Research in Nursing and Cultural Diversity: Working with First Nations Peoples

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Le profil démographique du Canada aujourd'hui trace le portrait d'une société plurielle du point de vue ethnique, culturel et racial (Masi 1993). Il est probable que l'immigration multiethnique vienne accroître cette diversité; cependant, les questions que cela soulève n'ont pas fait l'objet de discussions satisfaisantes en nursing et au sein du domaine de la santé. Alors que les infirmières, infirmiers et autres professionnels de la santé doivent désormais prêter attention aux dimensions culturelles de la santé et du processus de guérison, peu d'études solides et fiables ont été publiées en la matière, particulièrement en ce qui concerne des populations spécifiques. Les cadres de recherche et les schémas expérimentaux doivent être adaptés aux besoins de chaque groupe étudié; c'est ce qui permettra d'accumuler des connaissances solides sur les groupes concernés, et d'élaborer des théories qui pourront à leur tour être traduites dans des pratiques taillées à leur mesure. Dans le passé, plusieurs des ces populations ont fait l'objet d'études qui se sont avérées non pertinentes, paternalistes, culturellement déstabilisantes, et menant à une perte de pouvoir. Le présent essai se penche sur l'ethnographie critique, en tant qu'outil propice à l'élaboration de méthodes de recherche faisant état des différences ethnique et culturelles; il offre également des exemples de sa mise en application dans des études portant sur les peuples des Premières Nations. Des questions telles que le partenariat, les préoccupations d'ordre éthique et la propriété morale, vues comme des éléments essentiels à la conduite d'études appropriées, sont également mises en relief.

The current Canadian demographic profile indicates a society that is ethnically, culturally, and racially plural (Masi, 1993). Such diversity in our population is likely to increase with broad-based immigration, the implications of which have not been well addressed in nursing and health care. While nurses and other health-care professionals must attend to understanding the cultural aspects of health and healing, there is little published valid and reliable research to assist with this, especially with respect to specific populations. Research approaches and designs must be culturally suitable to the specific population, to generate valid knowledge about their culture and to develop theory, and to translate that into culturally suitable nursing and health care. In the past, many culturally diverse groups have been the subject of research that has been culturally inappropriate, patronizing, culturally threatening, and disempowering. This paper discusses critical ethnography as a culturally suitable research method and describes its application to studies involving First Nations (FN) peoples. Important issues in doing culturally suitable research, such as partnerships, ethical concerns, and ownership, are also discussed.

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Introduction

Canada's current demographic profile indicates a society that is ethnically, culturally, and racially plural (Masi, 1993), and such diversity is likely to increase with broad-based immigration. The implications of this have not been well addressed in nursing and in health care. The relationships among individual behaviour, values, beliefs, and perceptions about health and experiences of health and illness are culturally determined (Mensah, 1993). The challenge for health-care professionals is to understand the cultural aspects of health and healing in order to work with culturally diverse population groups for the improvement of their health and the care they receive. Competent1 nurse practitioners, educators, managers, and researchers are required to provide culturally suitable care.2 While the goal of culturally suitable care is consistent with the principles of primary health care (World Health Association, 1987), espoused as the foundation of health care in Canada (Canadian Nurses Association, 1995a,1995b), there has been little increase in health research addressing ethnic and cultural pluralism to assist nurses in their practice, especially in their work with specific populations (Anderson, 1993).

Research approaches, besides being appropriate in order to elicit proper responses, must be culturally suitable to the specific population in order to generate valid knowledge about their culture, to develop theory, and to translate this into culturally suitable nursing and health care. "Dominant cultural models that underlie our research approaches have failed" (Jackson, 1992, p. 14). It is becoming apparent that just as we need culturally sensitive instruments of measurement, responsive research designs, and appropriate analysis of results, we need the results to be interpreted within the cultural milieu and context of the groups being studied (Jackson). This paper will discuss critical ethnography as a culturally suitable method of doing research with people from ethnocultural and linguistic groups that are different from that of the researcher. Issues are identified in case examples of working with First Nations (FN) peoples. As background, a brief overview is provided of who FN peoples are, their changing health care, and the basis of nursing knowledge in working with them.

 Competence is the ability to integrate and apply the knowledge, skills, attitudes, and judgements required to perform safely and effectively (RNABC, 1996).

^{2.} Culturally suitable care is care that is responsive to the preferences of client(s)/patient(s), such as practitioners' knowledge of and respect for cultural values, beliefs, and practices; similarity of cultural background of the health-care provider; integration of traditional healing systems and contemporary health-care systems; and resources available.

Background

First Nations Peoples — Who Are They?

FN peoples are aboriginal peoples of Canada with Indian ancestry. Status Indians are registered as Indians under the *Indian Act* of 1876; non-status Indians are not registered under the Act. There may be changes in the future, but currently status recognizes aboriginal heritage and entitles Indians to certain benefits. The legislation has also had detrimental effects; it denies benefits to some — the non-status Indians. While they share many values and beliefs, FN peoples are culturally and politically diverse and geographically dispersed.

First Nations Health Care — Whose Responsibility Is It?

In the past, the federal government of Canada was responsible for providing primary health-care services to status Indians and provincial governments for providing hospital, ambulance, and other medical services, as well as all health care for non-status Indians. These responsibilities are changing, however. Federal responsibilities are being transferred to Indian Bands, and provincial ministries of health are decentralizing and delegating many responsibilities to regional and community health councils/boards. The aims of both federal transfer and provincial regionalization reflect principles of primary health care: greater public participation and responsibility, community-based programming, and more effective management of health-care systems. Thus FN peoples have to take on more health-care responsibilities themselves, by participating in band, regional, and community health planning and managing health-care services.

Nursing Knowledge — Where Is It?

Nurses are ideally situated to assist with planning for and implementing culturally suitable nursing and health programs, because they provide the majority of health services to FN peoples (CNA, 1993, 1995b). Where is the knowledge to guide the nurses in this role? While FN peoples, like other aboriginal peoples, have often been the subject of research, the results have rarely been a valid source of cultural knowledge and theory (Jackson, 1992). On the other hand, this population has often been excluded from research studies involving the general Canadian population. Valid knowledge, generated through culturally suitable research, is urgently needed.

Based on more than 30 years working with FN peoples in the areas of health care, research, and policy development, and having been mentored by the Arizona Native American Research and Training Center, I have found that feminist perspectives and critical ethnography methods are culturally suitable approaches for understanding the issues of FN peoples' health and working with them to bring about the changes they desire in nursing and health care. Knowledge generated through such research can help inform nursing involvement with FN peoples as they strive to improve their health.

Critical Ethnography

Historical Context

Ethnography, a classic research method for the study of cultures, provides a social-scientific description of a people and the cultural basis of their peoplehood (Spradley, 1980). However, it has distinct limitations, because observations that inform the description of and decisions about the saliency of data are always guided by the ethnographer's world images. In the past, descriptions and evaluations of races and cultures were provided by Western missionaries, explorers, buccaneers, and colonial administrators. Their reports were written from the perspective of a conquering civilization. It is understandable, then, that cultural groups such as FN peoples are sceptical, if not negative, about researchers coming in to study them and their culture, then leaving nothing, but taking away a biased interpretation of reality.

Critical theorists have challenged the positivistic paradigm to which traditional ethnography belongs, proposing that reality is shaped by an aggregation of social, political, cultural, economic, ethnic, and gender factors (Guba & Lincoln, 1994). Feminist researchers base their work on the assumption of intersubjectivity between researcher and participant and the mutual creation of data (Olesen, 1994). In a sense, participants are always "doing" research, for they, along with the researchers, construct the meanings that become data for later interpretation by the researcher. Anderson (1991) notes that over a decade some nursing scholars moved away not only from logical positivism, but beyond phenomenology and hermeneutics into a more critical theory paradigm and feminist form of reasoning. It has been my experience in doing research with FN people in British Columbia and Native Americans in Arizona that designs based on critical and feminist theories are most culturally suitable, acceptable, and productive.

My research with FN women started with an ethnographic study on childbearing issues with Coast Salish women. The results provided a classification of the sources of teaching/learning about childbearing and described ways in which women of a particular Band coped with the dilemmas they faced during childbearing. However, the research did not include a critical reflection of the findings or action, although Jordan (1990) comments on the utility of bringing together both emic (medicine-wheel) and etic (nursing) perspectives to inform the interpretation. It was not until the research was completed and I was in another role that I facilitated change in prenatal-care opportunities for the women.

Because there had been no significant involvement of the participants as researchers in this early study, and because no contract had been negotiated for ownership of data, only a general overview, rather than detailed results, were ever published (Clarke, 1990). Once again, research had been undertaken that failed to address factors perhaps more influential to women's childbearing practices than just teachings and experiences: social, political, economic, gender, and racial factors. Would publishing the specific results only serve to further marginalize these women, since there was potential for misinterpretation of health and health-care responsibilities? I thought so. Had I used a critical ethnography approach, the research would have had far greater potential to effect change and facilitate empowerment.

Key Concepts

Critical ethnography, an application of critical theory, is a style of inquiry, analysis, and discourse embedded in conventional ethnography (Thomas, 1993). Advocacy and activism are key concepts of critical inquiry. The researcher is cast in the role of instigator and facilitator, leaving judgement about needed transformations to those whose lives will be most affected by them. Critical ethnography is a reflective process "of choosing between conceptual alternatives and making value-laden judgements of meaning and method to challenge research, policy, and other forms of human activity" (Thomas, p. 4). Reflexivity involves a dialectical process involving the researcher's constructs and (a) the informant's common-sense constructs, (b) the research data, (c) the researcher's ideological biases, and (d) the structural and historical forces that informed the social construction under study (Anderson, 1989). Critical ethnography thus differs from conventional ethnography: "Conventional ethnography describes what is; critical ethnography asks what could be" (Thomas, p. 4).

Critical ethnography is a culturally suitable research method to inform nursing practice, based on the assumption that one of the aims of nursing in a context of cultural diversity is to transform social, political, cultural, economic, ethnic, and gender structures that constrain and indeed are at times detrimental to one's health (CNA, 1993, 1995b; RNABC, 1990). The concepts of advocacy, activism, reflexivity, participation, collaboration, and transformation resonate with the principles of primary health care (WHO, 1987) and assumptive premises of the culture caring theory (Leininger, 1991).

Research Methods

The cornerstone of critical ethnography is participation with the aim of bringing about action. The subjects are primarily those individuals who are significantly affected by the required transformation and whose level of knowledge needs to be expanded. The increasing use of participatory (action) research owes much to feminist researchers who have critiqued the aloofness and distancing methods of traditional maleoriented research (Anderson, 1989; Macguire, 1993; Thomas, 1993). The two terms participatory research and participatory action research, although they are seen as distinct methods of critical ethnography by some authors, are considered synonymous by others (Fals-Borda, 1992; Karlsen, 1991; Reason, 1994). The participatory approach in critical ethnography can be defined as "systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting social change" (Green et al., 1995, p. 4).

Case Examples

Following the childbearing study among the Coast Salish women, as a member of a multidisciplinary research team I was involved in two studies with FN women around cervical cytology screening. In one study the women resided on coastal and interior band reserves, while in the other they lived in a large city. The participatory research designs of both studies were informed by the critical theory paradigm and critical ethnography. As well, I incorporated lessons learned during my earlier research experiences with FN peoples and work with the Native American Research and Training Center.

The Problem

FN women experience a four to six times greater mortality rate from cervical cancer than the general population in the province of British Columbia (Band et al., 1992). They participate in the provincial Cervical Cytology Screening Program (CCSP) less regularly and less frequently than other women in BC (Hislop, Deschamps, Band, Smith, & Clarke, 1992). Furthermore, they are likely to have more difficulty than other women obtaining culturally suitable and consistent health-care services from respectful professionals (AMC Cancer Research Center, 1995). The first two facts above are readily available to health-care professionals and researchers, but the FN women are most familiar with the third fact. Thus what is likely to be defined as a problem by health-care professionals is not likely to be defined as such by FN women or their people.

Consistent with participatory research, defining the problem and research question(s) from an FN perspective was the first task I addressed. From previous experience I knew it was also important to address, in the early phases of project development, the following issues: partnerships and collaborative relationships between and among researchers and participants; ethical concerns related to access to women, points of entry into various systems, and confidentiality of names and data; ownership of data, results, presentations, and publications; and a culturally suitable research design that reconciles multiple scientific and community needs. These issues have been recognized by others as critical to the conduct of research with culturally diverse populations (Becker et al., 1992).

Our research team of nurse researchers and epidemiologists sought guidance from the FN peoples to determine how best to address the needs of the FN communities, whether reserves or urban communities, and yet maintain the necessarily scientific quality of the research. Meetings were held with FN agencies with an interest in or responsibility for health care to inform them of the inequities in the health status of FN women and to determine their perspective on and interest in addressing the problem. Eventually, for the two studies, a partnership was established between the research team and an FN agency. Based on the principles of critical ethnography, partnerships and collaboration were deemed essential to the advocacy and activism that would be required to make a difference in mortality and morbidity rates for cervical cancer among FN women in BC.

Aim/Purposes of the Studies

Collaboratively, but at different times, the aim of both the reserve study and the urban study was determined to be reduction in the mortality and morbidity rates from cervical cancer among FN women through early and regular participation in the provincially funded CCSP. Direct cost was not a factor in non-participation. Based on our partner's perspectives and my research on childbearing among Coast Salish women, I felt confident that ethnocultural and health-care provider factors influenced the women in their decision on whether to have a Pap smear test. Therefore, it was decided the immediate purposes of the studies would be as follows: to understand the values, beliefs, and experiences of FN women related to health promotion and Pap smear tests; to understand factors influencing their health-promoting behaviour, including whether or not to have the Pap smear test; and to design and implement culturally suitable interventions to reach the long-term objective.

Both studies were based on critical ethnography concepts of participation, respect and valuing, empowerment, and interpreting the social realities of FN women. While this approach was appreciated by the women, they and the Band Councils expressed fears that identifying cervical cancer as a problem would result in its being labelled a "Native problem" — another in the litany of health problems stigmatizing FN peoples. Considerable discussion between researchers and community representatives centred around the fact that while the most critical factor in preventing cervical cancer mortality is early detection through regular Pap smear testing, some people believe FN women are prone to the disease because of beliefs that stereotype the FN lifestyle (e.g., early intercourse, numerous partners) — lifestyle factors whose relationship to "causing" cervical cancer is equivocal. The FN partners feared the women would be further marginalized by racist perspectives.

Maintaining collaborative relationships with the Band Councils, FN agencies, FN health-care workers, and the women themselves was an ongoing challenge in both studies. Project partners' level of participation varied; some left, others joined. Frequent re-defining of the problem was required. While time-consuming, this helped to educate and involve more people than just the initial partners, reinforcing the aims and purposes of the studies. Macguire (1993) experienced a similar need to frequently re-define the "problem" when she initiated her participatory research project with Navajo women, and suggests that the male-centred aspects of participatory research may account for this issue. Do some of the unique characteristics of participatory research (participation, organization creating, action aimed at structural change) place different demands on women and on men? Has this been accounted for in the research process? As did Macguire, our research team found that resources (e.g., child care, transportation, honoraria) and organization structures (e.g., supportive Band and employer policies) are absolutely necessary to sustain collective participation and action over time.

Method

Similar critical ethnography data-collection and analysis methods were used in both the reserve study and the urban study. Individual interviews, focus groups, and community meetings were used with women and with care providers - FN women collecting the data after having been trained by the nurse researchers. These data-collection methods were deemed by the partners to be culturally suitable. Principles of "Talking Circles," consistent with the principles of critical ethnography, guided the discourse: respecting silence, listening without interrupting, taking turns — with everyone eventually having something to say and accepting what is offered. Guiding questions for each of the datacollection methods were developed in conjunction with FN women, with reflections on previous work carried out by myself (Clarke, 1990) and other researchers (Dignan et al., 1990; Hall & Branstetter, 1990). Data analysis, initially conducted by the nurse researchers, was discussed with FN women in community meetings, as well as with FN women acting as advisors. Challenges in data collection and analysis related to the researchers not living in the community of study, difficulty accessing and recruiting subjects, and making and maintaining contacts with all partners.

Location

Entering into true collaboration and partnership with participants who will benefit from the research is a challenge when the researchers do not live in close proximity to the communities in which the research is being conducted. An ethnographic approach, particularly one that is critical, demands that the investigator be there, exposed to the various factors to be critiqued — social, racial, cultural, and gender. Collaboration cannot develop if the researcher visits the reserve on a sporadic basis only. The women, except for the Community Health Representative, participated primarily as subjects and advisors. Although participation was apparent in the latter part of the project when interventions were being implemented and evaluated, it never truly reached the guideline criteria for participatory research as outlined in the Report of the Royal Society of Canada (Green et al., 1995). However, the interventions requested by the women, such as onreserve regular Pap smear clinics performed by nurses and production

of a video and a flip chart during the study, have been maintained as provincial responsibilities.

The urban study had the advantage of bringing FN women and the researchers together on a regular and ad hoc basis for community advisory committee meetings, program management, data collection and interpretation, and publicity. The community advisory committee of elders, women from FN agencies, and women from the city's health and social services department collaborated with the research team from the moment funding was obtained. The more participatory nature of the urban study facilitated the recruitment of a very difficult-toaccess population, promoted the health issue in the wider FN community, enhanced the relevancy of data-collection instruments and methods, increased the validity of data analysis and interpretation, and resulted in a wider range of proposed interventions. However, participation requires time, and the women, already busy with their daily lives, could not always participate to the degree and with the regularity that was anticipated. FN women who were not employed received honoraria for their participation.

Access and Recruitment

Gaining entry to the population of FN women and their environment differed according to study location. Park's (1993) description of the organizer or mobilizer role of the participatory researcher became reality to different degrees. One of the determining factors in access and recruitment in studies with FN women has been the gatekeeper function. For on-reserve studies, it is the Band Chief and Council initially, followed usually by the Community Health Representative (CHR). The Band Chief and Council have responsibility for determining who has access to the reserve and the records, including Band lists, while the CHR has responsibility for making contact with the individual Band members on behalf of the researchers and following up on requests for information. In an urban setting, gatekeepers are primarily FN agencies and health-service providers. They determine whether the researchers can speak to their groups, advertise, or seek the participation of their members or clients. Furthermore, they interpret the research study to potential subjects/participants and seek their consent to be approached.

Thus access and recruitment is often carried out by a third party, who perceives one of their primary responsibilities to be ensuring that an ethical approach is maintained: that informed, non-coercive consent is obtained; that no harm will be done, but that benefits will be maximized; and that justice will be given to the voices of FN women, yet in a

confidential manner. These ethical principles of respect, beneficence, and justice are as critical to participatory research as they are to health care (Jecker, Carress, & Pearlman, 1995). At the request of the FN partners themselves, they were visited many times during studies in which I was engaged, even though ethical approval had been given by the ethics review committees of local universities.

Gaining and Maintaining Contacts

The most obvious aspect distinguishing participatory research from the more traditional research mode is that community people participate in the research process (Park, 1993). This demands interpersonal and political skills on the part of the researcher(s) as organizer(s), as well as the collaborator(s). In addition, with FN peoples one must appreciate intervening factors such as past negative experiences with researchers, exclusion from general population research, and male-centred aspects of FN life. Paradigm shifts must occur with the researcher(s) as well as the participants.

To facilitate the contact process of gaining entry and making contacts, I and others (Dressler, 1992; Frate, 1992) have found it helpful to:

- · locate some project offices in the community
- hire staff from the community
- make project resources available to the community for purposes defined by the community
- use jargon-free descriptions of the proposed research in any discussions with the community
- incorporate a health benefit within the research design for those participating and possibly others.

Research to Action

"The path from knowledge generation to knowledge utilization is direct in participatory research, since the same actors are involved in both activities" (Park, 1993, p. 3). In the studies with FN women, the participatory approach assisted women who have little power, or at least little perceived power, to change the complex health-care system (Hislop, Clarke, Deschamps, Band, & Atleo, 1995). As well, they became more aware, more creative, and more active in changing health-care services for Pap smear testing for FN women. They debated interpretation of the data and relevance to different intervention approaches.

The most controversial proposed intervention was public advertising (e.g., public transit posters). Although this strategy was based on the finding that in general FN women were not aware of the Pap test — purpose, relationship to cancer detection and infections, recommended schedule — some felt public advertising would stigmatize FN women, while others believed they had a responsibility to all FN women to ensure they were aware of this cause of unnecessary death. It was decided to abandon this strategy. Thomas (1993) refers to our difficulty reconstructing knowledge as a defamiliarization process, revising what we have seen and translating it into something new. Reconstructing knowledge of a health-care system is a complex process.

On the other hand, there was general agreement about the interpretation of findings related to health promotion, choices, and caring for oneself or others, and there was general agreement that these findings could be reflected in a cultural visual image. An FN woman artist was contracted to develop such an image, which was subsequently used on posters, brochures, and follow-up pamphlets. The text of all print material was based on research findings, critiqued, and revised by FN women and subsequently subjected to further evaluation by a larger audience of FN women and health-care providers.

In translating knowledge generation to knowledge utilization, the research team was primarily responsible for listening, respecting advice/decisions, facilitating required actions, and ensuring that an evaluation component was included. It was at this stage that requests for project information came from the larger community. Who was to be spokesperson? Who would write articles? Who would be acknowledged in presentations and publications? While these issues were resolved among the research team in a written agreement of principles of publication, informal approaches were taken with the other research partners. On reflection, agreement about publications and other means of sharing knowledge should have included all project partners. Guidelines are urgently needed for these types of agreements and for determining how to present appropriate acknowledgements.

Summary and Discussion

In summary, using critical ethnography and a participatory research approach with FN women has many advantages, especially with respect to action outcomes. While engaging and invigorating, critical ethnography is likewise exhausting. But that is the beauty of it (Macguire, 1993). You cannot be detached. Critical ethnography is not only about trying to transform social structures and people, it is about

being open to transforming ourselves and our relationships with others. It is about becoming a learner rather than being the voice of authority. Nursing in our increasingly culturally diverse society requires new approaches to research, to ensure that health and nursing care are culturally appropriate and that they provide relevant choices.

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