

Progress Report

Immigrant Women's Experience as Family Caregivers

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1. Research Issues Addressed

Women caring for a family member experience burdens and personal health impacts that are compounded by the social isolation associated with immigrant status. Health care services and health-related policy reform have not been attentive to the specific needs of immigrant women, but have been based on economically driven restructuring. Information on how immigrant women family caregivers access support and the barriers they experience to receiving support is important for professionals and agencies that address health promotion of immigrant women. In addition, immigrant women's experience of family caregiving incorporates attention to the gendered issue of a false dichotomy between paid public work and unpaid private labour. The need for comparative information about subgroups of immigrant women is addressed by the inclusion of women who have immigrated from two different cultures (India and China), attention to the context and structural characteristics of their lives, and the selection of women whose time of arrival in Canada differs.

2. Study Purpose

The **purpose** of this study is to understand the experience of women family caregivers who are recent or past immigrants from China and India. **Specific objectives are:** a) to identify the nature of the material and social conditions within which immigrant women give care to a family member, b) to understand how they access support within their informal social network and the barriers to support they encounter; and c) to examine their experience in accessing health and social service resources.

3. Method

A qualitative ethnographic approach is used in this research. **Ethnographic inquiry** provides access to "in vivo" descriptions of the reality of immigrant women's experience of caregiving and the life conditions in which they provide care. Incorporation of an interpretive critical perspective within Ethnography gives emphasis to the cultural and structural conditions that are a source of power and control in the lives of immigrant women. This perspective directs attention to systemic, institutional characteristics as well as to the characteristics of individual women and their families.

An **advisory committee** comprised of women from the immigrant communities, representatives of voluntary immigrant serving agencies, and publicly funded health and social services agencies assist the research team. They help to develop the study so that it is relevant to the participating communities; assist in the selection of appropriate methods of contacting potential participants; and participate in the identification of implications of the study findings for policies and programs.

Recruitment of participants is ongoing through participating community agencies and local media. Thirty women will be recruited including Chinese and South Asian Indian women who are both recent (in Canada less than 7 years), and long term residents.

Data collection involves an open-ended **personal interview** with all participants. **Case studies** of selected women (n=8) will be developed on the basis of additional follow up interviews and participant observation of their caregiving activities. As caregiving may be a shared responsibility, if the caregiver wishes, another family member who assists them with caregiving

will also be interviewed. If the women prefer, interviews will be conducted in their first language and then translated into English. Interviewers maintain detailed fieldnotes of their observations and interviews. Information and documents about the policies and resources of official and voluntary health and social agencies, income support sources and employing agencies serving the women are being collected for analysis. A thematic form of content **analysis** is used in analysis of all data. Women on the Advisory Committee who represent the cultural groups will be asked to comment on the cultural accuracy of the interpretation. **Focus groups** with women participants, providers and policy makers near the end of the study will provide feedback on preliminary findings and promote discussion of implications as part of dissemination.

4. Progress to Date

The study was initiated in November, 1998. The Advisory Committee was established prior to initiation of the research and they assisted the investigators to establish plans for recruitment and to identify preferred approaches in communications about the study. By March 15, 1999, 20 immigrant women caregivers were enrolled in the study and had participated in the first interview. Family members to whom the women provide care vary in age and chronic illness or condition. Recruitment of study participants for the individual interview is still in progress. The second phase of the study which involves follow-up visits with a subgroup of women to gain more in-depth understanding of their caregiving situation will begin in May, 1999. Assistance from the Faculty of Nursing in the form space, computer resources and a graduate student research assistantship has facilitated successful implementation of the project.

5. Preliminary Findings

Although a statement of preliminary findings is premature, it is evident that there are cultural variations in the meaning of caring for an ill or disabled family member. The women describe barriers and facilitators in accessing support from both professional sources and family and friends. They describe perceptions of their caregiving situation that differ from that of other family members and professionals, causing some discomfort and challenges. Women are frequently unaware of existing resources or the available avenues to acquire such information.

6. Policy Implications

Agencies in health, social services, education, and legal sectors address the broad determinants of immigrant women's health, determinants such as jobs, income, culture and education. The investigators' preliminary consultations with policy makers and with service providers reveal a keen interest in the information arising from the project and willingness to discuss the implications for policies and programs. One indicator of this support is allocation of additional funds in support of the project from the Caritas Health Group. The Advisory Committee which represents policy makers, service providers and immigrant women will facilitate the development of collaborative linkages for communication of the key findings. The perspectives of the immigrant women on needed programs and policies will be shared and specific implications, potential partnerships, and advocacy initiatives will be developed through the focus groups for immigrant women and for policy makers and providers.

7. Project Staff

In addition to the team of investigators, the project staff includes two graduate students, one undergraduate student, a baccalaureate prepared research assistant and a transcriber. One of the

graduate research assistants is supported by a graduate research assistantship from the Faculty of Nursing. Three research assistants who are from the communities involved, and speak the languages of the women recruited, conduct the interviews. In addition to English, the languages spoken by the research assistants include Cantonese, Mandarin, Punjabi, and Hindi.

8. Dissemination Activities

Collaboration with representatives of the women's communities, immigrant serving agencies, government services and the university is ongoing throughout the study and will build links for dissemination of the findings to policy makers and service agencies. A paper related to the study was presented at the First International Conference on Advances in Qualitative Methods, held in Edmonton, February 18-20, 1999. The paper title was "Participation of Immigrant Women Caregivers in Qualitative Research". A presentation on preliminary findings of the study will be made later in 1999 to a conference sponsored by an Edmonton area immigrant serving community agency. At the end of the study, fact sheets will be developed that communicate key findings including immigrant women's perspectives on needed programs and policies. Potential for future partnerships for policies and programs will also be identified.

9. Completion Date

It is expected that the study will be completed by March, 2000.

10. Additional Funds

We are pleased to have received additional funding of \$5000 from Caritas to supplement the \$15 000 received from PCERII for the study "Immigrant Women's Experience as Family Caregivers: Support and Barriers".

11. Student Involvement

Currently a Masters student in Family Studies and an undergraduate student in Nursing are employed as research assistants on the project.

12. Papers

A paper entitled "Participation of Immigrant Women Caregivers in Qualitative Research" was presented at the First International Conference on Advances in Qualitative Methods, held in Edmonton, February 18-20, 1999.

13. Other Dissemination Activities

A presentation on preliminary findings of the study will be made later in 1999 to a conference sponsored by an immigrant serving community agency.

14. Potential Policy Contributions

Implications for policies and programs will be specified through the focus groups for immigrant women and for policy makers and providers. At the end of the study fact sheets will be developed that communicate key findings including immigrant women's perspectives on needed programs and policies. Potential for future partnerships for policies and programs will also be identified.

15. University Support

Support has been provided by the University of Alberta in the form of a McCalla Professorship awarded to the Principal Investigator, provision of space and computer resources and proposal development support and management of funds from the Research Office, Faculty of Nursing. In addition, support in the form of a graduate research assistantship provided to a Master of Nursing student has been provided through the Faculty of Nursing.