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Acknowledgments

Executive Summary

This investigation of First Nations women's encounters with mainstream health care services was carried out in a small reserve community in northern British Columbia. A qualitative research design was used, comprising a series of two interviews each with 10 First Nation women.

Women described their encounters with health care services under broad categories of invalidating or affirming. Although this report examines invalidating encounters in greater detail than affirming encounters, the discrepancy reflects the emphasis provided by the research participants. Both types of encounters are described along with their influences, and policy implications are raised and listed in the authors' conclusions. The women's stories may be read as illustrations of the broader social, economic and political forces at work influencing the lives of First Nations women in relation to the dominant social systems.

A second phase report on this research will examine in greater detail recommendations for change and possible alternative strategies to address the issues raised in this phase.

II

Background

First Nations women's encounters with mainstream health care practitioners influence their access to and utilization of these services (Browne, 1995; Frideres, 1994; O'Neil, 1989; Sherley-Spiers, 1989; Waldram, 1994). Although there have been numerous studies examining the nature of women's interactions with physicians in particular, few studies have described the ways in which First Nations women experience their encounters with providers and other aspects of the health care system.

The purpose of this study is to describe, in depth, Aboriginal women's encounters with mainstream health care services with a long-term view to generating ideas for improving health care delivery and policy. Building on previous work conducted by the project leader (Browne, 1993; 1995; 1997), attention was given to the issue of respect in the context of health care interactions between First Nations women and mainstream health care providers. This research adds to previous work undertaken by the BC Association of First Nation Women (Todd-Denis, 1996) and the First Nation Women's Group of Prince Rupert (Angus, 1995), and is informed by studies that have discussed or investigated the range of factors influencing First Nations peoples' encounters with the dominant health care system (Culhane-Speck, 1987; Dion-Stout, 1996; Dion-Stout & Kipling, 1998; Hooper & Hagey, 1994; O'Neil, 1989; Sherley-Spiers, 1989).

III

Objectives

The impetus for this study arose out of a series of community meetings involving northern women held by the Northern Secretariat of the B.C. Centre of Excellence for Women's Health (BCCEWH) located at the University of Northern British Columbia (UNBC). At these meetings we learned that First Nations women's encounters with mainstream health care systems and services were of particular concern. Discussions revealed that these encounters influenced not only the health and well-being of First Nations women, but also the health of their families and communities. In order to recommend changes to the health care system at either the micro or macro levels, more needed to be learned about the nature of women's encounters and the ways in which these experiences affected their health and well-being.

Two research questions guided our study:

• How do First Nation women describe their encounters with local, mainstream health services?

• How do these encounters influence the health and well-being of First Nation women?

IV

Research Methods

A. Design

In developing our qualitative research design, we were concerned with understanding women's accounts of their health care experiences from their own perspective. For this reason, we were influenced by phenomenological strategies of inquiry (Van Manen, 1997) and women-centred ethnographic research approaches. Understanding women's lived experiences, and accepting them as real and valid, for the purposes of "disclos[ing] the social processes from within as it is lived," are among the major principles women-centred ethnography shares with phenomenology (Smith, 1986, p. 12). Women-centred research principles can be conceptualized as having three broad goals: (1) to document the experiences and activities of women, (2) to understand these experiences from their point of view, and (3) to discern women's behaviour as an expression of social contexts (Reinharz, 1992). An egalitarian approach to the research process was a grounding principle shaping this study, which provided the opportunity to understand participants' narratives and their connections with social and political praxis (Enslin, 1994).

B. Data Collection

This study was conducted in a Carrier First Nation reserve community located in the northern interior region of B.C. This community was selected in part because of the renowned leadership in health provided by several community women, among whom are elders, health professionals and community leaders. The strength of female leadership reflects the respect the Carrier, who are a matrilineal society, bestow on women and the value placed on the authority held by female elders within extended family units. Additionally, two members of the research team have had a long-term working relationship in the community, which facilitated initiation of this research endeavour. In turn, the community believed that it would benefit from documentation of women's encounters with the local health services systems as it developed short and long-term goals for improving access to and utilization of health services for community members.

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The study was granted approval by the UNBC Ethical Review Committee before data collection began. Additionally, the Royal Commission on Aboriginal Peoples Guidelines (1993) for research with First Nations were followed. To this end, a memorandum of understanding was signed between members of the research team and the First Nation community outlining the research process, ethical principles, and ways of sharing control over data collected (Appendix 3). Finally, the women provided written consent before participating, confirming their understanding of the purpose of the study and the ways in which the results were to be used.

We conducted in-depth interviews with 10 women. Community leaders, elders and the investigator who was based at the reserve selected the participants using a purposive sampling procedure. Although general questions provided guidelines for discussions (see Appendix 2), participants were able to direct the conversation according to their preferences. As illustrated in the type of general questions posed, an effort was made to elicit participants' descriptions of "model case" encounters and "contrary case" encounters as a way of gaining an understanding of both positive and negative interactions (Browne, 1995;

Kaufert, Koolage, Kaufert & O'Neil, 1984).

All interviews were taped and then transcribed verbatim. Second interviews were held with all participants, except one who became ill, to validate and clarify information discussed in previous interviews. To maintain consistency in interviewing, all data were collected by one researcher. Field notes were recorded as soon after the interviews as possible in order to capture issues or insights related to interview content or process, to provide methodological notes for the research team, and to make theoretical connections to other studies and literature.

C. Data Analysis

Data obtained from interviews and field notes were treated as text, or text analogues. The interpretive thematic analysis was primarily guided by principles and stages identified by Van Manen (1997). First, the narrative text was reviewed as a whole by the research team for an overall understanding of the text. Second, the text was read repeatedly to identify patterns of regularities, and recurring ideas and experiences that linked participants' perspectives. Through this process we drew categories and themes from the data. Third, through critical questioning and by reflecting on the theoreti-

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cal perspectives, we developed further themes and linked these with sections of the narrative text. Fourth, as themes and categories emerged from the data, we sought critique and validation from community participants. Finally, excerpts of data and the themes and categories they illustrated were discussed with an outside qualitative research expert who assessed the degree of reliability within the analysis. Throughout the data analysis process, the "decision trail" (Guba & Lincoln, 1981) was spelled out so that others could audit the process.

D. Theoretical Perspectives

Following analysis of the text, we turned to issues of political economy and the position of the First Nation community relative to the decision-making structures that constrain health practice. How the women perceive and respond to health delivery services today reflects the consequences of a century of power politics in which decision making and policy development have remained in the hands of the dominant society. Like many First Nations in Canada, the people of this First Nation, whether they reside on or off the reserve, find themselves at the margins of the local political economy and virtually excluded from the powers of the state, whether these be the decision-

making bodies of federal, provincial or municipal regimes, or the democratic institutions of non-government organizations and social movements. As Frideres (1991) has argued, the linkages between government and non-government institutions are a dimension of the dominant health system; the power relations embedded in them, and the normality that they come to represent, are taken for granted by those who benefit from them to the extent that anyone who is excluded risks being seen as deviant. Cast as outsiders by social processes, First Nations are represented as the "other", a representation that is perpetuated through the colonial-like structures of mainstream health institutions.

Building on the concepts of "structural communication" (Arno, 1985) and "cultural safety" (Cooney, 1994; Ramsden, 1992, 1993; Wood & Schwass, 1993), we sought understandings of the structural barriers the women encountered and of the social and health implications of these barriers. We were concerned with the way structural communication reinforced inequality between First Nation and non-First Nation authorities, giving the state influence over local ideas and actions that affect women's cultural safety. Cultural safety moves beyond notions of cultural sensitivity to an analysis of power imbalances,

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institutional discrimination, and the nature of relationships between the colonized and colonizers as they apply to health care interactions at the macro and micro levels. The principles of cultural safety can be gained by understanding their antithesis, culturally unsafe practices:

"Any actions that demean or disempower the cultural identity and well-being of an individual. The crucial elements within the cultural safety concept are that unsafe practitioners diminish, demean and/or disempower those of other cultures, whilst safe practitioners recognize, respect and acknowledge the rights of others" (Cooney, 1994, p. 6).

Ultimately, cultural safety is concerned with changing attitudes and with gaining an awareness of the political and historical forces shaping the dynamics of health care interactions with Aboriginal people.

Repeatedly, participants who worked in health care commented on the limited impact of conventional cross-cultural training programs on providers' attitudes and behaviours. Recognizing this limitation, "cross-cultural training" could be better accomplished by deconstructing clinical interactions and studying them in the wider context of political, economic, historical and social determinants. The principles

of cultural safety provide a lens through which "cross-cultural training" could occur. An excellent model for this type of instruction is found in Kaufert, Koolage, Kaufert and O'Neil (1984) where "trouble cases" are used to examine the influence of socio-cultural and political factors on clinical communication.

Conditions of cultural safety, however, cannot be achieved solely through individual interactions. Relations of structural communication must be radically altered to allow for transfers of power to First Nations governments. Cultural safety can be achieved only through meaningful participation in decision making, that is, decision making that moves beyond marginalization to enhance rather than dismiss or violate cultural values and social practices. These premises, although expressed somewhat differently, underlie the "population health approach" advocated by the Canadian state, which calls for recognition "that a state of best health is not merely a function of physical capacity, but is also closely related to a whole set of personal and social resources" (Dion-Stout 1996, citing Standing Committee on Health 1995). Whether we draw from precepts of cultural safety or from the population health approach, we find that a key expression of women's health lies in encounters and prac-

tices that uphold "the high esteem that Aboriginal women bestow upon human life and family," and contribute "to Aboriginal social stability and social integration, thereby creating a healthy living context for Aboriginal women" (ibid.).

The concepts of cultural safety and structured communication help us to understand how political economic structures constrain isolated efforts to reform policy and practice. Hence, we now turn to a description of the historical and political context of the First Nation.

E. Community Setting

The First Nation with which we conducted our study has a population of 600 members, the majority of whom live on-reserve. Their community is located in a rural area, 20 kilometres by country road from a small rural non-Native municipality (population 4,400). A highway connects the First Nation community to a northern regional city (population 80,000) 125 km away. The largest southern urban city is 1,000 km to the south by road or one hour by jet from the regional city. An overview of the range of health care services in each centre utilized by women from the reserve is provided in Appendix 1.

Relations between the First Nation and the dominant community are marked by a hierarchy of power sites that disadvantage the members of the First Nation and bind them in relations of structural communication. Unlike the neighbouring rural municipality, the reserve community suffers from intolerably high rates of unemployment, underemployment, and reliance on social transfer payments. This leads to a social distance between the "white" and First Nation societies that has a marked impact on social well-being. Only rarely are members of the First Nation invited to join decision-making bodies, and on those occasions they are often invited as a sole representative (for example, on the Regional Health Board), giving rise to feelings of tokenism and frustration because of the inability to bring about meaningful changes to their circumstances. Pushed outside the social network that underlies the voluntary sector, the reserve community does not directly share in the socio-economic benefits garnered by voluntary agencies. This exclusion from essential decision making and the continuance of culturally alien educational and health practices has led the governing council of the First Nation to build its own health clinic and school.

In keeping with the federal government's constitutional duties to all Aboriginal peoples it recognizes as status Indians, members of the First Nation community receive some

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non-insured health benefits through the federal government Medical Services Branch. Although this service is a federal obligation, it has given rise to resentment from members of the dominant society respecting "free" health services and is often seen as an extension of welfare or charity. As we shall see, members of the First Nation are acutely aware of this resentment and recognize that these perceptions contribute to negative stereotypes and the process of "othering" that alienates them from public services.

All medical doctors in the nearby rural municipality work from a common medical clinic located near the municipal hospital. It is easy to understand the alienation felt by First Nation women who rely on these services. There are no First Nation employees. The clinic's routines are determined by the needs and expectations of the dominant community, both in relation to the organization of work as dictated by the medical fee system and in its spatial and temporal organization. The small reception area and adjoining waiting room do not allow any privacy, nor are disabled patients well served by the reception desk which consists of a high counter that blocks reasonable communication between chairbound patients and staff.

Timely patient schedules are a priority; the clinic charges a $20 fee for missed appointments. This practice, as we shall see, discourages the building of healthy patient/doctor relations because it is perceived as unnecessarily punitive by women who are unable to organize their lives by the dictates of the clock. The 20-kilometre trip to the clinic is not easy to arrange; a patient who neither owns a car nor has regular funds to reimburse others for travel expenses may be unable to prearrange a ride that will bring her to the clinic at the appointed time. She may be forced to hitch-hike, an unpredictable and risky way to travel. In many cases she will not be able to avoid the $20 penalty as she will not have a phone to call and cancel her appointment. In consequence, a woman may choose to avoid the clinic when she or her family members become ill and turn to the emergency services at the hospital, which again blocks the establishment of sound patient/doctor relations. These avoidance strategies do not alleviate the stress and humiliation felt by the women, but only serve to postpone an inevitable confrontation with clinic personnel.

Contemporary power relations are troubled by a cultural legacy of mistreatment and abuses that arose in past decades, in particular in educational practices. From 1917-

1946, children of this First Nation were compelled to attend residential school in order to receive an education. In 1946, a day school was opened on the reserve; however, many families continued to have their children placed in the residential school, often during times of stress and economic hardship. As has been made evident from recent disclosures of former students, abuses were common in the schools. Of all the privations and sufferings none is seen as more personally harmful than sexual abuse, which creates a lifetime of fear, humiliation and mistrust. Individual sexual violence, however, is not the only harm that carries through to today. The very strict teachings of sexual modesty and morality have also left their scars, not the least of which can be a sense of shame of one's body and therefore a fear of exposing it to medical staff. This dilemma is compounded by the lived extremes between ideals of sexual morality and lived experiences of abuses and hurts. A further consequence of residential school, which was strongly emphasised during the community review of our draft report, arises from imposed ideology of stoicism and suffering. As young girls, former students were taught to suffer pain in silence, which today leads women to avoid

seeking health care until they experience extreme symptoms. In sum, as we detail below, the combination of these complex, strained social and political relations affects the capacity of women to be accepted as credible medical subjects.

V

Findings

Two broad themes emerged from the analyses of participants' discussions of encounters with mainstream providers and services. These were identified as *invalidating encounters* and *affirming encounters*. Invalidating encounters occurred on a variety of levels that formed six patterns of experience. Similarly, affirming encounters were manifested in a variety of ways. For the purpose of this report, emphasis is placed on invalidating experiences because these were given greater attention by the participants, and because they point to possible policy reforms that could counter such experiences.

A. Invalidating Encounters

1. Being dismissed

Participants described situations in which their health concerns or subjective symptoms were not taken seriously, were trivialized, or were dismissed by health care providers, predominantly doctors or nurses. In many cases, participants felt that nurses and doctors assumed there was nothing wrong before assessing the patient's condition. The following excerpt captures this sense of dismissal.

"But a lot of these nurses, when they see Native people coming, they always tell them, 'No this is no problem. You shouldn't worry about it' and send them on their way, then they get more sick. I don't know. . . But some of these nurses that work in the clinics, they're really intimidating. They assume that nothing's wrong with you."

In addition to feeling that their concerns were dismissed by providers, participants expressed their sense of not being "listened to" by their providers. One participant, who works in health care, offered an explanation for providers' failure to listen to women from her community in the following way.

"Only problems I've had were with people who didn't listen to you. They think they're the nurse or the doctor and they don't really listen to what you're saying. That's the only problem I've had with them. Maybe be-

cause I'm Native. I don't know. You're not supposed to know these things. {laugh} That's the feeling I got from them, eh?"

This participant questions whether her provider's dismissal of her concerns stemmed from his or her views of her as a First Nation woman. This was not an isolated interpretation of the underlying causes of dismissive attitudes by providers; other participants expressed similar views, pointing to the ways in which the process of "othering" constructs Aboriginal women as patients who are "not supposed to know these things."

The risk of being dismissed was compounded by women's reluctance to admit to pain or outwardly express suffering, which they explain is what they had been taught by their Catholic teachers in residential school. Paradoxical situations are then created whereby a woman may wait until her condition is severe before seeking services, yet past experiences cause her to fear that she will be dismissed by her provider.

Participants felt that dismissal of their concerns was also related to providers' perceptions of First Nation women as passive participants in health care interactions.

Participants felt that dismissal of their concerns was also related to providers' perceptions of First Nation women as passive participants in health care interactions. However, participants described that what is assumed to be passivity during a clinical interaction is actually a culturally specific way of conveying respect to people who are consulted for advice or assistance. Furthermore, participants described how residential school staff reinforced this culturally defined behaviour in order to encourage conformity and lack of assertiveness. The propensity to be viewed as passive or unassertive created anxiety as participants worried about the possible consequences.

"I think that the one that had the biggest impact was someone that my mother knew when she lived in [the regional city]. She knew someone who went to the hospital and was very sick and was turned away because they thought maybe she was drinking or something. And I think that the woman went home and died, and that was quite horrible and that's kind of always, kind of haunted me. When I think of my mother going to hospital, maybe getting turned away because she's not aggressive. . . If they said they didn't want to see her, she would go [leave the hospital] even if she was really sick. You know, she's older. . . Anyway she was turned away for whatever reason and I think that if someone the same age would go there, who is not First Nations, who's white, they would have taken her because that's just the attitude."

It is not difficult to see how this combination of factors – dismissal on the part of providers, getting turned away, reluctance to admit to symptoms until they are severe, and providers' views of women as passive – creates the potential for tense or difficult health care interactions and potentially poor health outcomes for women.

2. Transforming One's Self

Participants described situations that they believed could be improved by transforming themselves in terms of appearance and behaviour. These acts of transformation were understood as a means of obtaining credibility and reliability as medical subjects. One participant described her experience in the following way.

"It seemed like any time I go to a doctor I would have to be well dressed. I have to be on my best behaviour and talking and I have to sound educated to get any kind of respect. That's what usually happened. If I went in, if I was sicker than a dog and if I didn't want to talk and I didn't care how I sounded or whatever, I'd get treated as such, like lower than low. But if I was dressed appropriately and spoke really well like I usually do then I'd get treated differently. . . Now why should I have to act like . . . not act, but why do I have to try harder to get any kind of respect? You

This participant felt that if she dressed well and presented herself as an educated person, she would be less likely to be dismissed.

know, why do I have to explain?"

The statement above about "having to try harder" is significant. This participant felt that if she dressed well (according to a standard understood to be appropriate for health care encounters) and presented herself as an educated person, she would be less likely to be dismissed. These stories help to illustrate the double bind that participants face. To accept responsibility for transforming oneself is to affirm judgements of incredibility or inadequacy in the eyes of health professionals.

In other circumstances, the situation was ironically reversed: participants were recognized by providers because of their leadership positions in the local community and were afforded what they understood to be special treatment. Participants described this special treatment either as tokenism or as occurring because of providers' concerns about a participant's capacity to be politically influential. Thus, participants were unable to take for granted the attention bestowed upon them by physicians in particular, and criticized the doctors' actions with skepticism.

3. Negative Stereotypes about Aboriginal Women

Participants' understanding of their overall relationship to the dominant health care system and health

professionals cannot be interpreted outside of the larger socio-political context stemming from the colonial legacy of paternalism in health care to First Nations people. The prevailing reality remains that "health care institutions are powerful symbols of a recent colonial past. In this context, seemingly innocuous behaviour is often considered by patients as racist" (O'Neil, 1989, p. 341). Given this socio-political and historical context, it was not surprising that encounters with discriminatory attitudes and behaviours were pervasive throughout participants' stories.

In some cases, participants realized that they were judged in stereotypical negative ways and treated accordingly. In other situations, participants described a pervasive sense of everyday encounters with racism and saw health care interactions as just one example of taken-for-granted experiences of discrimination. Subtle, everyday expressions of discrimination were encountered, for example, when participants showed their Department of Indian Affairs status card at dentists' offices, at the pharmacies, or when making purchases in the rural municipality. Two participants described their perspectives of everyday experiences of discrimination:

"I think too there's really a myth out there in the general society that First Nations people get everything. You know it's like they get their education paid, their medical paid. Anytime they want money they go to the government and it's handed to them and I think that's another misconception that's out there."

"Oh, I don't usually like to talk about discrimination because, you know, it seems like it's an ongoing thing and you have to be, it takes a lot of energy to be dealing with it all the time. And I think for myself I only deal with it maybe not even 50 per cent of the time. Like 30 to 40 per cent of the time I confront it when it happens. Sometimes instead of making the decision, I will just let it go or whatever. Because it's just energy draining. The negativity for me is, it just takes a lot of energy."

Perhaps the most troubling consequences of the colonial legacy in health and social service sectors are the discriminatory judgements levelled against Aboriginal women as mothers. Repeatedly, stories were shared that described how participants were viewed as negative stereotypes, an act that denies the centrality of mothers within Carrier communities. The most dramatic example was described by one participant as follows.

"I just had my first child. I was very

athletic. I played fast ball. I got hit in the face with a ball and my forehead was all swollen. I ended up having a black eye. And just at that time I saw Dr. K. He was my doctor and my daughter had a really bad rash on her bum and over the weeks he was trying different creams and it just got worse. It got really, really bad. Nothing helped and she got a fever one night and this is when I had the black eye. I went into the emergency. I had this black eye. I had my daughter, screaming, fever. Her bum was just really red and raw and they took her away from me. They apprehended her from me right there. As far as they were concerned because of the way I looked, and because they didn't check on her previous history, they apprehended her. And they didn't tell me right then and there. They told me the next day when I went to try to visit her because they kept her. And they wouldn't let me see her. They tried to prevent me from seeing her. . . And I just raised hell and I got hold of my mom and my family. . . Because I had a really good record with my own personal doctor. . . They didn't even contact him to ask what the history was and he was outraged. So, a few days after that, they contacted him and he set them straight and I was still upset. But they allowed me to visit, to see my daughter again, but I was still upset and I said I was going to take legal action against that. And they wrote me a letter of apology and regretted the whole incident and I couldn't believe it, and it just shows you, I said, just because I'm a Native person that came in with a black eye, that looked like I wasn't, you know, because my child had a really bad, severe rash, they just assumed the worse. And I said, 'You didn't even know who I was.' . . . It was just because of how I looked, eh? . . . So it just shows you what extremes people go to in making assumptions about another person based on race. . . . I was so hurt. I've never trusted doctors after that because I was very reluctant to bring my daughter in. Anytime she was sick or anything, that incident always comes back to me and I think, I don't want to ever go through that again. I don't want to be judged morally, that I'm a bad mom. I don't want to ever be judged like that again."

This apparent denigration of participants' roles as mothers is particularly troubling considering the leadership roles that some participants hold in the community, and their influence as female leaders in both non-traditional and traditional arenas (Fiske, 1992). These stories of negative stereotyping also underscore the perceived need for participants to transform themselves into credible medical subjects in order to be treated appropriately.

Participants who worked in health care also described the discriminatory attitudes displayed by providers toward Aboriginal women with substance abuse problems, and homeless persons who received services in emergency departments or hospital wards. In some cases, participants who worked in health care described how services were sometimes withheld from known alcoholics or street people. A health worker, for example, cited cases in which physicians had refused to treat certain individuals or had failed to provide adequate care even when a health worker had challenged the physicians to do so. As one participant said, "I feel that they're being treated, well, just like a piece of dirt. They talk to them like that . . . I had to tell one of [the physicians], 'It's still up to you, it's still your responsibility to make sure that he's okay.'" In other situations, participants described their sense of bearing the blame and burden for other women's substance use problems.

4. Marginalization from the Mainstream

Participants also described their experience of discrimination in terms of marginalization from mainstream health services. They expressed their sense of being on the "outside", as "intruding" on the system and as lacking connection to the social processes inherent in mainstream health systems. One participant described her impression as an "outsider" during visits to the medical clinic in the nearby rural municipality. She contrasts her experience with observations of non-Native women's propensity to navigate health care situations.

"I think with white women, they're more vocal, their families know one another. I go into the clinic and I see white people talking to each other, asking about sons, people that are common to each of them. You go, you have a Native person come in, you don't hear that exchange and conversation between Natives and whites saying, 'Oh, how's your family?' That really doesn't happen. So there's that. The social factor. We don't socialize together. So it's us and them. And we feel like we're using, we're intruders on their system. A lot of times, I feel that way. And probably a lot of Native people would feel the same, I think. That we're intruding, it's their service."

Paradoxical situations are created whereby the taken-for-granted dominant styles of social discourse do not necessarily include the style of social discourse with which participants are comfortable. The lack of participation in the "small talk" that occurs at the clinic carries the potential to further reinforce the

perception of Aboriginal women as others, as outsiders or as intruders on the system. The sense of marginalization continues to occur despite the fact that the reserve community and rural municipality are separated by only 20 kilometres of farmland and there is an ongoing flow of business from the reserve to the municipality.

5. Situations of Vulnerability

Participants described a common consequence of attending residential schools: an extreme sense of vulnerability when having to expose their bodies for physical examinations. One woman described her own experience at having to undergo a full physical exam for the first time as a young woman.

"I don't know why, I didn't want anybody to look at my body. Because we were told not to show our bodies. Maybe it has to do with our upbringing and by the way we were taken out of our homes and told to be ashamed of our bodies. Like in [residential school] they used to tell us we're just Indians, they call us worse names but I don't want to repeat what they call us. That we're forbidden to look at anybody, even the opposite sex, so you had a dislike for your body and your person, as a Native person. And I was scared. I was embar-

rassed. The doctor, I guess somehow I went through that and I really didn't like it. Every time I saw the doctor after that I was, didn't want to look at him. But now I'm a mature woman I look at it differently because I work in the nursing field too. . . It's just like a routine thing so now I understand. But when I was young . . ."

In the context of the recent disclosures of abuses endured at residential schools, it is understandable that some Aboriginal women would be reluctant to seek out health care encounters involving bodily exposure in order to avoid feeling invalidated or shamed. A younger participant described a similar sense of vulnerability experienced by Aboriginal women who may not have attended residential schools, but who had been physically or sexually abused in other situations.

"There's lots of sexual abuse too that happened, probably still happens in the community, and younger women, they hide their bodies. They don't want to draw any attention to themselves or to their physical ailments or whatever or because they're afraid to let anybody touch them because of the sexual abuse that's happening. Myself, I was sexually abused so I sort of know the feeling of being examined the first time by a doctor, I was ashamed. So you have to deal with that. And the doctors are not

The $20 fine levied against patients who miss appointments at medical clinics in the rural municipality and the regional city indicates a lack of regard for the difficulties many women face.

sensitive to this. You know, they don't know the full picture of what goes on behind closed doors, what happens in this community. . . And the same thing with physical abuse, . . . again, that's where you find really shy women. Especially when you have a male doctor talking like an authority to you or feeling that you're being talked down to. If you're the woman that was constantly being beaten, you're going to clam right up, you're going to be quiet, you're going to be submissive. You know, that's just an indicator of an abuse situation. You have these misinter-pretations. 'Is this part of their culture?' 'Is this why they're so submissive?'"

One can sense the concern expressed by this participant that providers might miss the underly-ing social factors contributing to women's apparent passivity, reticence or shyness.

6. Disregard for Personal Circumstances

For participants, lack of consider-ation for their personal circum-stances contributed to their experience of invalidation during health care encounters. Lack of regard for socio-economic pres-sures was one way that partici-pants felt their personal circum-stances were not considered.

The $20 fine levied against patients who miss appointments at medical clinics in the rural municipality and the regional city indicates a lack of regard for the difficulties many women face. Although the cancella-tion fee may be necessary to the economic viability of the clinics, it creates a double-bind for women from the reserve who cannot afford home phones and who do not have access to a phone, or who may not be able to secure transportation into town to attend their appointments or afford a taxi. The impoverished conditions in which many reserve women live preclude them from having the structures and conve-niences in place that would allow them to arrive for appointments on time or to phone ahead and cancel. In other situations, participants described how they were made to wait for excessively long times because they were a few minutes late for their appointment, represent-ing, to them, a form of penalization. The embarrassment associated with being late, or being asked to pay the cancellation fine when they lacked the money, illustrate the ways in which clinic policies framed partici-pants' experiences by blaming indi-viduals for circumstances beyond their control.

B. Affirming Encounters

Although the authors and participants

in this report have stressed invalidating encounters as a means to understanding what requires change in health care, we also gave serious consideration to affirming experiences. From the view of policy makers, these experiences are significant. They direct attention to what works best, for whom, and in what circumstances. They are useful in the quest for understanding what processes and practitioner/patient relations have best served First Nation women and have enabled some to move beyond disempowering experiences.

Given the context of the recent colonial nature of health services, and the difficulties that characterized participants' encounters with current mainstream services, it became apparent that descriptions of positive health care encounters were symbolic of what mattered most: sharing knowledge and power with participants over health care decisions, conveying respect for the participants as women with unique cultural heritages, and forming effective interpersonal relationships in ways that reduced the distance between participants and others in relation to the health system.

1. Actively Participating in Health Care Decisions

Being able to speak openly and to participate in health care decisions was extremely important for participants. One participant stressed the need for "a good talking relationship" that allows for an exchange of knowledge and contributes to personal empowerment. For one woman, this sharing included receiving a pharmaceutical book from her physician in recognition of her interest in medicinal properties. Another participant praised a physician who encouraged her to ask questions and who seemed more concerned about her patient's concerns than establishing time constraint.

"I had a doctor here and you know she was really good and I don't know if it has to do with being female, but she was really good. . . When I first went there, we talked, but every time I had to go, if there was some procedure or something happening, I could ask questions. There was no time limit and she helped me to become more in control of my own health, which was the big thing. So I didn't feel uncomfortable asking questions or [saying] 'Okay, well no I don't want to do that, can you try something different?' That's what I've noticed. That's why she was a good doctor. I wasn't just a piece of meat {laughter}."

The ability to exercise self-determination is seen by this patient to transform not only her immediate relationship with her physician but also to validate her as a respected

patient, who was acknowledged to be more than "just a piece of meat."

2. Feeling Genuinely Cared For

In some cases, participants shared stories of health providers who demonstrated an outstanding ability to convey a caring attitude. This was reflected in the interpersonal strengths of the practitioners, which highlight the importance of style and manner in interacting with patients. Trust was created when participants felt the practitioners truly cared about them and their families and when the women sensed that they were being treated like a "regular person" rather than being dismissed through negative stereotyping.

"I really felt by that doctor that he looked at my health and gave me the best care that he could, that was me and my family. And I always felt that about him and felt safe under his care. . . He always treated me like I was, I always felt that he talked to me and explained everything very clearly and he was very courteous to me and treated me like, you know, just like a regular person. You know what I mean? He was very, his manner was very warm and courteous and you knew that he cared for you."

The participants also expressed gratitude for moments when practitioners went the "extra mile" to offer emotional support at times of great stress, as happened at the death of one woman's husband.

"Well, the best treatment I ever had was when my husband died, my doctor came, phoned me to tell me to come in to talk with him and see if I was okay and things that happened and nobody had control over anything. . . And he explained it to me really softly, things like this happen. He was such a good doctor. He was really caring. And that was the best thing that ever happened to me was him phoning me on his own to tell me that. . . My own family doctor. He's passed away now. We can't find one better than him now. You know, to treat a patient. He knew everything about me, that doctor, and I trusted him with my life. {laugh} And he took really good care of me. I often remember him for doing that. I said if all the doctors were like him, it'd be nice. They listen to you and they care for you even though it's going that extra mile for you."

In some cases, outstanding care was described as unanticipated acts of kindness, and was highly valued by participants. Participants described their impressions of gestures and actions from health providers that were understood to be beyond the call of duty and unexpected. Examples ranged from the decision of a hospital nurse to remain with a participant during a premature

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delivery rather than leaving at the end of her shift, to respect shown by hospital staff toward culturally specific ways of attending to a dying relative. One participant spoke appreciatively of a gynaecologist who comforted her after a miscarriage; his soothing voice calmed her as he sought to reassure her.

"He said, 'Well, look you can try to have another baby.' But I'll never forget him. . . it must have been his voice that was so, so soothing."

The attending nurse was also seen as being very kind.

"I remember her, she was, I don't know who she was, but she stood with me. She stood there for a long time. She was holding my hand, eh?"

It was at these moments, when practitioners responded to the holistic needs of their patients by striving to offer emotional as well as medical support, that the participants felt both comforted and listened to.

Another participant described the kindness extended to family members who were attending to a dying relative in the local hospital.

"You know, they never once said, 'We want you guys to leave. It's after hours.' Or anytime we asked for anything they were helpful. . . When

she turned for the worse, they told us . . . you can call your family and they can come, stay and you can go have coffee upstairs and stuff like that. And they didn't mind us being there. . . and at one point, there was probably about twenty of us. But we were probably, after I thought about it a couple of years later, people have work to do in there and stuff. They never once got mad about it or I don't remember them getting mad."

As the participant described above, visitors expected that their presence would annoy staff, they would be asked to leave, or they would have to defend their reasons for wanting to remain at the bedside. Rather, the participant described the comfort taken from the unanticipated support and care provided by staff.

3. Affirmation of Personal and Cultural Identity

Affirmation of participants' identity arose from conditions of cultural safety. Fundamental to the validation of many First Nation women is recognition of traditional knowledge and the expertise founded on that knowledge, such as the expertise held by local herbal specialists. A significant shift in relations with the local municipal and regional hospitals, for example, has occurred with the hospitals' acceptance of patients' use of traditional medicines. Acceptance of this knowledge as a legiti-

mate medical practice reflects the esteem that First Nation women place upon both traditional and western epistemologies and helps to foster First Nation values. Affirmation of the value of traditional medicines by the mainstream health system therefore represents an important way of validating the caring practices of First Nation women.

Some participants reported being affirmed as Aboriginal women by practitioners who either validated their pride in their culture and history or affirmed culturally defined body images. Validation of self-identity and cultural pride signalled a willingness to listen to the patient and to understand her health within the social and cultural dimensions that she defined as most important to her. This stood out in sharp contrast to experiences that left the patient sensing she had not been respected. One participant described how impressed she was when her family physician recognized her pride in her cultural heritage, and the influence that it had on her self-esteem.

"He recognized that I was proud of my culture. He talked about my culture and the positives about the Aboriginal people, the land. He recognized that we were here first and he respected us for that. He talked about how he owes a lot to my race for them being here and those kinds of things. He was proud that, he was happy, I was going to school, I was doing well. I talked about my goals and things like this to him and he, he encouraged me. He encouraged me and he said that there's nothing holding me back and I can be better than he is. And that's what I liked, eh? He didn't set himself on a pedestal because he was a doctor. . . So that's why I say, I have a really good perspective on crappy doctors and really good doctors."

The participant also describes how the distance that characteristically exists between health professionals and patients was kept to a minimum, because the doctor did not put himself "on a pedestal" in relation to her.

For participants, an exceedingly important way of affirming cultural identity was providers' capacity to support and convey respect for families as they cared for dying relatives in home or hospital. Participants described how health providers demonstrated respect for women's roles as caregivers by extending themselves as supporters in appropriate ways. Participants also placed a high value on home visits by health care providers, particularly for elderly people or terminally ill people. This was not simply described as a personal preference; visiting someone in

Participants also placed a high value on home visits by health care providers, particularly for elderly people or terminally ill people.

her own home is an important, culturally based way of conveying respect to the patient and her family. For example, one participant described how significant it was that a doctor made a home visit on the reserve to her dying daughter several years ago.

". . . the doctor was good to us, like when my oldest daughter was very sick with cancer, the doctor even went to her house to visit with her. That was really, I thought really it was a very good doctor. Just out of his way, he had to check on her in her house, you know. Not very many do that nowadays."

Others described how appreciative they were of hospital staff who accommodated culturally specific ways of caring for dying patients. Home visits and support for grieving family members represent ostensibly simple, but powerful, ways of acknowledging participants' cultural identity, roles and practices. These gestures supported women's caring practices "which is in our culture, we feel for one another, and we can't let go of that."

4. Development of a Positive, Long-Term Relationship with a Health Care Provider

Affirming encounters frequently arose out of long-term, positive relationships with family doctors or community health nurses. Unfortunately, these types of relationships were difficult to develop and maintain. Lack of choice among small numbers of providers in the local area, high turnover rates among health professionals in northern and rural regions, the social distance and sense of other that typically existed in relation to health professionals, and the frequency of invalidating experiences all contributed to difficulties in forming long-term relationships with providers. Despite the barriers to forming satisfying alliances with health professionals, participants recognized the value of having a stable provider whom they trusted, and sought out relationships with family physicians in particular. This process was described by one participant in the following way.

"When I moved to [the rural municipality] and started to go to the clinic, you just get whoever, so I was getting bumped around and seeing whatever doctor was available at the clinic. I don't know how come they do it differently up there, but they do. Until I finally got hold of a doctor that I thought we could work something out with, and I asked him to be my doctor and that's who I just see now all of the time. But since talking to him, I've noticed a big difference in how I'm treated. . . I told him I'm tired of being bumped around all over and would you be my doctor {laughter}.

What does he think? And he was kinda shocked that anybody would ask. I guess they just have to take whoever they're given. But I wanted a better relationship so I didn't feel like a cow going through the clinic."

Thus, seeking out long-term family physicians helped participants to cope with the lack of continuity of care encountered otherwise. This strategy marks women's commitment to their well-being and the significance of provider/patient relationships grounded in mutual respect and dignity.

VI

Conclusion and Recommendations

In sum, findings from this study provided detailed insights into the nature of health care encounters from the perspective of First Nation women residing in a northern reserve community. The women's stories highlight the importance of viewing their perspectives in terms of the larger social, economic and political forces influencing Aboriginal women's lives and encounters with the dominant health care system.

From a political standpoint, the goals of research must move beyond simply exploring and documenting phenomena of concern to women. Research must also be critical, action-oriented, and contribute to the development of strategies for addressing women's oppression (Anderson, 1991; Enslin, 1993). The development and exchange of knowledge is a political process. To facilitate this process we address initial ideas for change with full awareness of the limitations of these suggestions in the context of structural and political forces driving health care.

The text arising from our research also helps to identify and clarify issues pertinent to policy analysis and development. However, when we view the tensions between the First Nation and the dominant sites of power as structural communication, it is evident that the power imbalances that give rise to the women's concerns regarding their health care cannot be redressed without radical changes in the political relations. Thus, when we considered implications for policy arising from our study, we recognized that incremental policy reform will only ameliorate aspects of service delivery that shape First Nations women's experiences and cannot, on its own, rectify the causes of their oppression.

Nevertheless, the policy implications we identify here are grounded in our findings and reflect the ways in which health service delivery can be improved for First Nation women of this community.

Recommendations

Cultural Safety

Further exploration is needed to develop ways of integrating the concept of cultural safety into policies guiding health services to Aboriginal patients.

For these reasons, policies that adopt principles of cultural safety may be one way of encouraging health care agencies to look beyond descriptions of cultural differences in order to gain a deeper understanding of factors influencing health care for Aboriginal women, their families and communities. Just as anti-racist policies brought issues of discrimination and racism to the forefront, policies addressing cultural safety can provide a mechanism for linking macro-level issues to micro-level interactions in a health care context.

Limits of Cross-Cultural Training

Health care agencies should recognize the limits of cross-cultural training programs in relation to the insights of cultural safety. In areas where there are high proportions of Aboriginal people, continuing education policies should recommend learning strategies for health providers, staff and administrators that move well beyond descriptions of cultural differences and etiquette to an analysis of the socio-political and historical factors influencing health care encounters.

The Role of Aboriginal Women

Health service delivery to Aboriginal women should be guided by policies that recognize the central caregiving role held by many Aboriginal women. These policies should safeguard against false accusations and negative stereotypes of Aboriginal women as unfit mothers. As gate-keepers to health care for family members, Aboriginal women must feel comfortable and have trust in the services received. Until policies are developed that protect Aboriginal women from institutional discrimination in mainstream post-colonial health care systems (Frideres, 1991), it will be difficult for Aboriginal women to fully trust these services.

Punitive Policies

Cancellation policies that impose financial penalties for circumstances beyond women's control should be reeval-uated. Blanket penalties applied to all, regardless of circumstance, obscure the social and economic context of health care interactions. These policies level undue blame on individual women for social problems such as poverty, unemployment and lack of opportunity.

Home Visits

Development of policies that would allow nurses, physicians and other professionals to run clinics or make home visits on reserve should be considered. Although home visits may not be seen as an efficient way of delivering services, they could help to foster connections between the reserve and sectors of the local

health system. Clearly, this would require revisions/exceptions to jurisdictional issues that currently impede implementation of alternate approaches to on-reserve health care delivery.

⬤ Input into Health Policy

Regional health boards and service agencies need to develop mechanisms and structures (and concomitant funds) that would ensure meaningful input by First Nation women into local health policies. For example, one area of service delivery policy that participants identified as immediately important was for Aboriginal liaison or support workers (and ultimately for Aboriginal health care providers) in health agencies. Participants highlighted the value of the Aboriginal liaison worker currently employed in the regional city hospital and recommended that this role be extended to other health agencies to alleviate women's sense as outsiders or intruders on the system.

⬤ Social Focus

With the focus of health care reform primarily on the financing and structuring of health care systems, attention has been diverted from the socio-political context of health service delivery. Health reform must also focus on policies that address those critical determinants of health, including:

the absence of discrimination, social justice to prevent systemic discrimination and health inequalities, and social relationships that respect diversity (cf. Canadian Public Health Association, 1996). Examining the ways in which these determinants can be addressed through policy will require meaningful involvement of Aboriginal women who are affected by such policies. (See also Lefebvre, 1996).

Appendix 1

Health Care Systems and Services Used by Participants

Residents from the First Nation community receive the majority of their primary medical care, community health nursing, and dental services from the nearby rural municipality. The medical clinic in the nearby community houses seven doctors and staff. Alternatively, residents who are unable to access a physician or who wish to use the services of other providers travel to the regional city. In both the rural municipality and the regional city, it is exceedingly difficult to find a family physician who can accept new individuals and families into their already over-burdened practices. Many women from the reserve therefore cope for years without a steady family physician.

Uncomplicated in-patient care is provided at a small rural hospital located in the rural municipality. If more extensive acute care is required, patients are transported to the larger regional hospital located in the regional city. Patients must also travel to the regional city for most diagnostic and specialist services. If community members require more intensive or specialized acute care and diagnostic services, they travel to the hospital in the southern urban centre 1000 km away.

Community health nursing services (for example, home visits to new mothers and infants, and childhood immunizations) are provided on reserve a few days per month. The community health nurses are based at a branch of the provincial public health unit located in the nearby rural municipality. At the time of data collection, a locally controlled health centre was being constructed on the reserve. When completed, this health centre will be responsible for providing community health nursing and various social services to reserve residents. No primary care medical services will be provided at the new health centre unless, in the future, a physician runs a clinic on an interim basis or a nurse works in an expanded scope of practice (for example, if a nurse practitioner is employed).

Appendix 2

Examples of Questions that Guided Interviews with Participants

• Tell us how health care providers behave toward you and your family.

• Tell us about a time when the health care you received had a big effect on you or your family.

• Tell us about a particularly good experience you or your family had with health care.

• Tell us about a particularly negative experience that you or your family had with health care.

• From your experience, what part of the health system really works for you and your family? What part does not?

• What do you think women from this community need most from the health care system?

Appendix 3

**Memorandum of Understanding Between Research Team
and First Nation Community**

I. Purpose of the Agreement

This letter of agreement between the Project Team and the First Nation is being undertaken for the purpose of engaging in research that examines First Nation women's encounters with the health care system. This study is funded by the BC Centre of Excellence for Women's Health.

II. Obligations of the Project Team

The Project Team and the First Nation wish to confirm by this Letter of Agreement that the Project Team will carry out their work according to the following terms.

A. The Project Team will be responsible for conducting the research according to the methods outlined.

B. All costs incurred as a result of the research will be covered by funding provided the BC Centre of Excellence for Women's Health. Full accounting of expenditures will be maintained by the Project Leader.

C. The Project Team agrees to comply with the guidelines set forth in the *Royal Commission on Aboriginal Peoples Ethical Guide lines for Research* (1993)*.

D. The Project Team agrees to keep the First Nation informed of the progress of the research.

E. The Project Team pledges to maintain the confidentiality of all persons involved in the study. The research methods have been designed to ensure that the identity of any persons will not be disclosed.

III. General Provisions

A. Conducting the Project

1. The First Nation reserves the right to provide advice or direction to the Project Team at anytime.

B. Utilization of Research Findings

1. The Project Team agrees to consult and collaborate with the First Nation prior to publishing findings or results of the research.

2. No findings shall be published without the consent of persons participating in the project.

3. Unless otherwise negotiated, the Project Team as listed above will hold first, second and third authorship on published materials.

C. Time Frame for the Agreement

1. The agreement will commence on September 30, 1997 and expire 18 months later unless otherwise negotiated.

2. This agreement may be amended by mutual consent of the parties concerned.

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