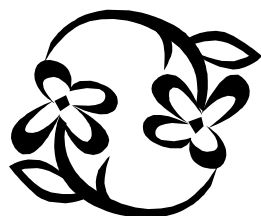


Immigrant Women's Experience as Family Caregivers: Support and Barriers



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REPORT



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Immigrant Women's Experience as Family Caregivers: Support and Barriers

Executive Summary

The purpose of this study was to examine immigrant women family caregivers' experience of support and barriers. The specific objectives of the study were to understand how immigrant women family caregivers gained access to community resources and to identify barriers to support from community resources. Barriers examined included those arising from social and material circumstances as well as values about caregiving.

Twenty-nine women who had immigrated to Canada from China (including Hong Kong and Taiwan), India, and Pakistan participated in the study. Two family members who assisted the women with caregiving were also interviewed. Fourteen women were interviewed in their first language. The majority of the women cared for elderly parents or parents-in-law. However, several women also cared for their children with a major disability or chronic illness or for children as well as adults. An advisory committee comprised of representatives of the ethnic communities of participating women, immigrant serving agencies, and mainstream health and social service agencies helped the research team to select appropriate methods of recruitment, data collection, and dissemination.

Connections with Community Resources

In order to meet their heavy caregiving demands and reduce the risk of negative impact on their health and their families, women often required assistance. The women's social networks, including friends, family, community or church associates and professionals, helped them establish connections with community resources. Friends with professional backgrounds interpreted expectations and characteristics of community resources while maintaining privacy. As one caregiver observed, women who did not have friends in professional roles do not always know what resources are available. Less frequently women knew of resources because other family members or friends utilized these services. Contact with community resources at times provided a bridge to other resources through referral and distribution of information.

Barriers to Resources

Half the women did not make any connections to community resources. A number of barriers were identified:

- Material circumstances, such as limited English skills, an inability to drive, and inadequate income were barriers.
- To provide financial support women often worked full time in jobs with limited flexibility and had insufficient time to locate resources and programs that could be helpful.
- Women who came to Canada through the family reunification program were sponsored by a relative who agreed to ensure provision of their essential needs for ten years. Their access to some publicly funded resources, such as income security, was restricted and they felt obligated to their sponsor.
- Personal and cultural values that were incongruent with community agencies' perspectives posed further challenges.
- Many women who valued privacy and were reluctant to disclose personal problems to a stranger, particularly when personal problems were associated with strong feelings.
- Conflict between beliefs in traditional herbal medicine and western medicine generated a dilemma for some Chinese women.
- For many women a core value was a belief that it was their personal responsibility to care for their family member. Relinquishing some of the care could represent a potential failure in their ability to fulfill their responsibilities and any change required family approval.

Policy and Program Implications

Policies related to structural conditions of immigration, resettlement, and access to employment and health care services should be reviewed to assess their long-term implications for the welfare of women and immigrant families. At the program level, collaboration and new initiatives are needed among all agencies that address the needs of immigrant women caregivers to facilitate access to community resources.

Immigrant women caregivers' experience in use of community resources was often unsatisfactory and some women with heavy demands had no assistance. Their experience of barriers to support illustrates the importance of advocacy to modify policies and programs affecting their ability to care for ill or disabled family members in the context of Canadian society.

Immigrant Women's Experience as Family Caregivers: Support and Barriers

Ethnic diversity is increasing in North America (Hall, 1999) and women in many cultural traditions provide most of the direct care to family members with a chronic health problem or disability (Harris & Long, 1999; Statistics Canada, 1997). Caring for family members with chronic health problems can affect women's work and social life as well as their psychosocial and physical health (Pearlin, Mullan, Semple & Skaff, 1990). In the extensive research on support for family caregivers in non-immigrant populations, social support from family, friends and community resources is beneficial for the health of the caregiver (Braithwaite, 1996; House, Landis & Umberson, 1988; Kiecolt-Glaser, Dura, Speicher, Trask & Glaser, 1991; MaloneBeach & Zarit, 1995; Rautkis, Koeske & Tereshko, 1995). However, there is little research on access to support for immigrant women family caregivers.

Immigrant women's access to support from community resources is influenced by policies related to immigration and health care. Support for women family caregivers may also be influenced by the cultural context of the women's country of origin and the disruption of social ties associated with migration. Disruption in social ties and the absence of traditionally expected sources of support from kin contribute to the need for access to support from professional services. Nevertheless, variations in immigrant women caregivers' experience of support from community resources have not been examined.

Background

Caregiving Context

The percentage of immigrants coming to Canada from the Asia Pacific region rose to 45 percent in 1987 and has continued to increase (Chard, Badets, & Howatson, 2000). Since 1976, applicants could enter Canada through either a family reunification or an independent category that provided for entrance as skilled workers, business class entrepreneurs or investors. Investors

who committed to investing \$450,000 in a Canadian fund for 5 years required 1/3 as many points for approval as applicants considered under the family reunification category (Fleras, & Elliott, 1999). Many of those who entered in the independent category subsequently applied for relatives to join them under the family reunification clause.

Immigrant families are often disadvantaged as a result of declining income and restricted access to health and social services. For example, in Canada, under the family reunification classification, immigrants are not eligible for receipt of social assistance; sponsors assume financial responsibility for the sponsored relative for 10 years. Despite possessing higher education (Chard, Badets, & Howatson, 2000; Simmons, 1990) and being more often employed full-time, immigrant women and men have lower than average incomes compared to the Canadian-born population and are concentrated in administrative, clerical, sales and service jobs (Beaujot & Rappak, 1990; Chard, Badets, & Howatson, 2000).

Women's access to support from community resources is influenced by policies related to immigration and health care. Although there is a universal health care system in Canada, coverage available to immigrant families may vary with immigration status (Fleras & Elliott, 1999) and province of residence. The policies and programs that influence the support available to immigrant women from community resources may lack cultural sensitivity, restrict their access, or be unacceptable to the women (National Forum on Health, 1997; Stevens, 1993). In addition, women immigrating to Canada often had less access than men to government sponsored English language educational programs (Ng, 1993). A lack of ease in speaking English can decrease a woman's access to health information.

Statement of the Problem

The purpose of this study was to examine immigrant women family caregivers' experience of support and barriers to support. Although support from community sources and family and friends are interrelated, emphasis in this study was given to community sources of support. Specific objectives were:

- a) to understand how immigrant women family caregivers access community resources
- b) to identify barriers to support from community resources including those arising from social and material circumstances and values about caring.

For the purpose of this study, family caregiving was defined as assuming primary responsibility for providing care, without remuneration, to an ill or disabled family member. We use social support to refer to the caregivers' evaluation or appraisal of key relationships with family, friends and service providers (Funch, Marshall & Gerbhardt, 1986).

Method

Ethnographic inquiry (Hammersly & Atkinson, 1995) in a sociological tradition provided access to the women's descriptions of how they obtained support from community resources. An interpretive critical theory perspective (Morrow, 1994) was employed to emphasize cultural and social characteristics of the caregiving context and locate the individual's perceptions and actions within social and structural settings.

An advisory committee comprised of representatives of the ethnic communities of participating women, immigrant serving agencies, and mainstream health and social service agencies was established. The committee helped the research team to ensure relevance to immigrant women and to select appropriate methods of recruitment, data collection, and dissemination.

Sample Selection and Recruitment

The participants were women who immigrated to Canada from China, including Hong Kong and Taiwan and India or Pakistan. Chinese and South Asian women were chosen for the study as these were the largest immigrant populations in the study area. Our focus was women who were voluntary immigrants as the impact of migration and the experience of support may differ for refugees. We sought to include women who varied in age, income, caregiving situation, facility in English and geographic area of their country of origin. The immigrant women family caregivers were initially recruited through advertisement in participating community agencies and local media. Theoretical sampling guided subsequent recruitment of participants, selection of women for a second interview and participant observation, and recruitment of focus group participants.

Data Collection

To provide information from varied sources, data for the study included interviews with immigrant women caregivers, participant observation, and focus groups with women and professionals from community agencies. All women participated in one open-ended interview; 6 women participated in a second interview in their home that included participant observation of their care for their relative. Two women chose to be interviewed in a group. We also interviewed two family members who assisted the woman with caregiving; the sister of one woman who cared for their mother and the father in law of a mother with a disabled child. Interviewers, members of the women's ethnic community, received preparation in interviewing in the context of qualitative research. They spoke Cantonese, Mandarin, and Punjabi. Fourteen women (8 Chinese women and 6 South Asian women) were interviewed in their first language.

The women were encouraged to tell the story of how they came to care for their family member and to comment on the help they received from outside the family. We also asked them

to describe the support they received from family and friends, support from community agencies, the difficulties they experienced in getting the help they needed and how their experience of immigrating to Canada affected their ability to care for their relative. Women participating in the second interview were asked to describe any changes in their experience of support and the kind of assistance they would like but were not currently receiving. Participant observation provided an opportunity to observe practical caregiving activities and demands.

After the interviews, 4 focus groups were held; two with women caregivers who had been interviewed previously (4 Chinese and 3 South Asian women) and two with health and social service providers (n=15). The principal investigator facilitated focus group sessions with the assistance of interviewers from the ethnic communities. We constructed four composite case scenarios to incorporate the primary findings of the study. The scenarios featured women from each of the ethnic communities of the participants in the study. To facilitate discussion we developed questions to guide discussion of the scenarios. The questions addressed the issues present in the situation, the type of assistance that would be helpful, potential changes needed in existing resources to provide more aid and possible barriers to achieving those changes. We explored the same questions and scenarios in group discussions with professionals and women.

Interviews and focus groups were audiotaped and transcribed verbatim. All tapes were reviewed against the transcripts to determine accuracy of the transcription. Audiotapes of interviews conducted in a language other than English were reviewed by the interviewer who did the original translation. The interviewers translated the interviews done in languages other than English prior to transcription. Interviewers met regularly with the Principal Investigator, attended Advisory Committee meetings and participated in some research team meetings that involved data analysis. Interviewers maintained detailed fieldnotes for all interviews and observations,

including comments about relevant social context, cultural practices or perspectives. They also documented in the fieldnotes any issues identified in the process of translation.

Data Analysis

Data collection and analysis proceeded simultaneously. A thematic form of content analysis (Lofland & Lofland, 1984) was employed. Data segments from multiple sources that pertained to a common idea were assigned preliminary codes. As distinctions among the codes became clearer, these sensitizing (Blumer, 1954) concepts were more specifically defined and used in the analysis. All members of the research team reviewed transcripts and participated in data analysis. A record was kept of all decisions made in the analysis process (Morse & Field, 1995). Study findings were considered in the context of existing literature. Atypical cases were noted and memos were kept of decisions and questions for further investigation. The Non-numerical Unstructured Data* Indexing Searching and Theorizing (NUD*IST4) software program was used to manage the data. Analytic procedures such as matrices helped to identify linkages among concepts (Hammersley & Atkinson, 1995). Comparison was conducted across ethnic groups, income, age, and caregiving situations to examine the possible influence of these variations.

Ethics. The local institutional ethics review board approved the study. All participants signed a consent form and were advised that their participation was voluntary and that they could withdraw at any time.

Findings

Profile of Participants

Twenty-nine women participated including 18 Chinese and 11 South Asian women. Fifteen of the Chinese women had immigrated from Hong Kong, 2 from China and 1 from Taiwan. Two secondary caregivers (who assisted the woman with care), the father-in-law of a

Chinese woman and the sister of another, were also interviewed. Ten South Asian women came from India, and 1 from Pakistan. The Chinese women included 4 recent (< 7 years), 5 intermediate (8-14 years) and 9 long-term residents (> 14 years). Secondary caregivers were both long-term residents. All South Asian women were resident in Canada more than 14 years. Further socio-demographic characteristics are displayed in Table 1.

Table 1

Demographic Profile of Participants

Demographic Characteristics	<u>Group</u>	
	Chinese (n=18)	South Asian (n=11)
Age in years		
Range	30-79	30-76
Education		
<Grade 12	1	3
Grade 12	6	0
Some postsecondary	4	3
University	7	5
Annual household income in dollars		
<20, 000	3	2
20,000-39,000	3	3
40,000-59,000	2	2
60,000-79,000	4	1
>80,000	1	1
Undisclosed	5	2
Labour force participation		
Employed		
Full-time	8	3
Part-time	3	5
Casual	1	0
Retired	3	1
Homemaker	1	2
Other or undisclosed	2	0

Professionals participating in focus group discussions included 7 representatives of mainstream organizations such as regional community health, home care, and educational services that served immigrant populations as well as 3 policy makers representing provincial and federal government departments. There were 4 participants from immigrant-serving agencies and one representative from an ethnic community agency.

Caregiving Situations

Most women had relatives in Edmonton, other parts of Canada, and their country of origin, but 10 women made no reference to family members outside of North America. With the exception of four women who came because they were seeking better employment or education, the women entered Canada as part of the family reunification policy that included a requirement for their financial sponsorship by a relative for 10 years.

The women were caring for a spouse, a parent or parent-in-law or a child. The caregiving situations included care of relatives with a variety of health problems or disabilities. Adult care recipients included relatives with cancer, kidney disease, arthritis, heart disease, and dementia. Most of the six children cared for had a developmental delay or cerebral palsy.

Women often referred to their caring role as part of their responsibility as a woman and as a mother or daughter in law. In some cases, they indicated that there was no one else available and the usual pattern of caring for relatives was altered because they were in Canada. For example, two women indicated that they would ordinarily care for their husband's parents in their culture. However, they could not ignore the needs of their own parent(s) as there was no daughter in law available to care for them. In some cases, this resulted in the need to provide care for 3 elderly parents.

References to experiences associated with direct discrimination and minority status were rare. However, one woman described the negative attitude of some nurses in the hospital where

her mother was admitted. The nurses seemed to feel she was not willing to assume her share of responsibility by giving insulin injections to her diabetic mother. Another woman believed that service providers did not understand the culture and therefore Chinese women did not receive the same assistance as others.

The women faced heavy caregiving demands that often included providing extensive assistance with personal care as well as cooking meals, monitoring medications, assisting with housekeeping, taking the care recipient to medical appointments and trying to maintain social contacts for the care recipient. Twelve caregivers were caring for several adults or for children as well as adults. The impact of combined caregiving demands was sometimes overwhelming.

Friends and Family Facilitate Connections with Community Resources

Although women had immigrated to Canada from two different geographic areas, their experience of seeking access to community resources was similar. In order to meet the heavy demands and reduce the risk of negative impact on their health and their families, women required assistance from community services. The women used resources such as speech therapy, respite care in a nursing home for an elder, school for special needs children, or home care for an elder or child. Some women established access only to formal sources of support, some were assisted by support from both formal and informal sources, and others did not describe receiving any assistance. The women's social networks including friends, family, community or church associates and professionals helped them to establish connections.

The most common way for women to connect with community resources was through personal friends or relatives in the informal social network. For 5 of the 12 women linked to resources by friends or relatives this was their only connection; for the remaining women initial connections with resources occurred through both professionals and the informal network. Assistance from a friend who was a social worker, nurse or physician was common. Friends with

professional backgrounds were able to ensure privacy, while interpreting expectations and characteristics of community resources in a meaningful way. One caregiver noted that many who do not have friends in these professional roles do not know what resources are available.

We have friends who are social workers and who are nurses, who are doctors... So, we get to know more about the system, but if you don't know these people... Sometimes it is really hard to get information. (Chinese Caregiver)

Another connection between relatives and community resources occurred when other family members required similar services. For example, one woman indicated she had sought assistance for her child from a local rehabilitation center because her niece/nephew also had a developmental delay and had received services there. When asked how she knew of these services, she responded

I didn't know anything. It is only because his other cousin went [to an agency] for the assessment. (Chinese caregiver)

Referrals to Chinese herbal medicine practitioners came from friends in the same ethnic community or church who had used similar services. One woman who was caring for her husband with cancer appreciated a church member's recommendation that she contact a Chinese medical practitioner. She was frustrated with her husband's inability to eat and the difficult challenge of cooking meals he could tolerate.

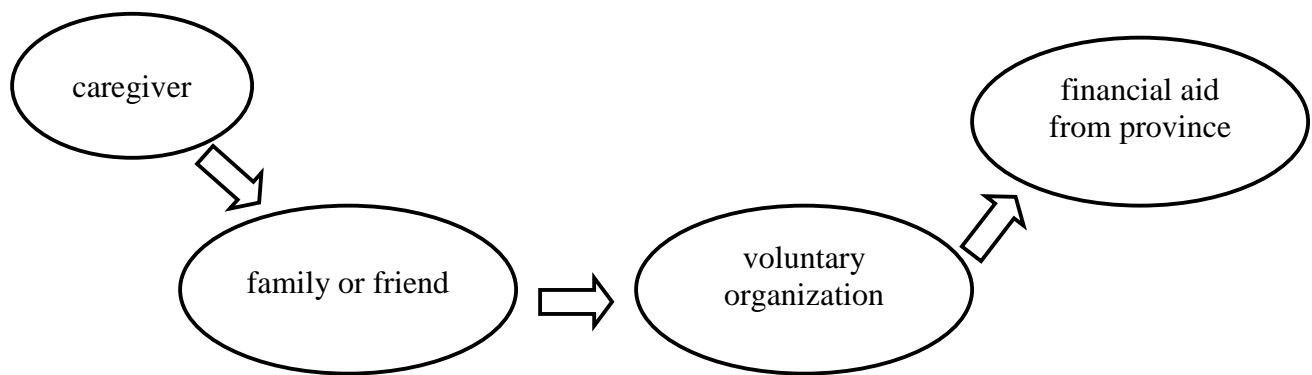
He couldn't eat again. He couldn't take the nutrients . . . he is uh referred by a friend in the Church. . . . we cannot just take the prescription and get the herbal medicine here. If the person in the church doesn't know the doctor, we won't be able to know this doctor [Chinese medical practitioner]. (Chinese caregiver)

One mother reported asking other caregivers in her community for information when she needed a wheel chair for her son. These inquiries helped to identify the advantages and disadvantages of different alternatives. In her case, this informal support supplemented information and advice available from a social worker.

A Chain of Linkages with Family, Friends and Professionals

Other women described a chain of linkages (Figure 1) with friends or family, professionals and community resources. These connections had a cumulative effect in ultimately establishing access to community resources. The process involved one contact, sometimes unrelated to caregiving, leading to others.

Figure 1. Example of a chain of linkages in connecting with community resources.



For example, one mother described how first a friend in a parenting class and then her child's teacher commented on her child's slow development. Through the teacher's recommendation that she contact her family physician, she was eventually connected with appropriate services.

They have parenting class, and I attend that and I get some friend, and then get some teachers. They told me he seems to have some problem. They suggest me talk to the family doctor and then the family doctor command me to go to the [rehabilitation center].
(Chinese caregiver)

In this example, participation in a community program was also a catalyst for forming new relationships that became a source of helpful information. In the context of a parenting class this mother made a friend who noticed her son's developmental delay.

The aunt of one woman referred her to respite services for her elderly mother. The respite service in turn became a link to other community resources. When asked how she discovered these services she replied

From the respite home. And this information, actually about the respite home, the aunt mentioned to me. That's how we came to know other departments. And then you come to know more and more. (South Asian caregiver)

These examples illustrate the interconnection of friends, family, professionals, and community services.

Contact with one community resource provided a bridge to other resources through referral and distribution of information. For example, one mother with assistance from an advocacy association for handicapped children successfully appealed the denial of her application for financial assistance from a government program.

So I talk to them . . . and then they just said you know, if you need it you have to fight because they don't give you that easy . . . they help me to do with the appeal. (Chinese caregiver)

In this example, one organization directly facilitated access to the resources of another. Often organizations and individual professionals provided women with specific phone numbers and information about a range of community resources.

Missing Links: Barriers Restricting Access to Resources

Although we have described the pathways that linked immigrant women caregivers to community resources, more than half of the women in our study (10 Chinese and 7 South Asian) did not report making connections to community resources. Of the 17 women who reported no linkage with outside resources, 9 were interviewed in the language of their country of origin. Women in this group included caregivers of an adult or child, recent, intermediate and long-term immigrants, those who were employed or not employed, and women whose relatives resided in

the local community and abroad. There was no identifiable pattern in their lack of access to support.

Barriers Restricting Access to Resources

The lack of an identifiable pattern in lack of access to support raises the question of barriers that may have prevented them from connecting with community services. We found that immigrant women experienced structural barriers arising from immigration policies, the material circumstances of caregiving, and barriers related to their personal and cultural beliefs.

Immigration policies. Caregivers often described a pattern of chain migration through the family reunification policy; one family member came initially and subsequently sponsored one or two other members, thus disrupting usual patterns of family care and support. The Canadian policy requirement that family members sponsor new immigrants for the first 10 years limited use of community resources by recent immigrants and created a potential burden for their relatives.

Since my brother applied us to come here, he's responsible for the expense for us for at least 10 years. So the Canadians are very bright in that way. (South Asian caregiver)

One woman complained of the inequity she saw between this policy and the benefits afforded to refugees who were immediately eligible for social assistance and health care benefits. She gave the example of people who were wealthy, but entered Canada as political refugees in 1989 after the Tianemen Square crackdown.

As you come from Hong Kong you cannot get any service. And if you work, the tax will "kill" you. But if you got political asylum, you get money. And so we always say being Hong Kong people are less fortunate... since you come from a modern city you get nothing. I only got \$400 as being janitor per month. I needed to pay tax even and they can receive money and don't need to work. (Chinese caregiver)

Material and physical circumstances. Material and physical circumstances limited the women's access to resources. These included inadequate skill in English, lack of transportation

to travel to receive services, lack of time to seek out resources and overwhelming responsibilities related to the need to work full time in order to provide income for their families.

Women were hampered in their ability to access services by inadequate skill in English, even when they had attempted to learn the language.

When I first came here I went there to learn English for like several weeks, but now I forgot most of it. (Chinese caregiver)

One woman was unable to apply for a walking aid because she could not communicate either her health care number or her name over the phone to the intake worker. Our primary focus was on initial access to community resources, but there is substantial evidence in the data that facility in English is also very important in sustaining a beneficial connection with a community service.

If he stays in the hospital or senior centre, he needs somebody to speak Mandarin or Taiwanese. If the agent doesn't provide such service, he prefers staying in the house. (Chinese caregiver)

In one situation, the family interpreter lacked the complex English vocabulary necessary to understand the medical terminology used by the specialist. Consequently the caregiver and family were unable to understand their relative's condition. Inadequate skill in English was also a barrier to expressing emotion. As one Chinese woman said, "It's hard to use English to talk about emotional needs".

Immigrant women's circumstances often restricted their physical access to services due to an inability to drive, inadequate income to purchase a car, or insufficient time to provide transportation. As many elder care recipients did not drive, they relied on their adult children to drive them to appointments with family physicians, medical specialists, dentists, ophthalmologists, to the laboratory for tests, or to shop for medical aids such as a walker. They were also dependent on other family members for transportation to participate in social or recreational activities. For caregivers that were employed, particularly those in lower income occupations with limited flexibility, this created a major demand. Some caregivers did not have a

car or had difficulty taking time away from work during business hours and/or from care of their children and household duties to drive their parent to appointments. Parking was difficult to locate and expensive, particularly when the care recipient was limited in the distance they could walk. Because many older immigrant family members were unable to drive, their socialization outside their families was severely restricted and the pool of potential friends and relatives who could relieve the caregiver and spend time with the care recipient was limited. One caregiver insisted that her mother learn to take public transportation. Because her mother could not speak English, a family member made a tag that she carried indicating her name, address and phone number. Although her mother was very hesitant, she did use the bus. Other family members worried about her, particularly in poor weather. But, as the caregiver said

This is very essential because it's not good if she stays at home all the time. I rather she takes the wrong bus instead of staying at home all the time. When first arrived, she got really bored as she did not know how to take bus. (South Asian caregiver)

Lack of time also made it difficult for caregivers to locate resources and programs that could be helpful.

Like, there's probably all kinds of programs out there, but for one thing, we don't have time to join. (Chinese caregiver)

We can't take time off from work either. It is very stressful. (South Asian caregiver)

Sometimes they had an immediate need for a service but often there were waiting lists, the time the service was available was insufficient, or they couldn't find sufficient time to seek support by contacting different offices and agencies.

Well, some services, they have a waiting time. . . but I find it, when you really need it, you sort of need it now. . . , we waited for over a month. In order to get support - you need to go to so many different places and offices and I just don't have time for that. (South Asian caregiver)

For many women family income was low as a result of immigration and they worked outside the home to support the family. Consequently they often faced overwhelming demands.

A South Asian woman who had only occasional help from her husband was caring for her in-laws in addition to her full time job and care for her children describes her situation

I get up 3:45a.m. in the morning. I prepare breakfast and lunch for my kids and in-laws. I leave for work at 5:15a.m. I give her bath in the evening - usually every 2nd day. Usually my husband helps out. We have no help from friends or any other family member. I come home in the evening, then prepare supper for the whole family, give bath to my small kids, clean the house. (South Asian caregiver)

Even when responsibilities are shared with another family member demands can be overwhelming if there is no assistance outside the family.

Caregiving values and limitations on access to community resources. Immigrant women's values (the internal criteria the women used to select and evaluate their caregiving goals, McPherson, 1990) also restricted their access to support from community resources. These values included a concern for privacy and tension between use of Chinese and western medicine. For women caring for elders, specific beliefs about care of elders within the context of the family were important for their ability to access services.

Women who valued privacy were reluctant to disclose personal problems to a stranger, particularly when personal problems were associated with strong feelings. One caregiver observed that a more indirect form of communication with a friend who is also a professional served as a substitute for her relative. Using this way of linking she overcame both the language barrier and concerns about privacy while gaining access to expert information. Reluctance to disclose the nature of their situation because of a concern for privacy within the family could preclude requests for assistance. For example, a child's developmental delay was something not discussed with strangers as it could reflect negatively on the family. A mother describes how her mother in law felt that no one outside the family should care for her developmentally delayed grandson.

Sometimes we also ask our relatives to take care of our son. If we cannot find any family member we would pay school teachers . . . my mother-in-law worry if an outsider takes care of the son. (Chinese caregiver)

Conflict between belief in traditional herbal medicine and western medicine generated a dilemma for some Chinese women. The parents-in-law of a Chinese woman were the primary caregivers of her developmentally delayed son for 5 years while she and her husband worked abroad. When she returned she wanted to consult a traditional Chinese medical practitioner for her son but her mother-in-law objected on the grounds that the child might have a reaction. The mother considered treating the child secretly but decided this was not possible and would reflect disrespect for her parents-in-law. On the advice of friends, she secured acupuncture treatment for her son that was not objected to by her in-laws.

Although he is my son, he is also like my in-law's son. Sometimes my friends referred Chinese medicine to me . . . my mother-in-law would say 'Don't give this poor kid any medication'. . . At first I plan to take my son to see this doctor secretly. . . my friends also referred acupuncture to me. I took my son there around 1 year. (Chinese caregiver)

Another caregiver agonized over her lack of knowledge of Western medicine when caring for her grandmother. After a fall her grandmother was treated by a traditional Chinese Herbalist for a year without improvement. Through her own subsequent education in Nursing and later follow-up with a physician, she discovered that her grandmother had had a fracture. However, it was no longer possible to correct her immobility.

She could not get up after she fell. Maybe we did not know the bone was broken. We brought her to see the herbalist for one year. At the end she could not walk. I did not know until I work here that we should not move the old people when they fell. (Chinese caregiver)

Values associated with care of elders and access to community resources. Twenty-three of the women in this study (13 Chinese; 10 South Asian) were caring for an older adult. We therefore specifically examined caregivers' values related to caring for elders. Twelve of the

women included in this analysis did not report receiving assistance from either friends and family, or professional sources.

Responsibility to care for elders. For these women, the core value was the belief that it was their personal responsibility to care for their family member. We use the term core value to refer to the primary perspective on family caregiving that guided the women. Chinese women referred to this as filial piety whereas South Asian women spoke in terms of their family responsibility and duty. This high commitment to fulfilling their responsibility to care for family members and respecting their wishes influenced many caregiving decisions.

Filial piety and caring are what we should do. . .What makes me feel satisfied is that I know how to care [for] her through filial piety. (Chinese caregiver)

I don't think there's anything rewarding. I do it just because it's my duty. (South Asian caregiver)

The women also held more specific beliefs about their role in caring for elders within the family context. One of the Chinese women caregivers saw her role of caring for parents in part as reciprocity for their care of her earlier in life.

What keeps us going is that in a big family, parents are the ones who look after myself. I have the responsibility to look after them when they get old. (Chinese caregiver)

No similar perspective was described by any of the South Asian women. South Asian women indicated that reciprocity or returning aid received was not an important part of their motivation to care. Instead duty and obligation were primary. Another related value was the women's concern to be a model for their children.

I also think that children will learn from my experiences that they should respect and help elders. (South Asian caregiver)

Women were responsible to care for family members, including husbands, parents, or parents-in-law. However, emphasis was given in this analysis to women caring for parents or parents-in-law. In Chinese families the wife of the eldest son was the preferred caregiver and

usually assumed the major responsibility for care of her in-laws. In South Asian families, women assumed primary responsibility for the daily care of elders but the eldest son was usually designated as the primary decision-maker.

Although caring for family members was the responsibility of women, with immigration, modifications occurred in who would provide care for elders. For example, one Chinese woman described how, as the daughter-in-law, she had responsibility to care for her husband's parents, but because there was no daughter-in-law available in her family, she cared for her parents as well. She valued her husband's support for her care of her own parents. She considered her role and her husband's support to be unusual.

Basically, I don't get any support...lucky I got my husband ... he's quite understanding. Because, well, for some traditional Chinese male, I would say if you marry:...you shouldn't be taking care of your own family again... (Chinese caregiver)

In one South Asian family, a retired woman agreed not to seek assistance from her brother in caring for their mother in exchange for his sponsorship of their mother's application to immigrate from India. In this way her brother, although assuming the responsibility of sponsorship, was released from responsibility for her ongoing care.

So, nobody to take care of her, so I thought we should bring her here... I was just afraid . . . they may refuse the sponsorship, so my brother did sponsor her ...on the condition that I would take care of her...So, I'm sort of bound uh, that way. (South Asian caregiver)

When the usual pattern of care was not possible and flexibility in family roles was limited, the women assumed responsibility for both their own expected role and the role of absent others. One woman described how, in addition to caring for her asthmatic son and her in-laws, she also had to provide care for her own parents. Her brother, the only surviving son, was not married. Although he relinquished a good job and returned to Canada from Hong Kong to live with his parents, she does not think her brother is capable of taking care of her ill parents.

I be a full time mom, a full time work...taking care of my parents...he's [surviving younger brother] the only son who come over to taking care of them. . He's living with

my parents. . . I don't...think he can even taking care of himself well enough, to [be] taking care of the sick parent. (Chinese caregiver)

For the women, encouraging elders to enter a continuing care facility could represent a failure in their ability to fulfill their responsibilities and any change required family sanction. Consequently they did everything possible to avoid admitting a relative. One woman had arranged for her in-laws and her mother to have homes close together so she could care for all three of them. However, her mother became demanding and difficult to care for and the caregiver's health was threatened.

Every one said she stepped over me. But I thought she is my parent. I would let it go. So that when she passed away, I know that I don't have to regret anything. I would not feel guilty ... no matter what, I'll try my best. (Chinese caregiver)

She was concerned that she was failing in her responsibility. This woman later consulted with several relatives before she agreed to admit her mother to a continuing care facility. In this way there was family sanction for a change in her responsibility.

Then the daughter-in-law said to me... "I suggested you let her go to the nursing home." My brother also said that, "sister, let her go, don't cry, it's no use." I cried for a few days...and so I decided let her go. (Chinese caregiver)

Often the available facilities were not culturally sensitive. This resulted in inadequate care for the elder due to inability to speak English, eat the food provided, or socialize with others.

Values affecting acceptability of community resources to elders and caregivers. Several women caring for elders talked about the reasons for rejecting community or institutional services for their relative. Frequently such services were unacceptable to the elders themselves and therefore declined by the woman. One Chinese woman who was caring for her parents and her mother-in law in separate houses sought to employ someone to assist her parents with the housecleaning. However, her parents refused because they were uncomfortable with strangers.

So I just say, how about I hire someone as a part time, like pay by hour basis ...to help them clean up the house? They don't want to. They kind of like, really, against strangers. (Chinese caregiver)

She also suggested her parents move to a sheltered housing facility to relieve the burden to herself and her brother. She saw her mother's refusal as a reflection of traditional views.

. . . after so many years, he [my father] saw me running around doing like crazy. And, he said 'I can, I, I rather live in an old folks home.' But my mom, she can't give up her...old, old ideas. (Chinese caregiver)

Another woman says her father says he would “. . . rather die than go into a home. Or even into a lodge.” “They want to stay with their own family.” Another woman described how there was no home care assistance available to her parents because they lived with her when assistance would be possible if they lived alone.

This one time I phoned this senior healthcare line. This lady on the phone said, “You think you're doing your parents, uh, a favor by keeping them in your house?” I said, “Why not?” She said, “Well, they're not mixing with their own age group, you know, you think they are happy living with you?” I said, “Lady, you don't know what you are talking about.” I said, “You come from a different culture where I came from.” (Chinese caregiver)

Her interaction with health care agencies to seek additional support to care for her parents at home illustrates a lack of agency understanding and respect for the caregiver's perspective on care of her parents.

Discussion

Our findings on the way women established connections with community resources reflect two levels of social connection. One is the level of social interaction at which women established links with community resources and the second is the level of the family unit that must organize care for its members.

At the social level, interpretation of the linkages women established with community resources outside the family is facilitated by consideration of theoretical perspectives on social networks. Granovetter's (1983) classic work on social networks proposed that weak links among

acquaintances can be important bridges to new information and resources. People connected by strong social ties often share a similar, overlapping circle of friends and have limited exposure to new information. Opportunity to develop new acquaintances outside this circle may provide indirect access to new information and ideas. This hypothesis has important implications for immigrant populations who may have strong ties with members of their ethnic community who share their values and traditions, but have restricted access to those outside that community. Because the support network functions as a screening and referral agent to community resources, small high-density networks of strong ties can increase dependency and act as a barrier to outside help (Grant & Wenger, 1993). On the other hand, lower density, heterogeneous networks with larger numbers of weak ties can be a connection to a wider source of advice and help and promote independence.

A limitation of Granovetter's (1983) work is his emphasis on the strength of the tie without consideration of the content of the relationship. Another study of migration (Pescosolido, 1986) examined the process of assimilation in the context of chain migration. Initially a few close ties were formed by the new immigrant with those who immigrated at earlier times and who served as cultural brokers to new immigrants. Over time the influence of these relationships decreased for new migrants as there was increasing contact with others outside the ethnic community. Migrants eventually adopted views similar to those of others in the larger community. Given this perspective, the nature of the influence of the social network depends on who people talk to about their problems and the values they hold (Pescosolido, 1986; 1992). For example, there may be increasing preference for western medical care as contacts broaden.

The chain form of immigration that begins with one or two family members who later sponsor others to come to Canada was characteristic of many of the families participating in this study. From the perspective of family resource management (Tam & Detzner, 1998), this pattern

of immigration breaks up an intact family that may never be fully reunited. Many of the women in our study who described this process of immigration had close family members resident in other countries. Chain immigration alters patterns of family caregiving and exchange between generations. Some families who have immigrated may see elders as a source of education on traditional values for their children. Others may see elders as a barrier to their children's acculturation. The extent to which either of these perspectives prevails may vary with geographic proximity as well as the middle generation's expectations.

The values and perspective on caregiving that the women described in this study were congruent with the findings of other studies of multicultural caregiving populations. Women considered giving care as their responsibility guided by filial piety or by family duty. A motivation to care on the basis of place in the family structure was also identified in a Japanese American sample (Harris & Long, 1999). In Korea a "filial piety prize" was awarded by the government to recipients who were willing to make sacrifices to provide parent care (Sung, 1992). In the context of filial piety, care by the oldest son usually meant hands on care by his wife without assistance from other family members. However, it is acceptable for women to accept assistance when caregiving demand surpasses a family and community defined norm (Yamamoto, Noriko & Wallhagen, 1998).

In summary, the findings of this and other similar studies raise questions about the potential fit between family caregiving systems that are collectivist in nature and community services that are rooted in more individualistic values (Pyke & Bengtson, 1996). There is a potential for lack of fit that needs to be addressed by program policies that are more congruent with the requirements of immigrant families for access to support from community services.

Policy Implications

In the findings from this study some barriers such as exclusion from government funding for health and social services were rooted in immigration and institutional policies. These placed largely non-negotiable constraints on women's decisions and action. This illustrates the linkage of individual women's experience to the larger social system and government policy. As Pescosolido (1992) argued, we need to link "actors to each other, to the larger social system, and to abstract entities like the state, the economy and the community" (p.1107). Policies related to the structural conditions of immigration, resettlement, and access to employment and health care services require review that takes into account their long-term implications for the welfare of women and immigrant families.

Other barriers were more closely associated with women's beliefs in privacy and personal responsibility. There is potential for change in the composition and beliefs of members in the social networks of immigrant families as their scope of contacts expand and acculturation increases over time. However, the implications of the changing characteristics of the network for immigrant families' linkage with and use of community resources are complex as there may be diversity, conflicting beliefs, and varied obligations among members of the network. Some research indicates that life may become more stressful with increasing length of stay and acculturation (Hyman & Dussault, 2000).

At the policy level our study illustrates the implications of the sponsorship policy in the family reunification program. Women may not get the assistance they need and are vulnerable to exploitation by the sponsoring relatives to whom they are obliged. In addition, adult dependants may be unable to receive benefits. The issue is further complicated by the fact that, in Canada, immigration is a Federal government responsibility whereas responsibility for delivery of health and social services is provincial.

Often women continued to work full time to contribute to the family income, but this can contribute to overwhelming demands when added to family caregiving responsibilities. Moreover, despite possessing higher education and being more often employed full-time, immigrant women have lower than average incomes when compared to the Canadian-born population (Beaujot & Rappak, 1990; Chard, Badets, & Howartson, 2000). Reduced income may be associated with employment in lower paying positions due to inability to establish equivalence of educational credentials and limited facility in English or French. Women immigrating to Canada in the past often had less access than men to government sponsored English language educational programs (Ng, 1993). A further consequence of restricted access language programs is limitations on women's ability to establish diverse and mainstream social networks. These broader networks are important sources of information about health care or social services (Pescosolido, 1992).

Program Issues

At the program level there are a number of salient service delivery issues. Women lack connections within mainstream society, face language and transportation barriers, and experience a lack of cultural sensitivity in the conditions under which service can be received. Even some of the strategies to deal with these issues can fail to realize the desired goal. For example, interpreters may violate privacy concerns.

Some examples of customary program approaches include mainstream government funded agencies that attempt to be responsive to differences in language or culture through the use of well qualified and prepared interpreters or hiring staff members to provide care who represent the ethnic communities. Immigrant serving organizations may provide information on access to resources through staff who speak the language and understand the culture of their clients. They may also provide interpreter services. Ethnocultural associations may offer health

and social services specific to their community and sometimes maintain a volunteer interpreter service, or provide information to their community. They can act as catalysts in getting people together to discuss the issues and seek alternatives. Cultural broker programs seek to work with specific ethnic communities to increase their awareness of available resources and influence delivery of community resources to become more culturally sensitive.

In addition to the isolation arising in relation to migration and cultural transition, isolation occurs as a result of heavy caregiving demands. Caring for ill or disabled family members also results in diminished personal and financial resources available for the caregiver. These characteristics mean that family caregivers' requirements for support usually exceed what is feasible for family and volunteer community helpers to provide. At the program level, collaboration and new initiatives are needed among all agencies addressing the needs of immigrant women caregivers to facilitate access to community resources.

Dissemination Activities Associated with the Project

Focus group discussions provided one venue for communicating the key findings and soliciting suggestions for program and policy changes. The focus group discussions. We held these discussions with immigrant women caregivers and service providers/policy makers at the end of the study. These discussions provided an opportunity to disseminate study findings and address the implications for program and policy change and development.

We have developed information sheets that summarize the key study findings (See Appendix A). In addition, findings will be reported through community and organizational newsletters of interest to immigrant women.

Community presentations have been made at the Prairie Center of Excellence for Research on Immigration and Integration (PCERII) brown bag lunch, and two local conferences; one sponsored by Changing Together in May, 1999 and a conference on seniors sponsored by the

Indo Canadian Women's Association in November, 2000. A list of presentations at international and national conferences is included in Appendix B.

National/International Linkages

National and international linkages are facilitated by the study presentations at national (Canadian Association on Gerontology Annual Meeting, October, 2000) and international conferences (International Metropolis Conference, November, 2000). Team members' affiliations with the Prairie Centre of Excellence for Research on Immigration and Integration and the Centre for Health Promotion Studies provide linkages to networks that include other researchers, service providers and policy makers.

Conclusion

Although there was evidence in our study that women used community resources, the services were often unsatisfactory and some women with heavy demands had no assistance. More than half of the women did not report making connections to community resources. The barriers to support that immigrant women described underline the need for advocacy to modify the policies and programs affecting their ability to care for ill or disabled family members within the context of Canadian society.

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Appendix A
Information Sheets

Appendix B

Presentations at National and International Conferences

Neufeld, A., Harrison, M. J., Stewart, M. J., Hughes, K. D., & Spitzer, D. L. (2001, April). Immigrant women caregivers: Bridges and barriers to support. Invited presentation, Alberta Association on Gerontology and the Centre for Gerontology, University of Alberta, Edmonton.

Neufeld, A. & Balsar, A. (2000, November). Caring for caregivers: Workshop discussion. Paper presented at the Conference on Seniors, Indo-Canadian Women's Association, Edmonton, AB.

Neufeld, A., Harrison, M. J., Stewart, M. J., Hughes, K. D., & Spitzer, D. L. (2000, November). Issues emerging in a study of immigrant women family caregiver's experience of support from community services. Paper presented at the Fifth International Metropolis Conference, Vancouver, BC.

Neufeld, A., Harrison, M. J., Stewart, M. J., Hughes, K. D., & Spitzer, D. L. (2000, October). Immigrant women caring for elders: Caregiving values and support. Paper presented at the Canadian Association on Gerontology 29th Annual Scientific and Educational Meeting, Edmonton, AB.

Neufeld, A., Harrison, M. J., Stewart, M. J., Hughes, K. D., & Spitzer, D. L. (2000, April). Bridges: How immigrant family caregivers connect with community resources. Paper presented at the Sixth Annual International Qualitative Health Research Conference, Banff, AB.

Neufeld, A., Harrison, M. J., Stewart, M. J., Hughes, K. D., & Spitzer, D. L. (1999, October). Support and Barriers for immigrant women who care for a family member. Paper presented at the Metropolis/Prairie Centre of Excellence for Research on Immigration & Integration, University of Alberta, Edmonton, AB.

Neufeld, A., Harrison, M. J., Stewart, M. J., Hughes, K. D., & Spitzer, D. L. (1999, May). Support for women who care: experiences of immigrant women who are family caregivers. Immigrant women for the millennium: Strategies for change. Paper presented at Changing Together, Edmonton, AB.

Neufeld, A., Harrison, M. J., Stewart, M. J., Hughes, K. D., & Spitzer, D. L. (1999, February). Participation of immigrant women caregivers in qualitative research. Paper presented at the International Institute for Qualitative Methodology, University of Alberta, Edmonton, AB.

