

Culturally safe research with vulnerable populations

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ABSTRACT

Culturally safe research processes, methodologies, and mutually aligned research endeavours are a fundamental right of those being researched. Vulnerable populations are at risk of experiencing inequalities in health experiences and health outcomes, and research beneficial to those being researched is crucial to address disparities. Often vulnerable populations are exposed to research that is driven by dominant epistemologies, research methodologies, and socio-cultural lenses that can exacerbate their vulnerability, negating their socio-cultural reality. In this paper it is contended that researchers should review the way in which research is constructed and developed by creating a culturally safe space for research to occur with those who are vulnerable. A framework based on partnership, participation, protection, and power is presented as a way of creating culturally safe research.

KEYWORDS: cultural safety; culture and research; vulnerable populations; marginalised groups; research ethics; research

INTRODUCTION

Research on groups with high health burdens is often carried out in order to better understand various aspects of their health experiences and improve interventions. However, research outcomes may be compromised due to the way in which the research has been conducted, with researchers unwittingly transgressing cultural boundaries, and drawing conclusions that inaccurately portray the experiences of those researched (Smith, 1999). The privileging of western research epistemologies, processes and ethics to the exclusion of other approaches leads to an implicit construct about the truth observed. Moewaka Barnes, McCreanor, Edwards, and Borell (2008) name this 'epistemological domination'. There is a need to improve the efficacy of research with those who

are vulnerable by embracing the cultural realities of those being researched who generally have a different cultural orientation to that of researchers.

Groups of people are considered vulnerable when exposed to disparate risk and health burden compared to others in their communities. They may be marginalised due to historical and contemporary experiences and by being different; subject to discrimination; underserved due to social, economic and political circumstances; or dependent upon others. As a result those who are marginalised, underserved, and/or vulnerable experience difficulties in obtaining full and timely access and use of health services (Dodgson & Struthers, 2005; Pacquiao, 2008; Wilson & Neville, 2008), interventions that are appropriate and acceptable, and life circumstances that increase their risk to

compromised health states (Wilson & Neville, 2008). Thus, children, people with disabilities, indigenous peoples such as New Zealand Māori, lesbian gay and bisexual (LGB) peoples, those living in poverty, and older adults are some examples of who may be exposed to potential threats to their health and wellbeing. However, undertaking research with those in vulnerable populations can be fraught when they are subjected to culturally inappropriate research.

Vulnerable populations experiencing inequalities in their health experiences and health outcomes are subsequently subjected to the enquiring lenses of researchers and their interpretations, striving to find better interventions and ways of working with them. While there are many definitions for vulnerable populations available, one by Pacquiao (2008) will be utilised in this article as a frame of reference. Drawing on the work of Aday (2001), Pacquiao (2008, p. 190) defines vulnerable populations as: '... those who are not only particularly sensitive to risk factors but also possess multiple cumulative risk factors. They are more likely than others to develop health problems as a result of exposure to risk or have worse outcomes from those health problems than the rest of the population.' Essentially, vulnerability leads to a disparate burden of disease and illness, yet along with the reality of having high levels of need the vulnerable are generally the least heard within the context of research. It must be noted that vulnerability is a contested notion; with some who are considered vulnerable by 'outsiders' do not view themselves as such (Cameron & Hart, 2007). However, we believe that there are aspects that must be considered when planning research with those who are at risk of vulnerability, as research processes and outcomes can exacerbate vulnerability.

The dominant socio-cultural lens that many researchers use to underpin their research processes can negate the socio-cultural reality of a vulnerable population. Researchers need to revisit the way in which research projects are constructed and developed, how they engage with vulnerable populations, and how they conduct

the research to ensure that the research is carried out in an acceptable and appropriate manner for those being researched (HRC, 2008; NHMRC, 2003). That is, research needs to accurately reflect the voice and needs of the participant group so that it reaches optimal relevance and utility – the findings of any research should be beneficial to participants both on an individual basis and as a collective group. We contend that cultural safety in research transpires if researchers fundamentally believe in the right of those who are considered vulnerable (including those who are marginalised or underserved) to be heard and treated with dignity and respect, and they align their endeavours and conduct to those being researched. In this article we discuss the role of cultural safety in research with vulnerable populations, drawing upon our research experiences with those who identify as Māori (indigenous to New Zealand), LGB, and older adults as examples to illustrate various points. We begin by discussing research with vulnerable populations.

RESEARCH WITH VULNERABLE POPULATIONS

Vulnerable populations are exposed to risk when researched by those who belong to the dominant group and experience privilege, inadvertently 'trample' on their traditions and protocols and/or are portrayed in a way that reinforces negative or discriminatory viewpoints (Bishop, 2005; Smith, 2005). Historically research with vulnerable populations has been problematic, especially research imposed by researchers with their agendas, and who gaze from the outside looking in upon the researched group (Flaskerud & Winslow, 1998). Such an approach can yield findings that are incomplete and do not accurately represent those being researched, and that misappropriates and misrepresents the knowledge and resources of particular vulnerable groups. For example, many indigenous groups like Māori have historically been researched to their detriment, often with little or no benefits for them. Time and again research findings from vulnerable groups such

as Māori have been interpreted and portrayed through the cultural lens of the researcher resulting in the portrayal of unhelpful stereotypes and deficit explanations (Smith, 1999; Sporle, 2003).

Gone are the days when it was accepted practice that researchers could determine the research agenda for those in vulnerable populations. The notions of social justice and human rights dictate that vulnerable populations are afforded the right to a voice regarding research agendas and processes that involve them (Mills et al., 2005; Smith, 1999, 2005). Researchers need to create spaces where those being researched can come together with researchers to negotiate the research and the terms under which it is to be conducted – a place also where researchers can develop a critical understanding and respect of the socio-cultural realities of those being researched (see Figure 1). Research with those in vulnerable populations should be predicated on their involvement to establish their needs and aspirations, right to self-determine the research agenda and approach, and to be able to develop their own research capacity (Bishop, 2005; HRC, 2008).

The cultural realities of most vulnerable populations are complex, making the establishment of relationships and negotiating the terms

of reference for research critical. Research should carry benefits for those being researched – that is, it should contribute to understanding the occurrences of their unique health experiences and problems, explore relevant interventions, and aim to improve health services and outcomes. The success and utility of research from the perspective of those being researched depends upon researchers having a commitment to understanding their socio-cultural reality, and critically analysing the deficit explanations and stereotypes they are subjected to (Bishop, 2005; Smith, 2005) so as to avoid repeating outcomes that at best are unhelpful. Undeniably, an over-concern with the negative ignores the positive aspects within vulnerable populations. Undertaking research without a commitment to working with and involving those being researched runs the risk of negating the realities of those being researched.

AN OVERVIEW OF CULTURAL SAFETY

The concept of cultural safety was initially an indigenous concern originating out of the disquiet Māori nurses had about the absence of recognising the cultural orientation and needs of Māori patients when accessing health care (Ramsden, 2002). Māori in Aotearoa New Zealand experience

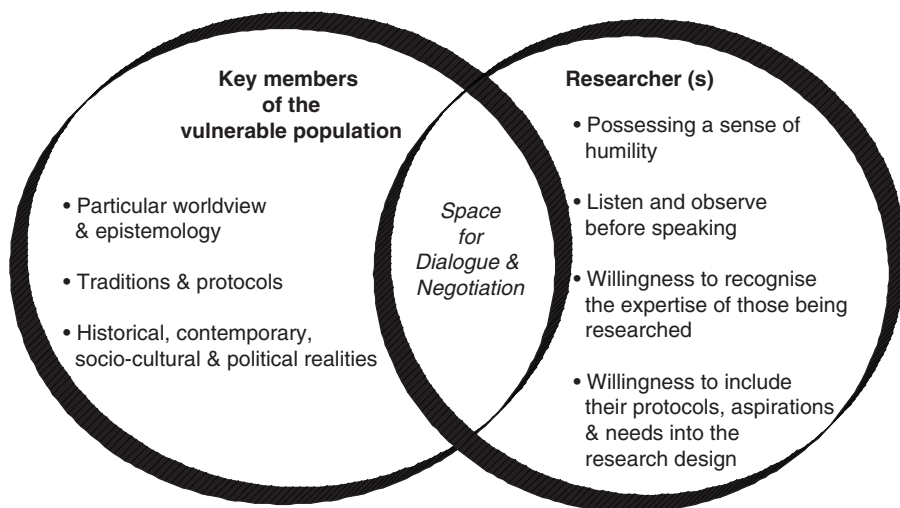


FIGURE 1: CREATING THE SPACE FOR DIALOGUE AND NEGOTIATION

disparities in health status when compared to other New Zealand citizens, attributed to the ongoing affects of historical traumas related to the processes of colonisation, and their subsequent contemporary socio-economic and political realities (Smith, 1999). The Treaty of Waitangi ('the Treaty') signed in 1840, is an agreement between the New Zealand government and Māori peoples that lays down the obligations of the government ('the Crown') and its agents to Māori. However, the Treaty has been subject to problems related to it not being honoured and recognised up until the 1970s, and continues to be a source of dispute and controversy. Enshrined in the Crown's obligations is their responsiveness to Māori by engaging in productive relationships, involving them in deeds that concern them, including planning, and decision-making activities that aim to protect their cultural beliefs and practices (NCNZ, 2005).

In its evolution, the notion of cultural safety has become more inclusive, expanding beyond Māori to include other ethnic groups along with other cultural groups. It is currently defined within a nursing practice context as:

'The effective nursing practice of a person or family from another culture, and is determined by that person or family. Culture includes, but is not restricted to, age or generation; gender; sexual orientation; occupation and socioeconomic status; ethnic origin or migrant experience; religious or spiritual belief; and disability. The nurse delivering the nursing service will have undertaken a process of reflection on his or her own cultural identity and will recognise the impact that his or her personal culture has on his or her professional practice. Unsafe cultural practice comprises any action which diminishes, demeans or disempowers the cultural identity and wellbeing of an individual' (NCNZ, 2005, p. 4).

Cultural safety first requires researchers to reflect upon their own cultural reality to identify their values, beliefs, and practices and how

these may impact on the research process when researching those from different cultural orientations. This includes having insight into the epistemological foundations that guide their research practice, consequently informing interpretations of data collected. Cultural safety necessitates researchers to have an understanding of the socio-political realities of those being researched in order to avoid reinforcing negative stereotypes and to produce research findings that would be beneficial (Durie, 2004).

Importantly, culturally safe research practice is primarily determined by those groups who are researched – not by the researchers themselves. When applied to research, cultural safety begins from the inception of a research idea when relationships are established with those who belong to the group being researched, and extends to the dissemination of the findings. It is about research participants feeling included, respected, and that they can trust the researchers and what they will do with the information shared with them. Explicating a culturally safe research project can be guided by using a framework based on the principles of partnership, participation, protection (based on the principles of the Treaty of Waitangi), and power – the '4 Ps'. Partnership requires the establishment and maintenance of relationships based on trust and respect. Participation entails the ongoing involvement of those from the groups being researched in the planning and decision making processes contained within a research project, and ideally in the research itself. Protection necessitates the respectful safeguarding of the participants' values, beliefs, practices, and worldviews throughout the research project. Power involves the researcher critically reflecting upon their own privileged position as a researcher, and the potential to unwittingly denigrate the position of the participants.

There needs to be a sense of authenticity for participants in research for it to be considered culturally safe (Belfrage, 2007). Culturally safe research should also consider the ethics of engagement, empowerment, and eco-connectiveness

(Bishop, 2005; Smith, 2005). Engagement requires the building and maintenance of ongoing relationships, which demands personal involvement so the researcher comes to understand the cultural beliefs of potential participants and what it means for them to partake in a research project and to become aware of concepts and beliefs that may be defined differently from the researcher. Empowerment is about enabling the groups being researched individual and collective autonomy and their right to self-determine the nature and terms of their involvement. It is about participants being protected from exploitation. Some vulnerable populations, especially indigenous groups, have epistemologies based on holism and eco-connectiveness, which acknowledges the ecological relationships and ties they may have with the environment and other living beings in order to facilitate their wellbeing and sense of balance.

Recipients of 'cultural safety' (in the case of this paper, vulnerable populations being researched) should be the ones to decide whether the research they are participating in is culturally safe. However, Wilson (2008) when discussing the health experiences of Māori women identifies the opposite occurs and that in reality it is the researcher(s) who decide or determine whether the research or study has met the cultural safety requirements. Therefore, it is important that researchers are aware when embarking on research with those from vulnerable populations that they need to be the judge as to whether the research topic, processes and outcomes were culturally safe.

CREATING A CULTURALLY SAFE SPACE FOR RESEARCH

Cultural safety in practice is about respecting the worldviews of those being researched, recognising their culturally-driven differences, and including these in the design of the research. It requires a commitment to honour the inherent rights of research participants as human beings and to genuinely 'work with' those being researched. Creating a space for dialogue and negotiation facilitates an opportunity to understand the

culture of a vulnerable population – that is, its particular worldview and epistemology, key traditions and protocols that need to be incorporated into the research design and honoured, and an understanding of the group's historical, contemporary, socio-cultural and political reality. For this to take place the researcher(s) need to possess humility that enables them to respect the 'expertise' of those being researched, to listen to what is being said and observe what is happening prior to speaking. Such a space must be predicated on a willingness to include the traditions, protocols, aspirations and needs identified into the research design and process.

Utilising a framework can assist in ensuring the desires of those being researched are upheld and respected. The '4 Ps' is one such framework, which is based on the principles of the relationships that are inherent within the Treaty of Waitangi, along with the concept of power that influences the researcher when working with those from a vulnerable population (see Figure 2). Undertaking a continual process of self-reflection enables the identification of the researcher's worldviews, epistemologies, and the power (among other things) that may adversely impact upon the research process. It also enables the researcher insight into how such power may influence the partnership relationships established, the willingness to involve participants by enabling them to participate in various aspects of the research, and the ability to protect their cultural values and beliefs. We will now describe the 4 Ps in more detail with reference to Figure 2, to optimise the outcomes of the research being both beneficial and relevant for the vulnerable population being researched.

Partnership

Partnership is about requiring researchers to create a space where the building of meaningful and ongoing relationships with those being researched can be established and maintained throughout the research process. This is central to the success and credibility of any research project, and is all the more salient when undertaking research

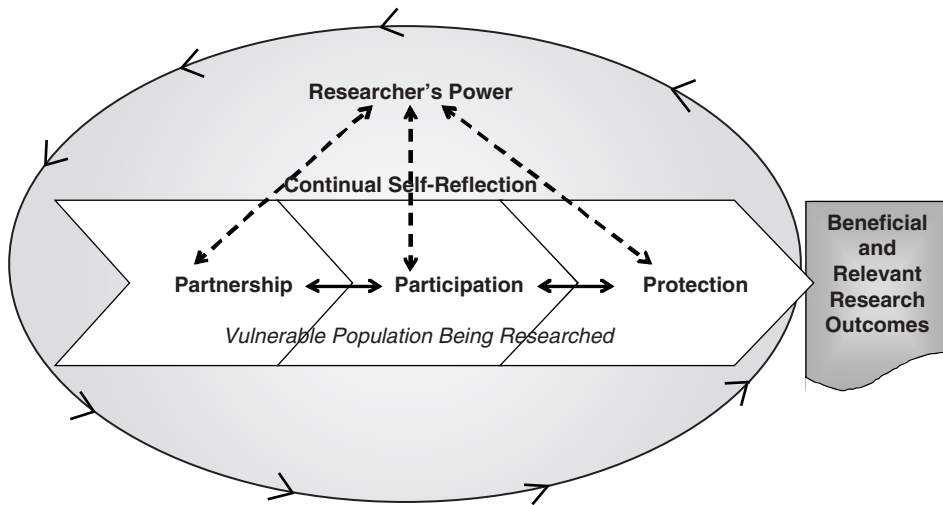


FIGURE 2: THE 4 PS OF RESEARCH WITH VULNERABLE POPULATIONS

with vulnerable populations as these groups are frequently identified as hard to reach and needing encouragement and support to participate in studies (Smith, 2008). For example in a large study (see Henrickson, Neville, Jordan, & Donaghey, 2007 for further information about his study) with LGB people, researchers engaged the wider community through the LGB media. This project began by calling for expressions of interest from the LGB community. From here a national community advisory group was formed who worked with the core research team. It was this group that determined the focus for the study culminating in specific questions that were included in the questionnaire.

The ethics of engagement is essential in firstly building relationships with any groups considered vulnerable being researched, and secondly in establishing the needs of such groups in relation to the research. An underlying premise of such a relationship is the recognition of the shared and different ideas, the ethics of the researcher(s) and those being researched, and how they can be defined to co-exist. Face-to-face personal involvement is crucial, especially where a tradition of research suspicion and mistrust has evolved (Bishop, 1994, 2005; Dickson, 2000; Irwin,

1994). It is only through the development of such relationships that the researcher can come to 'know' about a group's cultural beliefs, and what it means for them to take part in the proposed research.

The nature of such a partnership is about those in a vulnerable group being researched having input into the research design and its explication. Sometimes it is only through the establishment of a meaningful relationship that some areas key to the success of a research project can be identified. For example, Wilson (2008) found the relationship developed with Māori women enabled their input into the development of the research question, the recruitment of participants, and ensuring that the research was philosophically and epistemologically aligned with their worldviews.

Participation

Participation involves the meaningful inclusion of key members of the vulnerable population initially in the planning phases of the research. Importantly, participation should begin early, and the nature of participation should ideally be a product of negotiation. Our experiences highlight the importance of involving key people with the aim of obtaining valuable advice and guidance

with regard to engagement of potential participants, research techniques that are likely to work or not work, identifying aspects of the method that are likely to be flawed when researching a particular vulnerable population, and interpretation of findings. It may be that members of the vulnerable population being researched are involved as researchers or research assistants, which also results in the building of research capacity within the group (HRC, 2008).

As previously discussed vulnerable groups are frequently hard to reach making it difficult for researchers to recruit people as potential study participants. Participation can include methodological techniques that are useful for recruiting hard to reach and vulnerable populations. Neville and Henrickson (2006) and Henrickson et al. (2007) make reference to viral sampling as being an example of what they name as social epidemics that spreads quickly once they reach a set of well-connected people. Viral sampling, similar to snowball sampling, utilises existing friendship networks and e-links, organisations and venues where vulnerable populations frequent or are members, as well as using the public media. Wilson (2004), however, utilised face-to-face conversations for initial consultation and discussions, which led to the involvement of two key women in her research. These women knew the community well, became knowledgeable about the research methodology, and undertook the recruitment of participants based on their knowledge of the research aims and the inclusion and exclusion criteria.

Protection

The concept of protection entails safeguarding vulnerable populations from the potential for exploitation, and the danger of research results further reinforcing negative depictions or explanations that do little to benefit them. Being able to protect those who are vulnerable during research activities is very dependent on researchers incorporating key aspects that arise from partnership and protection activities, already mentioned.

Identifying key beliefs, traditions, and protocols that must be observed during the research process make it possible for researchers to ensure they observe and honour these. This may involve adapting the research process to incorporate these. Protection also involves recognising and respecting the knowledge and epistemologies a vulnerable population may have to avoid the privileging of the dominant research epistemology to the exclusion of any other that may exist.

Often vulnerable populations are portrayed within the dominant cultural context negatively, with health issues being rendered as the responsibility of individuals without recognition of the systemic and structural impacts on their health. Therefore, protection should also focus on the benefits of the research for those being researched, and that means avoiding research that adds force to negative stereotypes and any deficit explanations that may exist.

Cultural safety is closely aligned with ensuring research is ethical – that involves doing the right thing, at the right time, in the right way, which can only be determined by working with those being researched. An ethical issue of particular importance for research involving vulnerable populations is the fine line between making a difference to the health and well-being of people who identify as vulnerable and being exploitative. O’Byrne and Holmes (2008) assert that while researchers need to protect study participants from being exploited it is a researcher obligation to ensure that vulnerable groups are not under-represented. Underrepresentation can lead to study results lacking validity, and therefore being of questionable use to improving health and well-being. Protecting vulnerable populations from the potential harms of research is important when consideration is given to both the overt and covert discrimination and marginalisation these people experience. For example, older people experience discrimination and marginalisation on the basis of age in the form of ageist practices like being denied healthcare on the basis of age (Neville, 2008; Phelan, 2008). More specifically,

older people can be treated like children, as well as not being provided appropriate data collection methods that considers the age-related effects on vision, hearing, and the ability to complete tasks within narrow timeframes, as examples.

Power

Foucault (2002) maintains power is integrally related to knowledge and discourse. Within the realm of western research, the pervasive supremacy of the western empirical perspectives is evident within its knowledge and research discourses, negating any alternative view. Therefore, researchers working with vulnerable populations must critically reflect upon the epistemology of the knowledge base they use and the discourses that pervade the dominant research cultures. For example, Kontos (2005) argues biomedicine has become a pervasive and dominant influence in shaping understandings of being an older adult. The proliferation of biomedical understandings about ageing displaces and ignores subjective experiences of being older. However, critical gerontology has promoted qualitative interpretative and critical understandings to capture the meaning and experience of ageing over the last decade (Hepworth, 2000).

Ideally, researchers should employ a 'power with' rather than a 'power over' approach. 'Power with' requires researchers to be willing and confident to engage in power sharing, apparent in the development of a partnership relationship with vulnerable populations. We propose that engaging in a 'power with' approach requires researchers to understand their epistemologies and discourses that could prevent such an approach.

CULTURAL SAFETY APPLIED TO RESEARCH

The 4 Ps (partnership, participation, protection, and power) described above are principles that can be used to underpin the planning and development of research processes. These, in addition to a process of self-reflection on one's own cultural values and beliefs both personally and professionally, facilitate researchers being able to recognise

and respect the worldviews of others. The following discussion explores methodological considerations when working with those in vulnerable populations.

When planning any research project the research question should always drive the choice of methodology (Beanland, Schneider, LoBiondo-Wood, & Haber, 2000). However, there are specific research methodologies, usually qualitative in nature that are better suited to researching vulnerable populations. For example, critical research methodologies are particularly useful as these are specifically focussed on giving voice to participants, and can be emancipatory in their intent (Moreton-Robinson, 2000; Neville, 2005).

Critical gerontology is an example of a research methodology useful for giving voice to older people, particularly those who are frail, disabled or cognitively impaired. As previously mentioned, critical gerontology recognises and promotes the multifaceted nature of ageing that is alternative to the pervasive biomedical approaches (Kontos, 2005). The proliferation of biomedical understandings about ageing displaces and ignores its critical and political aspects. Thus, a critical gerontological approach would both be appropriate and beneficial, and Neville (2005) found it aided privileging and foregrounding the voice and narratives of older people with delirium. This method illuminated the contradictions and gaps in the literature and provided opportunities for the narratives of older people to be heard as opposed to being objectified and silenced. In addition, critical gerontology has particular congruence with issues that are of concern to gerontological nursing. These concerns include the socio-political acts of eliminating ageism, promoting person-centred care; ensuring older adults are viewed as a heterogeneous population and allowed the critique of the appropriateness of existing modes of generating knowledge.

It should be noted, that vulnerable populations may choose to resist the label of vulnerable and focus on their strengths. This is something that researchers can agree to. Henrickson et al. (2007),

in consultation with LGB communities, agreed that their research was a means to disrupt the heteronormativity inherent in New Zealand society. At that time, much of the LGB research was deficit focussed, biomedically centring on HIV, alcohol and drug use, and suicidality, for example.

Wilson (2008) used a methodology that privileged indigenous epistemologies and processes. Having created the space for dialogue and negotiation, the outcome was a Glaserian grounded theory research process that was first and foremost informed by a Māori-centred approach. This is an example of where indigenous epistemologies and ontologies can co-exist with western research methodologies and methods of data collection and analysis (Cunningham, 2000). Such an approach enabled the research process to be guided by Māori tikanga (protocols), such as the process of engagement where interviews begun with a karakia (a form of prayer) if participants desired, followed by whakawhanaungatanga (a process of connection) where the researcher and the research participant talk about where they are from and who they are, and establish mutual connections. The researcher would also provide koha (a gift) in the form of food or vouchers for petrol or the supermarket to reciprocate the time the participants gave to partake in the research. Such processes are considered culturally appropriate and aim to put the participants at ease and feel culturally valued.

Another culturally appropriate strategy when working with vulnerable groups is having the status of being an 'insider' or a member of the population. For example, those who identify as LGB has its advantages in accessing what are considered 'hard to reach' populations such as men having sex with men (MSM). Being an 'insider' can give insight into the day-to-day realities of life for members of vulnerable groups, providing information on how to appropriately engage and work with them. For example, Adams and Neville (2008) used 'insider' status to describe and interpret why MSM were not consistent users of condoms when having anal sex. Combined with the

utilisation of a critical realist position (Willig, 2001), these researchers were able to give voice to MSM that was reflective of their reality, and had the potential to increase mainstream society's understanding of the issues associated with condom use.

Potential 'insider' researchers are frequently trusted because they possess an understanding of the socio-cultural requirements associated with interacting with these groups. However, having said this 'insider' status does not guarantee immediate cultural safety and may also involve barriers, such as being compromised by simultaneously being seen as a 'researcher'. Regardless of 'insider' or 'outsider' status, the importance of following cultural processes is critical. Nonetheless, being an 'outsider' does not exclude the ability to undertake research with vulnerable populations of which they do not belong to (Tollich, 2002).

CONCLUSION

The bottom line is that research participants from populations considered vulnerable must feel their voices are being heard, that they are respected, and that the research process feels safe. In discussing the need for culturally safe health care, Belfrage (2007, p. 537) advocates; 'People need to feel like *themselves* [sic] and believe that the [research] is connected to *their* [sic] lives, that they are involved and have choices, that it's not primarily someone else's agenda.' The 4 Ps, that is partnership, participation, protection and power, is a useful framework that can guide researchers to engage with vulnerable populations in a culturally safe manner. It is important that researchers have a genuine commitment to undertaking a process that involves engaging and working with those who belong to vulnerable populations, in order to produce research outcomes that are relevant and reflective of their realities.

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