance in the community. Many participants were uncertain of my role in their community as a social scientist in contrast to a nurse or doctor. Even after six months of fieldwork in a number of rural communities in Nairobi Province and participating in Kenyan customs, building trust and gaining access to the research field was difficult. The proper time to disclose a researcher's identity should be made on a case by case basis in consultation with a supervisory committee to avoid jeopardizing the potential for establishing rapport with community members or follow up research.

When working with vulnerable groups, collaborating with community members or peer-to-peer recruiters is advantageous in assisting with recruitment. This established relationship creates a sense of trust between both groups and helps graduate researchers overcome many of the practical and methodological barriers other disciplines encounter when studying the topic of vulnerability. There is potential for conflict between the dual roles of a community member serving as both peer recruiter and potential participant. Peer-to-peer recruiters attempting to fulfill the role of a community member while assisting with the study reinforce hierarchal power relations in the field, which may influence participants' decisions to become involved in the study. For instance, obtaining informed consent should be free of undue influence, including the professional nature of the researcher. Anthropologists and researchers from other disciplines studying topics in the clinical setting may encounter similar experiences in the field. A valuable lesson that I learned in conducting fieldwork in Kenya was to use my supervisory meetings to discuss and address practical barriers as they were encountered in the field.

## Vulnerable researchers in the field

In the course of conducting studies among vulnerable groups, researchers can experience harm to their emotional wellbeing (Nordentoft and Kappel 2011). Feelings of vulnerability for researchers often emerge after conducting a number of interviews focused on sensitive topics and dealing with issues related to data analysis. These feelings of emotional distress may negatively affect data collection processes and other aspects of participants' personal lives (Dickson-Swift et al. 2007). Nordentoft and Kappel (2011) document the vulnerabilities they encountered as researchers while conducting ethnographic research in the clinical setting. They argue that personal involvement with subjects or engaging in the act of sharing stories with participants is a barrier throughout the data collection process, which may produce emotional, psychological and social injury. One researcher documents the nature of their emotional state after the data collection process:

> I would often become choked with emotions during tearful interviews. These same emotional responses were repeated numerous times in the course of reviewing and transcribing the tapes and analyzing the data. I experienced anger, powerlessness, which resulted in sleep disorders and other somatic complaints that were similar to those voiced by informants. (Dunn 1991:390)

Maintaining professional relationships with gatekeepers (informants or peer-to-peer researchers) and participants can influence the outcome of the research study. To protect the integrity of the study, it sometimes is important for the researcher to maintain their identity as an outsider to reduce bias in the research as much as possible (Ramos 1989;

Dickson-Swift et al. 2007; Nordentoft and Kappel 2011). To ensure that these emotional responses do not solely influence the interpretation of qualitative data, some researchers suggest seeking social support from colleagues or mentors, participating in stress reducing activities (e.g., physical training) and recording journal entries detailing ongoing research activities (Dunn 1991).

Researchers are at risk of experiencing psychological and emotional distress during the research process. My fieldwork in Kenya was an emotionally challenging experience. Listening carefully and responsively to the illness narratives of women living with HIV in Kenya often brought me to tears in the field, a subject researchers often omit in their publications perhaps because the emotional reactions of researchers may be seen as unprofessional, inappropriate, or humiliating behaviour. Researchers like Davies and Spencer (2010) and Gross (2002) suggest that expressing strong emotions toward participants may in fact help to establish a researcher-participant relationship. Becoming aware of emotional triggers while studying sensitive topics and learning how to resolve these feelings is important to the ethical integrity of the study and of the researcher's wellbeing. Further research is required to address concerns related to developing an awareness of emotional appropriateness in the field and how to deal with emotional triggers when returning to field notes or research subjects' narratives.

## Methodological challenges in working with vulnerable groups

The difficulties of recruitment and retention in research focusing on sensitive topics, specifically in social sciences, are well documented in the literature (Chiang et al. 2001; Gemmill et al. 2012; Bonevski et al. 2014; van Wijk 2014). The challenges of recruiting potential participants are identified as the lack of trust between potential participants and researchers, difficulty in retaining recruited participants, and concerns related to data analysis techniques (Chiang et al. 2001; van Wijk 2014). Traditional methods of recruiting vulnerable groups such as peer-to-peer recruitment, online or flyer advertisements, and gatekeeper referrals are still relevant in current qualitative studies. Innovative research methodologies and data collection processes are needed for the examination of vulnerable groups.

### Recruitment of research participants

Building rapport with community agencies assists in defining and planning a study involving vulnerable groups, establishing research goals that are relevant to the population, and gaining a better understanding of the target population (Horowitz et al. 2002; Kavanaugh et al. 2006). The gatekeeper may or may not be a single person in the group under study. The role of the gatekeeper is to ensure that ethical principles for the research study are followed, help to refine the project if necessary, and to provide access to vulnerable populations. Benoit et al. (2005) proposes that vulnerable populations share the following characteristics: 1) vulnerable groups do not identify with traditional definitions of vulnerability; 2) identifying as part of a vulnerable group can lead to stigmatization, ostracism, and other forms of interpersonal rejection; and, 3) vulnerable populations avoid identity disclosure to non-members before establishing a researcher-participant relationship to avoid discrimination. Collaborative relations with gatekeepers assist to overcome these barriers and address the concerns of potential respondents before the data collection process.

Although the role of the gatekeeper in community research is critical to the success of the study, there are a number of problems encountered in developing these collaborative relationships. This includes issues of trust, beneficence and methods of data dissemination (Shoultz et al. 2006). Lee (1993) suggests that some gatekeepers may limit potential participants from research studies based on the concern of emotional or psychological harm and perceive little community benefit from participating in the study. The inclusion of community based agencies in the development of the research design allows gatekeepers to ensure that the beneficence of the community is upheld throughout the project, and creates ongoing dialogue between partnerships to alleviate any mistrust that may exist from participating in previous health studies.

Gaining access to vulnerable populations can be achieved with the help of gatekeepers and seeking social support from colleagues or mentors. Some researchers may also provide participants with appropriate reimbursement (e.g., cash or gift certificates) for their enrollment in the study and to acknowledge the value of participants' time. Participant payment raises a number of ethical issues pertaining to the individual's ability to make an informed decision (Sikweyiya and Jewkes 2013). The availability of financial incentives may be perceived as coercion in health-related studies with vulnerable populations (UyBico et al. 2007). It is the responsibility of research ethic boards to assess the ethicality or integrity of using financial incentives while working with vulnerable populations on a project-by-project basis.

## Retention of research participants

The use of incentives to recruit and retain participants may assist in the enrolment of potential respondents for sensitive research, but does not ensure that individuals involved in the study will fully disclose their stories to the researcher (Hadidi et al. 2013). Reasons for participant withdrawal from sensitive research studies are well documented in the literature (Raymond et al. 2004; Edwards 2005). It is important to be aware of the limitations of potential participants and integrate this knowledge in the final report. Some of the most frequently cited reasons for non-participation include lifestyle demands, lack of transportation, identity disclosure and time constraints (Hadidi et al. 2013). As mentioned previously, informed consent is an ongoing process. Maintaining open dialogue with participants throughout the study may address some of the concerns or fears for continuing their involvement. Hadidi et al. (2013:41) proposes "it is important not only to explain the study and the participant's obligations if he or she enrolls, but also to ask the participant to explain in his or her own words what participation in the study entails." The use of supervision or advisory committee meetings to discuss data collection processes, such as recruitment and retention protocols, can help in addressing some of the barriers researchers encounter after ethics board approval. Advisory boards also help graduate researchers address analytical and data integration problems.

## Data analysis procedures

Gatekeepers or community partners emphasize the need for research projects, specifically those involving vulnerable populations, to be accessible to the general public to improve public policy and service delivery. The term *accessible* refers to providing gatekeepers or community agencies with a summary of the study's findings in non-technical language (Beauvais 2006). Research framed strictly for academic purposes does not benefit potential respondents or the community nor does it meet beneficence principles maintained in ethical guidelines. This can hinder a researcher from accessing their population of interest (Beauvais 2006).

Conflicts of interest may arise during the interpretation and analysis of the collected data, and after the publication of the project findings. The involvement of a professional third party source to assist in transcription or data analysis processes poses a threat to the participants' autonomy, anonymity and confidentiality associated with the study. The research design and ethics proposal must be transparent about the inclusion of a third party source involved in the research study. This is to assure the validity and reliability of the collected data and project. Researchers are required to inform gatekeepers or community agencies and participants about the use of third party researchers to address any concerns related to the ethicality of this approach (Brannen 1988). The research ethics board must also authorize the inclusion of third party sources. The approved third party must provide informed consent for their role in the study and maintain the ethical principles identified by the funding institution. The inclusion of a third party source can be beneficial during the process of transcribing interviews. This can be a time consuming task for the researcher, especially when there are a large number of participants enrolled in the study. Benoit and colleagues (2005) recommend that, if a researcher chooses to include a third party source in the transcription phase of their data analysis, a spot check or review of the transcriptions must be conducted to ensure verbatim transcription of interview data. The *spot check* method refers to a random sampling of transcribed interviews to ensure a level of accuracy and consistency across the transcribed data (Benoit et al. 2005).

## Engaging in community-based research

Anthropological and other social sciences disciplines use the community-based research (CBR) approach as a strategy to develop trust and build rapport with communities and gain access to vulnerable populations (Shoultz et al. 2006). CBR is a growing approach in the social sciences to study vulnerable groups. This approach has evolved as a multidisciplinary framework to involve communities in the research decision-making process, evaluation of health disparities, and the development of culturally appropriate interventions (Shoultz et al. 2006; Lesser and Osós-Sánchez 2007). The CBR may also be particularly meaningful to a researcher as a co-learning experience that increases self-awareness and allows the researcher to investigate the self as a non-member of the community (Horowitz, Ladden, and Moriarty 2002). Shoultz et al. (2006) suggests that the merging of CBR with qualitative methodologies (i.e. participant observation, interviews, and focus group discussions) leads to the development of innovative methods to study vulnerable populations. The development of culturally appropriate methodologies is region specific by nature, and refers to the use of both quantitative and qualitative approaches.

The involvement of communities in sensitive research creates ongoing dialogue to understand the experiences of those being studied, the interrelationships between vulnerable populations, and the sociocultural realities of the group while maintaining respect for the participant (Scheyvens et al. 2003). Scheyvens and colleagues (2003) propose that to enhance research dialogue with communities, advisory boards comprised of academic and community representatives may assist in recruiting potential respondents, address how to maintain trust in the researcher-participant relation, and educate the community about the study (Scheyvens et al. 2003).

Knowledge exchange is a guiding principle in the CBR approach. Kurelek (1992) asserts that beneficence of a study should contribute to the wellbeing of participants and researchers and is a primary research goal. Participants' preconceived notions about the context of beneficence relating to lifestyle improvement rather than cultural or community progress can inform their decision to become involved in a study. It is the responsibility of the researcher to ensure respondents understand the goals of the study (Kurelek 1992). Findings from research on vulnerable groups may be provided to the community including a summary report or training workshop to maintain the integrity of the study (Scheyvens et al. 2003). Dissemination of research findings to the community maintains trust in the researcher-participant relationship and ensures the principles of beneficence are met in order to improve the care of the population (Scheyvens et al. 2003).

## Conclusion

Anthropologists and researchers from other social science disciplines have contributed a nuanced perspective to the construction of the concept of vulnerability using a sociocultural lens. The work of Coeckelbergh (2013) examines the theoretical framework of vulnerability and argues that the reconstruction of this concept is shaped by individual and societal experience. "Apart from being vulnerable in relation to the things we do and what might happen in a particular situation, we are also vulnerable by virtue of our capacity to imagine that something bad might happen" (Coeckelbergh 2013:45). This refers to the idea that theoretical understandings of vulnerability are important to ensure that research design processes are culturally appropriate and protect the integrity of the potential respondent.

Although anthropology has studied vulnerable populations from a cultural perspective, this paper further contributes to the theoretical and methodological discourse on vulnerability. Existing knowledge on the methodologies used to study vulnerable groups can be used to create innovative strategies to approach the concept of vulnerability during data collection processes. This will help to reduce the preceding challenges identified in this article such as maintaining the integrity of data, establishing rapport with the community of study, and resolving emotional distress related to the undertaking of sensitive research. This article provides graduate students with advice on preparing for and resolving challenges when conducting a project with vulnerable groups. This paper is a valuable contribution to the literature addressing the challenges of working with vulnerable populations, such as those living with HIV, which can often be less of a focus in anthropological discussions concerning vulnerabilities.

Anthropology and some other social science disciplines such as sociology and health studies continue to use traditional methodologies of data collection and analysis for conducting ethnographic research. Some suggest that there is a need to implement frameworks that provide a more meaningful analysis of vulnerable groups (Sacks 2008). It is recommended that social scientists continue to build relationships with the communities of study. The use of an advisory committee assists in overcoming ethical, practical, and methodological challenges in the field. I contend that the availability of published accounts of researcher's experiences working with vulnerable populations can assist graduate students, and also academics, in addressing concerns underlying sensitive research as discussed in this paper (Dickson-Swift et al. 2007). Both of these suggestions will lead to more meaningful research studies with vulnerable groups. Limited research has focused on the individual experiences of researchers working in the field. The experiences of social scientists conducting studies on sensitive topics can be used to guide the development of models to address an investigator's risk of harm in the field, establish rapport with community groups, and ensure that current ethical principles are revised to account for the sociocultural nature of individual experiences.

## Notes

1 See U.S. Department of Health and Human Services (1979).

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