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Reflections on researching vulnerable populations: Lessons from a study with Bhutanese refugee women

Jamuna Parajuli | Dell Horey

Department of Public Health, School of Psychology and Public Health, La Trobe University, Bundoora, VIC, Australia

Correspondence
Jamuna Parajuli, Department of Public Health, School of Psychology and Public Health, La Trobe University, Health Sciences Bldg 1, Bundoora, VIC, Australia.
Email: j.parajuli2013@gmail.com and j_parajuli@hotmail.com

Abstract

This paper explores the critical roles of researchers in research involving vulnerable populations. Its purpose is to reflect on the complex nature of vulnerability of Bhutanese refugee women who had resettled in Australia involved in research looking at the barriers to accessing preventive cancer screening. First, we describe the vulnerabilities considered prior to the research study and the actions taken to protect participants while the study was conducted. Second, we discuss those vulnerabilities that we did not anticipate, but were subsequently revealed during the study and consequently included in the study findings. These vulnerabilities should be considered for future research involving similar populations. It is important for researchers to use appropriate research designs that enable the voice of vulnerable people to be heard and to use research strategies that ensure findings are robust and participants are protected and empowered. Potential implications include the development of research practices that take account of the sources of vulnerabilities and consideration of how different vulnerabilities can evolve and affect findings and research recommendations.

KEYWORDS

accessing services, reflection, refugee women, resettlement, the refugee experience, qualitative research, vulnerability

1 | INTRODUCTION

Qualitative research involving vulnerable people can be ethically challenging and practically complex, especially when studies explore lived, deeply personal, experiences. Ethical guidelines advise qualitative researchers to take special account of the specific vulnerabilities when designing and conducting such studies (National Health and Medical Research Council, 2018). Vulnerable study populations can affect every step of a research study from planning, data collection, data validation to dissemination (Marsh et al., 2017) and may interrupt or distort the way that research can be carried out (Von Benzon & Van Blerk, 2017). In the report of their study of 11 funded international bioethics training programs, Loue and Loff (2019) contend that central to research ethics is how we understand vulnerability. In their study, conceptions of vulnerability differed across the training programs; a minority portrayed vulnerability as a "multi-dimensional construct"; one program described the vulnerability as layering or intersecting.

The varied descriptions of vulnerability in the literature include a relative state or condition that occurs as a result of external or structural factors; a consequence of social dynamics, such as inequality and social exclusion (Johnstone & Kanitsaki, 2007); a perception of social groups and individuals and so conditionally dependent on how someone sees themselves in relation to a

dominant social group(s) (Aldridge, 2015); as an association with risk of exploitation because of demographic, social or economic circumstances (Pyer & Campbell, 2012); as arising from powerless, exclusion or marginalisation (Liamputtong, 2007; Wilson & Neville, 2009); or related to the risk of harm or death, experiences of ongoing hunger or poverty or the inability to make personal life choices independently (Aldridge, 2015).

Such variations in vulnerability conceptions highlight the responsibility of researchers to understand the ways that their study participants are vulnerable if they are to appropriately protect them from further harm. Such protections commonly involve practical matters to address issues of consent, risk of harm and social justice (Loue & Loff, 2019).

The purpose of this paper is to reflect on the complex nature of the vulnerability of a particular study population group, 30 Bhutanese refugee women who had resettled in Australia, and the actions taken to protect them in research looking at the barriers to accessing preventive cancer screening. This qualitative study, which formed the doctoral studies undertaken by the first author (JP), involved interviews with 30 Bhutanese refugee women who had resettled in Australia after almost two decades in refugee camps in Nepal. Findings from the study have been reported elsewhere and include: low levels of breast and cervical cancer screening due to poor knowledge of the value of screening and health-care seeking triggered only when problems arise (Parajuli et al., 2019a, 2020a); and cultural discontinuity, changing dependencies within families and perceptions of not belonging creating unexpected challenges with resettlement (Parajuli et al., 2019b). Participants were also asked their ideas for health screening programs for refugee women (Parajuli et al., 2020b).

Consideration of the vulnerabilities of these Bhutanese refugee women was critical to the successful completion of the thesis and this paper allows further reflection of issues not previously explored in any depth. First, we describe the vulnerabilities that were considered before the study and the subsequent actions taken to protect the study participants. Next, we discuss those vulnerabilities that were not anticipated, but that were nonetheless revealed during the study and included in the study findings, and that had the potential to be addressed in some way during data collection. Recognition of these vulnerabilities may be useful to future researchers.

2 | ANTICIPATED VULNERABILITIES

In many ways, understanding the vulnerabilities of the study population was straightforward as the primary researcher, a Nepalese-born woman, who although not a refugee herself, has many social, cultural, and linguistic characteristics that are shared with the Bhutanese women who participated in interviews. The author's role as a community nurse in Melbourne and her past experience as a nurse in the refugee camps in Nepal was instrumental to the study (Ramji, 2008; Rowland, 2011). This association is not unusual, researchers often explore issues and topics in people and communities who share common backgrounds, language, race, ethnicity, nationality or heritage (Dwyer & Buckle, 2009).

Understanding the potential for compounded vulnerabilities among the Bhutanese refugee women in the study was important. These vulnerabilities were due to several reasons. Importantly, as Bhutanese women, their gender meant that they were subject to generations of cultural domination before becoming refugees. Then, as members of an oppressed minority in Bhutan, traumatic experiences led them to flee their homeland with their families and to begin difficult lives in refugee camps in Nepal, where they remained for almost two decades until their resettlement. As resettled refugees, they faced new and unexpected challenges in their new country (Parajuli et al., 2019b). Three specific issues that were anticipated as contributing to their vulnerability as study participants needed to be addressed when thinking about how the study was designed and would be conducted: their low cultural status, their refugee experiences, and their known resettlement difficulties.

2.1 | Overcoming low social status

Research involving any group that has a low status in a community raises several challenges for researchers. The low social position of women in the Bhutanese-Nepalese cultural context means that women's health issues are often hidden and not widely discussed (Menon et al., 2012). The participation of Bhutanese women in any research study needs the agreement of the Bhutanese men in their household and when proposed research focuses on women's health issues and/or could be viewed as contentious, careful consideration of the study design and protocol is needed.

The cultural dominance of men in Bhutanese families was evident in the refugee camps in Nepal, and has been observed in other studies, where men retain the social position from their home country as the household heads. Bhutanese men make all decisions and exercise all economic power, and are seen to have the right to control the lives of all family members in all areas, including education, employment, health care, social participation, economic decisions and even personal care (Donini, 2008; Human Rights Watch, 2003).

Daughters in Bhutanese and Nepali families are considered burdens and are counted as the assets of others, not as someone who belongs to the family of their birth. Sons carry the family name and legacy, and so are more important than daughters. Family homes and family life revolves around sons. Consequently, females experience discrimination and are less likely to be given access to opportunities and may even be prohibited from attaining education, economic independence or social autonomy (Tamang, 2000). Lack of education has important consequences for literacy, which, in turn, has implications for research participation, as it can affect how consent is obtained and conveyed and how data are collected.

To address the anticipated vulnerabilities resulting from the cultural status of the Bhutanese refugee women in our study, several strategies were employed. Unmarried women were excluded to

avoid cultural stigmatization related to suggestions of sexual activity outside marriage or before marriage. As the research topic, access to breast and cervical cancer screening services was potentially very sensitive and personal for this group, privacy was very important. All interviews took place in the homes of participants in separate rooms, alone, as this is where the women felt most comfortable. All were offered the option of an alternate location. To further help the women feel confident and comfortable during the interview, and to ensure their understanding that the study would be published, participants were given the option of choosing their pseudonyms. Age ranges were used to describe participants to further maximise anonymity.

It was critical to address the likelihood that study participants might not be literate and so verbal explanations about the study were important. Most women (21, 70%) were illiterate. Written information about the study, including plain language statements in Nepali, was provided before the interviews, but the interviewer also explained the study orally to ensure understanding.

We also employed the use of photo-elicitation in data collection where needed. This occurred in interviews with seven women who were unsure of what was meant by breast or cervical cancer screening. The women were shown photographs of equipment used in screening to ensure that they understood what was being asked of them. The images helped women recall the equipment and the experience, even though they were unaware that the procedure was associated with cancer screening.

2.2 | Responding to refugee experiences

Refugee populations are often deemed to be vulnerable, because of their difficult and/or traumatic life experiences (Taylor et al., 2013; Von Benzon & Van Blerk, 2017) and because of their fragmented lives that involve fleeing their country of birth to live in refugee camps with scarce resources before resettling in a new country (Corcoran, 2017; Donini, 2008; Evans, 2010; Ferguson, 2011). Most Bhutanese refugees lived for nearly two decades in camps in Nepal before resettlement across eight different countries (Parajuli et al., 2019b).

To address the specific vulnerabilities resulting from their past experiences as refugees, it was critical that the women in our study understood that they could withdraw from the study at any time, had the right to decline to answer any question(s) and could ask that any information provided in an interview not be used. It was necessary for the interviewer to prepare for the possibility that a participant may become upset when recalling certain events during the interview. The interviewer was prepared to pause an interview, provide time for a woman to settle, and then ask if they would like to talk to a professional counsellor. A list of professional counselling services was prepared, comprising agencies with policies that gave priority access to refugees, which were locally available and free of cost.

2.3 | Recognising resettlement difficulties

Resettlement can offer many opportunities for refugees, such as access to education, reliable food supplies, safe shelter, good medical treatment and better employment opportunities, but can also create new challenges. In Australia, refugees are recognised as vulnerable groups, or groups with special needs, and as a consequence, they are given priority for health-care service provision (DHHS, 2019). Resettling in a new country and starting a new life can be overwhelming for anyone (Colucci et al., 2015), but adjusting to a new culture and new language can be even harder for refugees (Clark et al., 2014; Lawrence & Kearns, 1905). To address vulnerabilities resulting from the potential difficulties with resettlement among the refugee women in our study it was important that interviews took place where the women felt most comfortable. Study participants were offered a range of options but all chose that interviews take place in their homes. As noted above, the interviews were conducted in separate rooms so that the women felt safe to talk and were not disturbed by other family members. During an interview, the researcher took care to reflect back to interviewees what was said to make clear any difficulties arising from resettlement and to make clear that these were not unusual. This approach was effective in helping the women to feel heard and supported.

3 | UNANTICIPATED VULNERABILITIES

Next, we will look at vulnerabilities that emerged during the study and that were not anticipated. These were included in the study findings and influenced the recommendations that were formulated. Now they may offer insight for other researchers undertaking research with this group.

3.1 | Communication and dependency

In every interview, women raised problems with dependency due to not being able to understand or communicate with others, including health care workers, shopkeepers and teachers at their children's schools. Communication difficulties were common and widespread. The women were unable to understand signs, labels or even addresses, which were unfamiliar to them after their years in refugee camps. Challenges such as these fostered heightened feelings of vulnerability and created an unexpected dependency on their children. While issues with communication were not unexpected with resettlement, in the interviews the women repeatedly associated their poor literacy with dependency on their children. It was evident that an unfamiliar and unexpected vulnerability had formed among these refugee women, an ongoing reliance on their children had developed for many day-to-day tasks, including shopping for food, using public transport and making and attending health appointments. The women were concerned that their dependency on their children was upsetting the internal and social authority structures

within their family, making the women feel insecure and marginalised. For example, Maya felt miserable as she was unable to express her feelings, her problems or her needs to others. She felt that her voice had been suppressed. She was reluctant to rely on her children's support to communicate with others, especially when seeking health care. Maya believed that such dependence on her children would expose her private health concerns to them and in doing so would create insecurity and threaten her capacity to maintain her role as 'mother', as she expressed it "Without children, it's hard to live here. I feel I am a child, not a mother" (Parajuli et al., 2019b).

While information about how to access professional counselling services was prepared in regard to trauma and refugee experiences, we had not anticipated the issue of disempowerment and its association with children. If we had realised earlier, we could have alerted the counselling services and developed possible responses.

Similarly, while the effect of illiteracy was anticipated, the extent that it exacerbated women's sense of identity and dependency was not. In the refugee camps, lack of literacy was common and readily accommodated, and as such was not then perceived by the women as a source of vulnerability. However, once in Australia, not being able to read and write, even in their own language, made everyday life difficult, particularly for older women, who already had to rely on others. This was made worse when it was their children who had to acquire the information the women needed, including how to navigate health services. To address this issue, the women themselves suggested that more social support was needed. They nominated community education, oral peer education and bilingual workforces as potential areas of support (Parajuli et al., 2020b).

3.2 | Neighbours, religious festivals and not belonging

Difficulties in fulfilling cultural and spiritual needs were the issues raised most commonly in terms of cultural discontinuity. While the significance of religious practices was known, what was not anticipated was how much the loss of a shared community experience in the celebration of religious festivals would be felt. All women mentioned that with resettlement, they felt confined to their households on these, once shared, occasions and how they were now mindful not to disturb their neighbours when celebrating inside their homes. As one woman said, "We always need to be conscious of other people and think about how to answer their questions. We can't make our minds and hearts very open during those times" (Parajuli et al., 2019b).

Occasions that were formerly celebratory were now muted, and a sense of marginalisation and of not belonging was reinforced. These feelings were particularly evident in some of the older Bhutanese women who were discouraged from any interaction outside their homes. Overcoming a sense of not belonging is likely to require a mix of strategies, including some that include the refugees themselves, the communities in which they are resettled and the services that they need to access. Encouraging social connections between refugees and their neighbours following resettlement may be useful, but does not always work, especially in disadvantaged communities where resources are scarce and refugees can be seen as competitors for them (Hebbani et al., 2018). Anticipation of this vulnerability could be addressed by preparing pictograms encouraging different ways to interact socially without language to help women build social contacts and link women to services.

3.3 | Health professional behaviour

The women in our study had high regard for health professionals. They had used primary health services many times since their resettlement. However, it soon became apparent in the interviews that the behaviours of health professionals were potentially reinforcing vulnerabilities in the women. On many occasions, the women reported that during health visits instead of using professional interpreters, family members acted as interpreters making it hard for the women to talk about sensitive issues. It appeared that the health professionals were unaware of the impact this approach had on the women. Other behaviours that negatively affected the women included failure to explain the need for procedures, such as those associated with cancer screening.

Some women had been given written information in Nepalese, apparently without awareness that the women could not read. These examples provide important lessons for researchers as well as health professionals. Efforts are needed to test basic assumptions, such as literacy, including health literacy. For example, in our study, the majority of women were illiterate and had no understanding of the concept of preventive health care. Health professionals, who undertake research involving vulnerable populations have a heightened responsibility to be aware of the impact of their authority and their influence and take steps to mitigate these.

4 | DISCUSSION

Research involving vulnerable populations can only be judged successful when it helps to make the voice of vulnerable people heard. This requires research to be designed and conducted in ways that address the needs of those involved appropriately and to ensure participants are protected and empowered. Vital to the conduct of ethical research is how researchers understand and respond to the vulnerabilities of others (Loue & Loff, 2019). This means that all researchers that involve such groups need to incorporate reflective practice into their research practice, both when planning their approach and after their study is complete, to consider what might be have done differently.

Our reflections on the findings of the primary study, which looked at barriers to accessing preventative cancer screening services by Bhutanese women after resettlement in Australia identified

new vulnerabilities largely related to the impact of language difficulties and cultural disconnection (Lumley et al., 2018). We were able to identify strategies that could have been adopted to provide further support to the study participants.

The nature of any vulnerability is often affected by societal structures, which means that the circumstances affecting vulnerabilities are subject to change over time. This has implications for researchers who need to think beyond simple checklists to carefully consider the particular participants in their study and the sources of their vulnerabilities. While these may seem obvious for studies involving refugees, refugees are not a homogeneous group and will be affected by different issues and be at different stages of their journeys from their homelands. The strategies needed to address specific vulnerabilities may also change over time.

Some refugee groups seem to be particularly vulnerable, and Bhutanese refugees in several countries have displayed particular vulnerability (Ferguson, 2011; Shrestha, 2011). A Canadian study involving 110 Bhutanese refugees found that they were at risk of developing psychological distress at any age due to their premigration experiences (Subedi et al., 2019). In Australia, high rates of anxiety, moderate levels of depression and moderate to high levels of acculturative stress were observed in one Bhutanese refugee community (Lumley et al., 2018). Several studies of resettled Bhutanese refugees in the United States have found health and social outcomes that are poorer compared with other refugee groups (Bhatta et al., 2014; Griffiths & Loy, 2018; Haworth et al., 2014). Such outcomes point to different levels of acculturative stress—the stress experienced when adapting to a new culture (Berry, 2005)—and highlight the need for specific consideration of the approaches needed for different research studies.

Recognition of vulnerabilities is a consequence of exercising reflexivity, which is an invaluable tool for any researcher, and one that should be used both before and after conducting any study. A reflexive approach can guide researchers in ways to recruit participants, how to seek consent, how to design possible interventions and how to collect and analyse data (Berger, 2013). Sound knowledge of the root causes of vulnerability can also be a key to ensuring that findings are relevant and robust (Clift et al., 2018; Pyer & Campbell, 2012). Other researchers have also shown ways that reflexivity can facilitate how to identify and address underlying issues (Marsh et al., 2017; Von Benzon & Van Blerk, 2017; Wilson & Neville, 2009).

While all research involving vulnerable people should aim to empower participants as well as to contribute to the understanding of their unique experiences, the evidence from this study shows the importance of recognising the complexities of vulnerability for some people. For the Bhutanese women in our study, their vulnerabilities did not stop with their resettlement, it changed.

5 | CONCLUSION

The potential implications of this reflection lay in the development of research practices in studies involving vulnerable populations that take account of the sources of vulnerabilities and consider their impact. Reflection starts with the research design and includes thinking about the background and needs of participants as well as how to conduct the study. As consideration of lack of literacy shows, there can be implications for obtaining consent and for data collection but to not leave participants even more disempowered, thought also needs to be given to how information and follow-up support are provided.

The interconnectedness of vulnerabilities needs to be explored, recognised and appreciated so that we might adapt our research practices and decrease the risk of creating further vulnerability.

COMPETING INTEREST

The authors declare no competing interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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