

Résumé

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**Offrir un lieu sûr : l'adoption d'une perspective de sécurisation culturelle dans les soins prodigués aux femmes autochtones vivant avec le VIH-sida**

**Jane McCall, Bernie Pauly**

Les femmes autochtones qui vivent avec le VIH-sida sont plus susceptibles de mourir de maladies liées au sida et moins susceptibles d'avoir accès à des traitements pour leur infection au VIH que la population générale infectée par le VIH. Une étude examinant la vie et l'expérience de femmes autochtones faisant face à d'importants obstacles socio-économiques et vivant avec le VIH-sida a mis à jour divers thèmes liés à leur expérience des soins de santé, y compris la peur du rejet. Les participantes étaient réticentes à accéder aux services de santé parce qu'elles craignaient les jugements et la discrimination. Il était évident qu'elles ne se sentaient pas en sécurité dans un contexte de prestation de soins. Les auteures examinent la façon de mettre en œuvre les principes de sécurisation culturelle dans les relations thérapeutiques avec les femmes autochtones afin de faciliter le processus d'accès aux soins et le rendre acceptable, en temps opportuns.

Mots clés : femmes autochtones, VIH-sida, sécurisation culturelle

# **Providing a Safe Place: Adopting a Cultural Safety Perspective in the Care of Aboriginal Women Living With HIV/AIDS**

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Aboriginal women living with HIV/AIDS are more likely to die of AIDS-related illnesses and less likely to access treatment for their HIV infection than the general population infected with HIV. A study examining the lives and experiences of Aboriginal women facing significant socio-economic barriers and living with HIV/AIDS uncovered a number of themes related to their experiences with health care, including fear of rejection. The participants were reluctant to access health services because they feared judgemental and discriminatory attitudes. It was evident that they felt unsafe accessing care. The authors examine how cultural safety principles might be applied in therapeutic relationships with Aboriginal women as part of the process of facilitating access to care that is acceptable and timely.

Keywords: Aboriginal women, HIV/AIDS, cultural safety, access to health services

The history of Aboriginal peoples in Canada is fraught with discrimination, marginalization, and disempowerment as a result of the colonial forces that have shaped (and continue to shape) Canadian law, policy, and program delivery (Loppie Reading & Wien, 2009). Many Aboriginal women have borne the effects of colonization, and have been left to struggle with disproportionate rates of poverty, ill health, and violence (Dion Stout, Kipling, & Stout, 2001).

Despite the development of numerous innovative HIV prevention and treatment programs designed for hard-to-reach populations, there are still high rates of infection, poor uptake of treatment programs, and disproportionately high rates of mortality and morbidity amongst Aboriginal women living with HIV/AIDS (Public Health Agency of Canada, 2010; Wood et al., 2003). Compared to non-Aboriginal women, Aboriginal women are diagnosed later in the course of their infection, are less likely to access treatment, and tend to have poorer treatment outcomes (Legare, Ross, & Bognar, 2003; Vernon, 2000).

A qualitative study examining the experiences of a small group of Aboriginal women living with HIV/AIDS with the health-care system

has illuminated the struggle faced by Aboriginal women as a result of judgement, discrimination, and stigma (McCall, Browne, & Kirkham Reimer, 2009). For the most part, the women's experiences with the health-care system contributed to suffering and feelings of being unsafe when accessing care. Structural inequities or the way in which policies and practices reflect embedded racism, discrimination, and stigma impact both the health and the ability of people, including Aboriginal women, to access health care (Farmer, 2001, 2009). Such inequities are structurally produced and are remediable (Whitehead & Dahlgren, 2006). Redressing them can positively impact women's ability to access the resources needed to improve and maintain their health.

The purpose of this article is to interpret the findings from a qualitative study with eight Aboriginal women living with HIV infection and their experiences accessing health care, in order to inform understandings of cultural safety in the provision of health care. It is clear from the findings that it is critical for nurses and other health-care workers to understand the positioning of Aboriginal women in the health-care system and the need for safer environments. We begin with a discussion of culture, followed by a review of the concept of cultural safety. We next provide a review of key findings and how these may be interpreted in light of cultural safety. We then discuss the implications of the findings for culturally safe nursing practice.

What is culture?

It has long been acknowledged that, when planning and delivering care, it is important to consider the cultural heritage of people who use the health-care system and to take ethnicity into account. Although most if not all nurses understand and support this concept, there are large differences in shared meanings and understandings of culture. Traditionally, culture has been viewed as synonymous with ethnicity. There has been considerable work done in nursing to acknowledge "other cultures" that have tended to emphasize understanding of different cultural traditions. This approach tends to highlight differences in groups or whole societies that can lead to generalizations. It also runs the risk of inadvertently stereotyping people by creating lists of what we think they do or what we think they believe based on assumptions about the group we think they belong to (De & Richardson, 2008). A further problem with this approach is that it tends to restrict cultural considerations to minority groups and has the effect of emphasizing the differentness of those who have less power and fewer resources. A third concern is that this approach suggests that "others" have culture and it often obscures or misses the importance of culture in social structures such as health care.

Coward and Ratanakul (1999) observe that health care itself is a culture, "with its own belief system, social structure, initiation rituals, lan-

guage, dress and educational system. Modern medicine does not occupy a neutral position from which to relate itself sensitively to other cultures. Rather modern Western medicine is itself a culture alongside other cultures — Muslim, Buddhist, Hindu, Chinese, etc.” (p. 13). Thus, we are urged to expand our view of culture to include a much broader and deeper set of influences on the behaviours that shape both the personal and the social (Stephenson, 1999).

An expanded view of culture positions us to understand culture as a relational process with accompanying power differences. Culture is embedded within a shifting set of meanings that are related to historical, social, economic, and political processes. Culture is neither reducible to an easily identifiable set of characteristics nor politically neutral (Browne & Varcoe, 2006). Such a view brings into focus not only relational processes but also the power differentials associated with different positions in society. We use relational processes to refer not only to interpersonal processes but also to the organizational and systemic processes that produce structural inequities affecting both the health of Aboriginal women and their ability to access care.

What is cultural safety?

Cultural safety is a concept developed in New Zealand to address the needs of Maori health-care users who were experiencing poor health outcomes as a consequence of cultural inappropriateness and insensitivity on the part of the health-care system (Ramsden, 1996). It has now become apparent that cultural safety has the potential to address the needs of a wide range of social groups when factors such as age, gender, sexual orientation, socio-economic status, ethnicity, religion, and different ability or lifestyle contribute to discriminatory behaviours or practices (De & Richardson, 2008). For example, nurses at Insite, a supervised injection facility, have identified cultural safety as an important aspect of caring for people with problematic drug use (Lightfoot et al., 2009).

Cultural safety is about recognizing one’s own privilege and the positioning of certain groups within a society (Anderson et al., 2003; Browne et al., 2009). It is predicated on understanding the power differentials in health-service delivery (Aboriginal Nurses Association of Canada, 2009). This understanding is critically important for redressing inequities — more important than what the members of a particular group think or do (Polaschek, 1998). The goal of cultural safety is to counter tendencies in health care that create cultural risk or cause patients to feel unsafe, which in turn can cause people to avoid or delay seeking care.

Cultural safety is based on health-care providers’ analyses of their own cultural selves, the cultural meanings that they bring to the therapeutic relationship, and their reflection on the broad structural factors that shape such interactions (Anderson et al., 2003; Browne et al., 2009). It calls for

recognition of the power imbalance that exists between providers and users of health care (Doutrick, Arcus, Dekker, Spuck, & Pollock-Robinson, 2012). Unlike transcultural nursing or cultural competence, which require the learning of cultural characteristics of particular groups and application of this knowledge to individuals, cultural safety demands that the provider form a relationship with the user such that the user is able to make a judgement about whether the therapeutic relationship is safe and appropriate (McEldowney & Connor, 2011). It is important to be culturally aware and sensitive to practices and customs, but it is *critical* to ensure that providers examine how their own beliefs, values, and assumptions can impact on the therapeutic relationships they form with their patients (Bearskin, 2011). Our cultural beliefs are internalized; generally, we do not consciously think about them. There is a tendency to perceive one's beliefs and practices as the norm and others as different. However, our beliefs form the basis of our judgements about people and events. In other words, the manner in which health care is provided starts from the perspective of one's own culture and an understanding of what the provider brings to the relationship and the culture in which care is provided. Cultural safety helps health-care providers resist the temptation to pigeonhole and stereotype based on beliefs about the group to which they think people belong.

The concept of cultural safety prompts nurses to reflect on the structures, discourses, and assumptions that frame the delivery of health care (Browne et al., 2009). It makes nurses consider the impact of not just relational processes but also systemic and organizational processes and their effect on patients. Cultural safety also prompts nurses to question their cultural selves and how their self impacts on those with whom they work. It allows us to form a relationship with patients that is based on the values and beliefs that each patient holds as an individual. Most importantly, cultural safety serves to remind us that the power relationship is skewed in favour of the health-care provider. In a culturally safe relationship, the service user is given the power to say when he or she feels that an encounter is safe or unsafe. A culturally unsafe relationship is reflected in signs that express a lack of tolerance for foul language or abusive behaviour. There are no signs warning against both subtle and overt behaviours that can affect patients' sense of safety, such as labelling patients as "frequent flyers" or "junkies." Cultural safety is a concept that can be used to operationalize equity and social justice in nursing and health-care practice (Anderson, 2003; Browne et al., 2009; Pauly, 2012). Given that inequities in access to health care are structurally produced and remediable (Whitehead & Dahlgren, 2006), cultural safety is a strategy that nurses can use to enact social justice in nursing practice.

From a perspective of culture that seeks to illuminate power inequities and to challenge organizational discourses and assumptions, cultural safety aligns with the goals of social justice in nursing practice. For example, the Canadian Nurses Association Code of Ethics specifies nurses' responsibility to not discriminate when providing health care, to preserve dignity, and to redress health inequities (Canadian Nurses Association, 2008).

## **Research Methodology**

### ***Theoretical Underpinnings***

Allen (1999) points out that cultures and cultural differences are constructed, and that unless this construction is well articulated, social inquiry will inevitably create an "other," an "outsider," a "not us." In order to minimize the potential for colonialist appropriation, we used a post-colonial feminist perspective to inform the research approach for the study. Such a perspective allows for identification of the multi-layered sociopolitical contexts of health and illness and for the inclusion of sub-altern voices (Anderson, 2000). Since the study sample comprised Aboriginal women whose voices are not typically heard within the health-care system, it was crucial that the research design provide ways of ensuring that their voices be heard.

### ***Research Objectives and Question***

This interpretive, descriptive, qualitative study had three objectives: to explore Aboriginal women's experiences of living with HIV/AIDS in their daily lives; to gain an understanding of how Aboriginal women living with HIV/AIDS experience formal support systems, including AIDS service organizations and health services; and to make recommendations for program design and policy development specifically addressing the needs of Aboriginal women living with or at risk for HIV/AIDS. The following research question was considered most pertinent to the study: *What are the experiences of Aboriginal women when they are accessing health care?*

In this article we focus on aspects of the findings that indicate whether the participants felt safe, with no fear of stigmatization and rejection, when accessing care.

### ***Methods***

The study used an interpretive descriptive methodology (Thorne, Reimer Kirkham, & MacDonald Emes, 1997). This is an appropriate methodology for such a study given that it acknowledges the constructed and contextual nature of human experience whilst allowing for shared

realities (McCall et al., 2009; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). Its emphasis on examining the constructed and contextual nature of everyday life made this methodology a good fit with the post-colonial feminist perspective that framed the study. A postcolonial perspective allows for identification of the multilayered sociopolitical contexts of health and illness and for the inclusion of subaltern voices (Anderson, 2000). Further, a postcolonial perspective fits well with the concept of cultural safety, which acknowledges that an individual's or group's positioning affects their experiences of the health-care system and that power differentials impact on patient safety.

Data analysis in interpretive description involves movement beyond the theoretical framework towards an abstracted interpretation that will illuminate the phenomenon being investigated in a novel and meaningful fashion (Thorne et al., 2004). The researcher becomes immersed in the narrative accounts in order to develop themes within each account and, through constant comparison, to describe patterns between and amongst the narratives (Irwin, Thorne, & Varcoe, 2002).

### ***Ethical Considerations***

Strategies to protect the participants' identities included the use of a unique code number for each person on all data sheets, avoidance of participant identification in transcripts and analytic memos, and the use of fictitious names in the final report. Ethical approval was obtained.

### ***Sample***

The sample consisted of eight Aboriginal women who self-identified as HIV positive. This number aligns with the recommendations of Sandelowski (1995), who proposes that qualitative studies to capture the essence of experiences have approximately six participants. Participants were recruited through one inpatient HIV unit and one outpatient HIV clinic. Nurses at these sites identified potential participants, gave them information about the study, and asked them if they were willing to be approached by the researcher. If the women agreed, the researcher approached them, reviewed the study protocol to ensure that they understood it, and obtained their consent.

### ***Procedure***

Data were collected via in-depth semi-structured interviews, which were audiorecorded and transcribed verbatim. The interviews took place in private rooms at the two sites. Interview questions were broad-based "trigger questions" intended to stimulate conversation. For example, the women were asked to tell the researcher about their experiences in the

hospital. The participants' responses were used to generate more in-depth exploration of a particular area.

### **Data Analysis**

The transcripts were read repeatedly to identify recurring, converging, and contradictory patterns of interaction; key concepts; emerging themes; symbolic examples; and possible connections to the underlying theory. The transcripts were coded and emerging themes and categories were identified. The emerging themes and categories were reviewed with two of the participants in a follow-up phone interview; the insights and feedback of these two participants were incorporated into the analysis.

### **Findings**

The study produced some disturbing data (McCall, 2006). The women in the study were subject to marginalization in a variety of ways. They were of Aboriginal ethnicity, they were HIV positive, and a number of them used illicit drugs. Although they lived in a province with a universal HIV treatment program, most of the women were not being treated for their HIV infection and five had AIDS-related illnesses. Previous research has shown that the lack of medical follow-up for HIV is an issue, so this finding was unsurprising (Legare et al., 2003; Wood et al., 2003). A number of themes emerged. These included *looking for friendship*, *finding strength in adversity*, *the struggle to stay well*, and *HIV is just one problem among many*. All of these themes are relevant in some way to the concept of cultural safety, but the theme that is most relevant and that will be explored in this article is *fear of rejection* (McCall, 2006).

Fear of rejection by health-care providers is clearly linked to feelings of being unsafe as a result of the marginalizing social processes of stigma and discrimination. There is a wealth of research, particularly that conducted amongst people who use drugs, indicating that fears related to rejection or poor treatment are significant barriers to accessing health services (Latkin et al., 2010; McLaughlin, McKenna, Leslie, Moore, & Robinson, 2006; Room, 2005). Whilst not explicitly stated, such fears are underlaid with concerns related to stigma and discrimination, with implications for future access to health services and the development of trusting relationships with health-care providers (Browne, Johnson, Bottorff, Grewal, & Hilton, 2002; Pauly, in press). The finding of fear of rejection is discussed in this article with an emphasis on how it relates to Aboriginal women's sense of safety when accessing the health-care system and implications for the delivery of culturally safe care.

The participants all indicated that fear of rejection had a significant influence on how they lived their daily lives, including who they dis-



closed to, who they associated with, and where they lived. All but one of the women chose to live in a large city, where they believed they would be less subject to stigma and to censure by their neighbours and by service providers. As reserve communities are small and not conducive to maintaining confidentiality and anonymity, almost all of the women isolated themselves from their families and traditional support systems in order to protect their privacy.

The women spoke of both a reluctance and an inability to access health care due to fear of rejection or poor treatment. Cathy<sup>1</sup> said, “Why should I put myself in that position? I know what they’re going to say and what they’re going to do . . . I don’t go to the hospital until I’m practically dead.” Elizabeth, who had gone through a miscarriage, described her experience in a hospital emergency room: “I told them I was HIV positive, pregnant. They just — they were so cold.” Justine found it difficult to bear the stigmatization and the disregard for her positioning in society: “We’re mainly labelled as the drug addicts and the prostitutes and the unworthy, right?” Elizabeth’s lifestyle precluded access to the health care she needed. She acknowledged that “leaning on the crack pipe” made it difficult for her to get to the clinic during its regular hours. People who use substances often prioritize their needs because it is difficult to manage their addiction. The women’s experiences speak to fears about labelling by health-care workers and reflect the values of the dominant society with regard to who is worthy and unworthy. Labelling of these women served to associate them with the drug culture and the sex trade, in accordance with social norms, and subjected them to censure and judgement.

All of the women were reluctant to disclose their HIV status to health-care workers because they feared that confidentiality would not be respected and that they would be judged and censured. They were concerned that their status would be disclosed to other health-care providers and other patients without their consent. Fiona said, “When they ask me if I have \_\_\_\_, I just say, ‘Look in my file,’ you know, because sometimes they ask me in front of a whole bunch of people.” After Elizabeth’s daughter was born, a nurse disclosed her status in front of some other patients and their visitors: “And the nurses and everything, they didn’t even care, they just blurted everything out right in front of everybody else . . . and right away they threw it an AIDS case: Look at what you did to your kid . . . How can you live with yourself? What kind of . . . woman are you to have kids in the first place? . . . You shouldn’t even have sex.”

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<sup>1</sup> All names are fictitious.

The women also experienced some overt stigmatizing behaviour. Cathy spoke of having “doctors who won’t even let me in their office because they figure I’m going to infect everything, infect their whole staff members.” Mary spoke at length about her negative experiences with health-care workers: “I’ve had some experiences with health care in hospitals . . . when I had my daughter. God. They had big signs saying I was positive and, you know, the whole nine yards — the gown and the mask.” Aboriginal identity complicated the stigmatization. Fiona explained that her Aboriginal identity made her a target for discrimination: “Being First Nations, well . . . it just makes it worse. People treat you badly.” It is clear that these women were subjected to intersecting stigmas of gender, race, ethnicity, lifestyle, socio-economic status, and disease, which made it that much more difficult for them to navigate the health-care system (Benoit & Shumka, 2009; Wailoo, 2006). They recounted numerous episodes of judgemental and racist behaviour by nurses and others. In addition, the participants felt that nurses did not take the time to develop a therapeutic relationship with them based on communication and respect for or understanding of them as Aboriginal women.

Fear of rejection is almost universal amongst people living with HIV/AIDS (Paxton, 2002), but the fear of rejection expressed by the women in this study was complicated by a number of intersecting factors, including assumptions around “bad” behaviour such as illicit drug use or sex work, the idea that they were polluted in some way, and the perception that they posed risks to others. The racism that is inherent in the lives of many Aboriginal women compounded the stigma. The fear of rejection is unsurprising when the context of their lives is considered. Most of the women had experienced poverty, abuse, and issues around substance use, and these factors intersected with their social positioning as Aboriginal women and concomitant racist stereotyping. They all had firsthand experience with rejection on many levels. There are many dimensions to HIV/AIDS-related stigma, and the women’s personal and social vulnerability put them at high risk for rejection. They were already experiencing marginalization and exclusion, so they were pushed even further away from the supportive elements of human society (HIV/AIDS Legal Network, 1999).

Wood and Schwass (1993) describe culturally unsafe practice as that which diminishes, demeans, and disempowers. It is clear from the women’s stories that they experienced not only a feeling of being unsafe but also a lack of culturally safe care. A predominance of culturalist discourses in nursing and health care use popularized, stereotyped representations of culture as the primary analytical lens for understanding presumed differences in various groups (Browne et al., 2009). These marginalizing processes create cultural risk. It is important for nurses to

examine their own selves as well as the systemic and organizational processes that put patients at risk for marginalization within health care and that perpetuate rather than mitigate harm. This is essential in order to promote access to health care and to ensure that Aboriginal women receive appropriate and adequate treatment. It is ethically concerning to think that women in need of care are not receiving it because of their social position.

### ***Culturally Safe Nursing Practice***

It is clear that the women in this study felt unsafe within the health-care system. They related experiences of being judged and stigmatized by the health-care workers with whom they came in contact. It is apparent from their stories that assumptions were made about them based on their “culture,” drawing on societal norms related to drug use, HIV status, gender, and Aboriginal identity. The findings suggest that women often delay or avoid seeking health care as a consequence of feeling unsafe. This has significant implications in terms of both timely access to health care and their ongoing health and well-being.

The first step towards the provision of culturally safe care is for health-care providers, including nurses, to engage in a process of self-examination. Being aware of one’s own culture, including dominant values and beliefs as well as privilege, is essential in recognizing how innate concepts impact on others. According to Regan (2005), “unsettling the settler within” is required in the effort to move from unconsciousness, denial, racism, and guilt about our history to an attitude of critical inquiry, reflection, and social action in which history is used as a catalyst for change. Hart, Hall, and Henwood (2002) propose that practitioners develop an “inequalities imagination” to help them understand how different constellations of disadvantage can come into play for their patients. In this approach, health professionals take a questioning attitude towards the subject of inequality and disadvantage. It allows the practitioner to reflect upon and adopt strategies that will close the inequality gap and lead to safe care. Such a process is particularly important for the population from which the participants in the present study were drawn, as these women were clearly disadvantaged in a number of ways, including poverty, gender, identity, historical trauma, and HIV status.

Culturally safe nursing practice is about acknowledging people’s differences and taking these differences into consideration when drawing up each plan of care. It is about providing care that is regardful, not regardless, of difference. It is important for the nurse to establish a partnership with the patient that fosters respectful, holistic care (Bearskin, 2011). Fulcher (2002) describes this partnership as a “ritual of encounter” that uses a cultural lens along with a baseline assessment. A ritual of

encounter is based on four criteria: positively expressing caring, understanding cultural practices, understanding the patient's background, and purposeful relationship building. For women such as the participants in the present study, who had negative health-care experiences on a frequent basis, it is important to establish a relationship based on trust and respect. It is imperative that they be partners in care and be given an opportunity to contribute to the decisions that are made about their treatment.

Two important considerations in the provision of culturally safe care are respect and communication. Nurses must endeavour to develop a therapeutic relationship that gives patients a safe space in which to communicate their needs and preferences. There are significant power differentials between health-care practitioners and people who are marginalized. These power differentials can make it difficult for those requiring care to communicate with health-care providers, who are perceived to be in a position of authority. Nurses need to be alert to subtle forms of communication such as non-verbal behaviours and need to create an environment that gives patients the confidence to express their needs and wants. People who are frequently marginalized and mistreated by the health-care system are very sensitive to non-verbal cues (Latkin et al., 2010). Even seemingly innocuous behaviour such as not responding to requests immediately or failing to make eye contact may be misconstrued as rejection.

The concept of cultural safety was developed to address the structural inequities that have been part and parcel of the experience of colonized Indigenous peoples, although it has become apparent that in fact this is a general concept that can be applied to other oppressed groups. Nurses need to routinely ask themselves and their clients if the health-care situation in which their patients find themselves can be considered safe. The cultural dimension in health care is not an abstraction. It is located in a specific context that structures relationships between care providers and patients (Polaschek, 1998). Cultural safety is an integral aspect of ethical nursing practice.

## **Conclusion**

It is crucial that patients feel safe when accessing and using health care. When patients feel unsafe, they delay treatment and avoid accessing health services. The participants in this study faced barriers to forming therapeutic relationships with the providers with whom they came in contact, due to a lack of communication and a sense of powerlessness and fearfulness about how they would be treated. The women's experiences of judgement and stigma compounded their discomfort with the care

that was provided. The findings show clearly that the women felt unsafe. Through the use of a cultural safety framework, nurses are able to develop therapeutic and safe relationships with their patients. When nurses practise in a culturally safe manner, they not only help to improve the lives of their patients but also stand to achieve a heightened state of self-awareness and professional growth.

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