*Canadian Journal of Nursing Research, 2001, Vol. 33, No. 3, 81–86*

# *Designer's Corner*

# Conducting Health Research with Vulnerable Women: Issues and Strategies

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Over the past two decades, the topic of women's health has garnered increased attention and research. However, health research with vulnerable groups of women has been limited. Vulnerable women are defined as women who are susceptible to harm because of their minority status, socio-economic status, or some other stigmatizing status (Demi & Warren, 1995). Other terms used to describe such women include disadvantaged, marginalized, and disenfranchised. According to the Prairie Women's Health Centre of Excellence (1998), marginalized groups of women in Canada include but are not limited to: Aboriginal women, women of colour, immigrant women, refugee women, disabled women, women living in northern locations, lesbians, elderly women, rural women, and farm women. These vulnerable women are at increased risk for health problems (Federal/Provincial/Territorial Working Group on Women's Health, 1990) and deserve to receive greater priority in research. Issues related to conducting health research with vulnerable women will be discussed and various strategies for dealing with these issues will be proposed.

## Issues Related to Recruitment and Retention

Barriers to women's recruitment and participation in research must be identified and eliminated if we are to increase the number of participants. The issue is broader than recruiting women; it is recruiting women from diverse racial, ethnic, cultural, socio-economic, and age groups (Swanson & Ward, 1995). Barriers to participation include the time and inconvenience involved, negative personal and family atti-

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tudes towards research, and inadequate evidence of the benefits of participation (Swanson & Ward). Among women from minority populations and women of colour, there may be widespread fear and distrust of the health-care system. Recruitment of minority women is hindered by their lack of access to health-care services and their suspicion and scepticism regarding medical research (Larson, 1994). Knowledge of past abuses by researchers, such as in the case of the Tuskegee syphilis experiment, serves as an additional barrier (Moore, 1997).

Clinical trials present several barriers to participation (Cockburn, Redman, & Kricker, 1998; Swanson & Ward, 1995). Vulnerable women may find that information about a trial is too technical or complex to understand, and thus fail to appreciate its potential therapeutic benefits. Invasive protocols or undesirable side effects may also discourage participation. A woman may be fearful of becoming a "guinea pig" in clinical research, or believe that the investigator is more interested in the research than in her well-being as a patient. A trial may demand a great deal of time, with transportation or travel time being particularly problematic.

In longitudinal studies, participant retention can be a greater problem than recruitment, especially for vulnerable women of low socio-economic status. Demi and Warren (1995) describe some of the problems they have encountered in conducting research with families of low socio-economic status: "They may live with others, in crack houses, in a shelter, in a car, or on the street. They tend to move frequently and may be difficult to track through traditional methods. Many families do not have transportation or telephones. They live turbulent lifestyles, because of their many stressors and lack of resources, and thus fail to inform the research team of changes in residence" (p. 193).

A variety of strategies may be used to secure the participation of vulnerable women. Researchers often experience difficulty locating, enrolling, and retaining economically and socially disadvantaged women such as those from ethnic minority, immigrant, or drug-using populations. Incentives may be useful in this regard, such as offering them tangible benefits in return for their participation and making the incentives more attractive as the study increases in longevity (Demi & Warren, 1995; Kelly & Cordell, 1996; Moore, 1997). Follow-up might be facilitated by completing a contact sheet for each woman upon her enrolment, listing the names, phone numbers, and addresses of two persons who are likely to know of her whereabouts at a later time (Johnson & Arfken, 1992). Recruitment should take place in settings

where women are found, such as ethnic meeting places, drug-treatment centres, or primary-care clinics (Kelly & Cordell). Provision of transportation and child-care services may help remove impediments to the participation of women who are primary caregivers. Appointments should be scheduled at convenient times and locations (Demi & Warren; Kelly & Cordell). Vulnerable women are more likely to go to a study site if the research is conducted in the target community; they might find it more convenient — requiring less travel time and expense — and be less distrustful of the research (Arean & Gallagher-Thompson, 1996).

In addition, researchers must demonstrate their respect for participants by being non-judgemental and supportive (Kelly & Cordell, 1996). Demeanour can play a role in this regard, as can interactions with participants; researchers should show that they value the contributions of participants (Demi & Warren, 1995). Trust will likely develop if the field staff are drawn from the population that is being studied, as trust is more easily established when staff and participants share a language and culture (Kelly & Cordell).

In research with women from minority groups, members of the target community should be involved in as many dimensions of the study as possible (Johnson & Arfken, 1992; Lillie-Blanton & Hoffman, 1995). Community networking can help to establish rapport with potential participants: one-on-one contact will be more successful if the investigators have already made contact with neighbourhood groups and coalitions. The investigators should become familiar with cultural practices and beliefs and accommodate these in the research design. They should also be sensitive to cultural nuances within an ethnic group, as various subgroups may exist (Arean & Gallagher-Thompson, 1996). When members of minority populations are being recruited, the recruiters should use the language of the community. It is beneficial to use recruiters who are of the same race and ethnicity as the potential subjects and who are familiar with local culture and customs. To ensure cultural relevance, minority women could be asked to become involved in developing recruitment strategies and preparing recruitment or educational materials. Minority women could also be invited to join the research team, to add credibility to the research and to help establish rapport with the community. Linkages with the community may also be forged by employing as many local residents as possible for the project. Finally, the investigators should share the research results with the minority community and discuss with them how the results may be used to improve the health status of the community (Johnson & Arfken; Lillie-Blanton & Hoffman).

When working with Aboriginal groups, researchers must demonstrate respect for traditional beliefs and practices and develop a team relationship with the community. The Royal Commission on Aboriginal Peoples ([RCAP] 1996) offers ethical research guidelines for the respectful treatment of Aboriginal cultures, languages, and values. In studies that are conducted primarily in Aboriginal communities, researchers should establish collaborative procedures to enable community representatives to participate in planning and implementing the research and in evaluating the results (RCAP). The *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (Medical Research Council of Canada, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada, 1998) contains a section on research with Aboriginal peoples as well as "good practices" for researchers working with Aboriginal communities.

### Issues Related to Reliability and Validity of Instruments

Research instruments developed using White middle-class individuals may be inappropriate for use with vulnerable low-income women. An attempt should be made to obtain instruments that are reliable and valid for the group being studied (Demi & Warren, 1995). The instruments should reflect knowledge of the culture and norms of the population group, including sensitivity to age, social class, language, reading levels, and religious customs as well as race/ethnicity (Lillie-Blanton & Hoffman, 1995). If this is not possible, focus groups can be used to review instruments for relevance and comprehensibility; the instruments can then be revised and pilot tested. An effort should be made to obtain norms for the current population, and not to compare data from the sample under study to norms for middle-class samples (Demi & Warren). Educational level, literacy, and language abilities must be taken into account in selecting a data-collection method. Interviews may be more appropriate than self-completed questionnaires for collecting data from immigrant or low-income women.

### Ethical Issues in Conducting Research with Vulnerable Women

Two primary ethical concerns are informed consent and the risk-benefit ratio. To protect vulnerable women from exploitation, the investigators must ensure that they are fully informed about the risks and potential benefits of the study (Demi & Warren, 1995). To provide truly informed consent, women need appropriate and comprehensible information about the nature and purpose of the research, possible costs and benefits, what is involved in terms of filling in questionnaires or providing

personal information in interviews, whether invasive procedures will be performed, whether medical records will be accessed, and their right not to participate and to withdraw at any time (Cockburn et al., 1998). Unfortunately, many consent forms are too complex to be understood by vulnerable women even when they have been reviewed by a research ethics board. One strategy is to have consent forms and other information about the study reviewed by a group of relevant consumers, to ensure that the content is clear and appropriate (Cockburn et al.).

Confidentiality is an additional area of concern, especially when the topic is sensitive or stigmatizing. Data must be aggregated in reports to conceal the identity of participants (Demi & Warren, 1995).

Another ethical issue is that of recruitment for clinical trials. Most women are invited to participate in a trial by their physician. A woman may be reluctant to refuse because she is grateful to the physician or because she believes she might lose the physician's support and interest. She may also perceive a conflict between the physician's two roles: as her treatment provider and as a researcher conducting a trial. Possible strategies include: giving women time to decide whether to participate; providing written or audiovisual resources that clearly describe the trial and the concept of randomization; training physicians in appropriate communications skills; and providing telephone support with a nurse, after the initial consultation, so that the woman can ask questions about the trial (Cockburn et al., 1998).

## Summary

This paper has summarized a variety of methodological and ethical issues in conducting research with vulnerable women, and has also proposed strategies for dealing with these issues. Because vulnerable women are at increased risk for health problems, it is imperative that nurses and other health-care professionals make strenuous efforts to include vulnerable women in health research.

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