

Equitable Access to Healthcare, Health Promotion, and Disease Prevention for Recent Immigrant Women Living in Nova Scotia, Canada: Report on Phase 1

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ABSTRACT

This project focuses on exploratory research with recent immigrant women in Nova Scotia and their experience with and access to healthcare. This report is based on a pilot exploratory study.

We conducted focus groups with 23 women migrated from 11 countries. Focus groups seem to be an appropriate method for data collection while providing a venue for participant empowerment. The informed participation of immigrant community organizations, participants and family members is key to the success of ethnocultural research. Several other findings emerged: dissatisfaction towards diagnosis and prescription; provider and consumer communication problems; clashes between ethnocultural beliefs and the Western healthcare system; and a link between unemployment or underemployment and physical and emotional health.

This research-based knowledge revealed the need for further research leading to policy changes in healthcare.

1.0 SUMMARY OF THE RESEARCH PROJECT

1.1 INTRODUCTION

Integral to the Canadian healthcare system is the ideal of 'equal access for all'. However, research is revealing that access to healthcare is influenced by factors such as income, education, age, culture and gender. This project focuses on how the specific experience of being an immigrant woman in Canada affects access to and interaction with healthcare.

Our target group was recent immigrant women who are over 35 years and have resided in Canada less than ten years. We believe that this group is at a higher risk for diseases such as breast and ovarian cancer, as well as being more likely to be isolated in their homes than younger women or women who have been in Canada for over a decade. This group includes women who accompanied their husbands into Canada as well as those who have come alone. This report deals exclusively with the first phase of a larger vision that will need to provide in-depth analysis of the issues, paying attention to the divisions and differences within cultural groups and countries.

1.2 GOALS AND OBJECTIVES

The long-term goal of this project is to educate immigrant women about healthcare programs and policies, and identify the unique problems and needs that these women experience when they access healthcare. Ultimately, this combination of education and research will lead to recommendations for changes in the healthcare system that would ensure equal access for immigrant women.

The goal of the first phase was to obtain information to determine the direction of the next stage of this research. We also aimed to explore the best strategies for reaching immigrant women and to encourage their participation in research. In this phase we hoped to plant the seeds for this

project; those seeds are the voices of our focus group participants.

The focus groups were conducted with 23 women from 13 different countries. This report presents the research methodology and preliminary outcomes of these qualitative focus groups which reflect the experiences, feelings, and beliefs of these women.

1.3 CURRENT KNOWLEDGE

Many studies conducted in the United States and Canada have identified the affect of culture on health and illness. These studies indicate that people's beliefs about their illness are associated with their treatment compliance and pattern of social support seeking and self-care (1,2). Cultural belief systems can dictate preventive measures and in turn discourage reliance upon Western medical treatment and preventive measures (3). Studies have suggested culturally competent and sensitive programs are key to the success of patient compliance (4,5). However, the findings of studies conducted in the United States may not be directly applicable to Canada due to differences in ethnic diversity and healthcare systems. Some studies conducted in Canada have targeted special groups or sectors within ethnic populations such as the elderly (6), mentally challenged people, or maternal and child care sectors. All these studies suggest significant differences between marginalized cultural groups and the mainstream Canadian population. However, very few studies have focused on immigrant women's health and well-being. In some studies, for example the Nova Scotia Health Survey 1995, the ethnicity variable was not surveyed in order to increase the participation rate.

Given the limited scope of this project, a thorough examination of current literature and knowledge on this issue has not been completed. The researchers are aware that there is

a paucity of knowledge and research in issues surrounding Atlantic Canadian immigrant women and healthcare.

1.4 METHODOLOGY

1.4.1 PARTICIPANT RECRUITMENT

A two-stage process was implemented to recruit potential participants: contacting organizations and then contacting immigrant women.

1.4.1.1 CONTACTING ORGANIZATIONS

Since the active participation of immigrant women was the primary goal, the researchers compiled a list of organizations that deal with immigrant people on a daily basis. Due to time and financial money constraints, our contact was limited to brief phone calls, e-mails, and faxes. Unfortunately, thorough presentation of the project to these organizations before asking for their help was not possible. The response from organizations and associations was 14%. Once we talked to interested parties, we received the names and telephone numbers of potential focus group participants who fit the criteria of our target group.

As we began contacting these organizations, it became evident that organizations and individuals that work with immigrant people reacted to our request in one of three ways:

Response 1: Expressed interest in our research topic and agreed to support it by providing contact names. These individuals recognized the need for more information and research in the area of immigrant women and health.

Response 2: Approved of the topic we are studying and appreciated the general vision of the project. These individuals were wary of our research tactics due to previous negative experiences with other researchers. These people were concerned that immigrant women not be ‘guinea pigs’ in research that would

never directly benefit the healthcare needs of immigrant women.

Response 3: A third, more complex response to our request elicited a paternal, or parental, reaction. The organizations and individuals who responded in this manner assumed a protective role, presuming to speak ‘on behalf’ of these women and deciding for them whether or not to participate in our research. The majority of these people informed us that women would not want to participate. Through the focus groups, we discovered that one of the greatest misperceptions about immigrant women is that they are unable, or unwilling, to participate in research or even to speak out about their lives.

After obtaining names and telephone numbers from the participating organizations, we began contacting these women by phone.

1.4.1.2 CONTACTING WOMEN

This part of the methodology had both positive and negative consequences. In research with immigrant people, language is a major barrier in communicating information. Also, cultural differences in family dynamics, the role of the woman in the family, and appropriate topics of discussion all contribute to how women will respond to our phone calls. These cultural differences and pragmatic complications need special consideration when involving immigrant people in research. In our phone calls, in simple English, we explained who we were, what our research was, and asked if they would be interested in participating.

In addition to the aforementioned differences, researchers had two occasions (out of 13) where contact with the woman could only be facilitated through a male family member. In response to this unforeseen barrier, researchers decided to avoid leaving messages on machines or with people, and to wait until they could speak with the woman directly. However, this

meant extremely isolated women, who may have the greatest need for healthcare information, were not being contacted. Ten of our participants were contacted through an English language school and no phone calls were made to their homes.

1.4.2 CONDUCTING FOCUS GROUPS

The focus groups proved to be an effective and powerful tool for encouraging women to speak out about their experiences, criticisms and suggestions for change in their access to healthcare. They were conducted with 23 women from 14 countries from Africa, South-east Asia, East Asia, Europe, and Latin America.

Focus groups not only provided researchers with information, they became sites of empowerment for women as participants exchanged stories, discovered shared experiences and realized that they were not alone in their frustrations. Focus groups provided a space where women could be honest without fear of judgement and where their confidentiality would be respected. Many women expressed feelings of guilt that were dispelled in the focus groups by the realization that many of their barriers to accessing healthcare are embedded in the system, not in themselves.

Researchers used pre-arranged questions as a guide for the direction of the focus groups (Appendix A). However, it quickly became clear that each focus group had its own dynamic and specific focus. The researchers had to be flexible and allow groups to discuss things as they chose; this flexibility further empowered the participants.

The first group chose to focus on language and cultural differences that made healthcare less accessible for immigrant women. The second and third groups adopted a more emotional tone, emphasizing mental health issues for immigrant women. The fourth group focused

on employment barriers for immigrants and its connection to health. The final group discussed the healthcare system itself and women's expectations of health in Canada compared to the reality of what their experiences are. It is important to note that women in group five were the most recent immigrants and finding out about the system in general was important to them. Many women responded positively to the focus groups and suggested that group participation for immigrant women would be an excellent way to conduct health education and provide social support for immigrant women. One woman noted:

If I look to our group now, I see that we speak and express ourselves, if we are in different group with Canadian women, I don't think we are going to be so open ... when you feel you are among people who understand your problems, your issues, you feel more free to speak.

Another woman expanded on this idea saying:

I think it is very important to help a woman, because when you help a woman you help a family, a complete family.

1.4.3 ROLE OF EACH PARTNER AND DEVELOPMENT OF PARTNERSHIPS

This project was submitted as a university and community collaborative research project between the Nova Scotia Council of Multicultural Health (NSCMH) and the Department of Community Health and Epidemiology, Dalhousie University. Infrastructure support was provided by the University. Dr. Swarna Weerasinghe, a faculty member in the Department of Community Health and Epidemiology, spent most of her research work time devoted to this project. Dr. Terry Mitchell, another faculty member in the Department of Community Health and Epidemiology, provided her expertise in qualitative research. This

partnership was strengthened by the involvement of Dr. Mireille Ragheb from the School of Nursing, Dalhousie University, and Ms. Linda Hamilton representing the Nova Scotia Council on Multicultural Health. Dr. Ragheb was instrumental in facilitating contact with women and aiding in translations. Researchers were operating within a very small budget (\$5000), and performed many tasks without access to useful resources.

In the future, the researchers would like to see more developed and comprehensive relationships between organizations and individuals interested in supporting this very important research. Immigrant and multicultural organizations should be brought into the partnership at the initial planning stage of the study and active involvement from all sectors, including the community and the University, should be encouraged. More funding, as well as a more organized and detailed understanding of these partnerships, is crucial to the future development of this research.

1.5 EXPECTED OUTCOMES AND FINAL RESULTS OF PHASE 1

Important unanticipated barriers were identified in the process of reaching women suggesting strategies to access participants should be further explored. Our findings confirm our belief that immigrant women confront barriers when accessing healthcare. The goal was simply to hear the ideas and voices of these women, and to use their comments to direct future research in this project.

1.5.1 ANALYSIS

This study was exploratory in nature. The purpose of the study is mainly to test the ethnocultural data collection methodology. This includes determining an effective method of recruitment, pilot testing the focus group

template (Appendix A), and training researchers to collect information.

Although there was a pre-structured focus group template, researchers quickly realized that the emotional nature of the first focus group would demand flexibility. In this type of ethnocultural research, it is important to gain trust between the researcher and the participant. In our experience, this is essential partly due to negative perceptions about academic research. In order to increase the reliability of the information, researchers had to create a positive and trusting environment with the participants. Therefore researchers had to show flexibility in following the template. The focus group environment provided an arena where women could air their emotional feelings, exchange their stories, and voice their opinions. Traditionally, researchers hold a certain degree of power to control and shape the focus group environment. However, there were incidents in the focus groups where participants controlled the direction and focus of discussion. Therefore, it was an empowering experience. Researchers felt that they received the trust and confidence of the participants which is crucial to the successful completion of the next phase of the study. Whenever there was a pause in conversation, researchers made an effort to return to the template.

The conversations of the focus group participants were taped. The researchers listened to these tapes and noted important themes related to the study. This provided a foundation for the findings presented in this report.

1.5.2 LIMITATIONS

The major limitation of this study was due to lack of financial support to encourage informed participation through a workshop. In addition, we had to limit our sampling strategy to a convenient sample of women; their experiences in accessing the healthcare system may not

represent the majority. Minor limitations were a lack of support to facilitate interpreters, time constraints, and a lack of financial support to analyze qualitative data using a grounded theory approach. Some of the important findings of the focus groups, especially those relevant to women's experience in healthcare accessibility, are included in this report. The limitations of our funding did not allow us to provide interpreters for participants, therefore, language difficulties created some minor barriers to effective communication between the participants and the researchers. Some important statements clearly reflected a participant's frustrations with healthcare, yet they could be interpreted in many ways. With limited funding available to us, we were unable to verify these findings with the participants and clarify these ambiguities.

1.5.3 MAIN OUTCOMES OF FOCUS GROUPS

When we use the term 'all immigrant women' we are referring specifically to the women who participated in focus groups; we cannot assume that their views represent all immigrant people. We acknowledge that length of time living in Canada, the country of origin and more specifically, the region of the home country, socio-economic status, income, education level and English skills all contribute to the diversity of these women and their personal experiences (Appendix B). Future research needs to specifically address these differences and link them to our findings.

Focus group participants expressed both positive and negative attitudes toward the Canadian healthcare system. It is hypothesised that these immigrant women formed their opinion of the Canadian healthcare system through direct comparison to the level of care they received in their country of origin. One woman noted: "In **** [her country origin] is not matter if you are sick or not. The doctor will check you every [time] with a machine, every

part, if [you] are healthy or not." In contrast, another woman who was satisfied with the Canadian healthcare system stated: "Thank God. Canadian healthcare system is the best. I am still alive. God bless these Canadian doctors."

Basic communication with physicians seemed to be a major barrier for women who migrated from non-English speaking countries. As one woman noted: "But here the doctor ask you, 'what is your problem'...If you didn't say 'I'm sick', it's finished. But in my opinion, sometimes you are sick in the beginning."

Canada has some of the largest multicultural communities in the world. However, this exploration of the cultural sensitivity of its healthcare system suggests that Canada may not be meeting the needs of diverse cultural communities. One participant implied that women experience clashes between their ethnocultural or religious beliefs and Western medical care. This participant's mother was given a body wash by a male healthcare giver during her hospital stay. She said: "My mother, she don't want to end her life with men seeing her body, she wants to face her creator with nothing done wrong. This is an emotional aspect ... so it's difficult."

These findings strongly suggest that immigrant women living in Nova Scotia have experienced problems in accessing the healthcare system. Future research is needed to confirm this.

1.5.4 SCHEDULE OF ACTIVITIES

The initial meeting involving the principle investigator and research co-ordinators resulted in an agreement that the vision of a long-term research project investigating immigrant women and healthcare was too ambitious without substantial funding. Instead, it was decided to conduct a 'pilot project' which would explore culturally-sensitive strategies to increase participation of immigrant women in

research. It would also involve talking with immigrant women about their experiences, establishing their voices as the foundation for any future research. This pilot project would also test the effectiveness of our research tools (the focus group template).

A template for the focus groups and a quantitative questionnaire were prepared and a list of contacts was drawn up.

It was decided that before conducting focus groups, a workshop would be held to inform women about our research. The workshop would emphasize the informed participation process we hoped would be embedded in our research. The researchers were aware that too often immigrant women were used as ‘guinea pigs’ by researchers and hoped a workshop would allow women to be directly involved in the research process. However, it became clear that conducting an informative workshop before establishing focus groups was not financially feasible. Unfortunately, this meant that one of the core ideals of this research (education), was compromised. The inability to conduct a workshop also affected the quality of the methodology as researchers found themselves contacting women and asking for their participation without having had the opportunity to introduce their research, or inform women about Canadian healthcare, in a relaxed community setting. In order to compensate for the loss of this workshop, researchers allocated the first 15 minutes of the focus groups to explain the project and continually emphasized the right of the woman to refuse to participate, to change her mind, or to ask questions at any time.

It became clear that finding study participants and conducting focus groups with our target group of women in the summer was impractical, and the research was postponed until September 1999. In September, the researchers once again began contacting people. Women

were contacted and researchers explained the process of the focus groups and the goals of our research to women over the phone.

Information was sent by mail to most participants, and a brief information session was conducted at an English learning centre. Once women agreed to participate, we established the time and place of the focus groups.

Five focus groups were conducted of approximately 1.5 to 2 hours each. Altogether 23 immigrant women attended the focus groups.

2.0 DISSEMINATION PLAN AND KNOWLEDGE SHARING

The dissemination plan includes presentations of the study findings at national and international conferences. Abstracts have been presented at the international women’s health conference Women’s Status: Vision and Reality – Bridging East and West, New Delhi, India, February 2000, and accepted for presentation at Qualitative 2000 in New Brunswick and the Qualitative Health Research Conference in Banff, Alberta.

The research findings were also presented at a February 2000 regional workshop entitled, A Policy Forum on Women’s Health and Well Being organized by the Maritime Centre of Excellence for Women’s Health under the title “Healthcare accessibility and policy implications: the findings of research with immigrant women in Nova Scotia, Canada.” A similar presentation was made at the National Metropolitan conference in Toronto in March 2000.

Researchers have submitted a letter of intent to Canadian Institutes of Health Research (CIHR) to further explore the issues identified in this study.

In order to disseminate these early findings, and to expand knowledge on this topic, further research is necessary. The following recommen-

dations are intended to guide the next phase of this project in a way that will involve the immigrant community in the informed participation process of the research. In addition, recommendations for future research should aim to provide strategies of empowerment for immigrant women to control their own health, in turn increasing their awareness about health promotion. These recommendations also suggest that a strong alliance of the community, academic and government sectors is essential to successful ethnocultural research and dissemination.

3.0 RECOMMENDATIONS

- Future ethnocultural research must include informed participation through community-based workshops. These workshops should include immigrant women, their family members and community organizations.
- Future research should include the participation of care providers and policy makers in order to address their perspectives on these issues.
- It is necessary to involve the federal and provincial government health departments in order to transform research into action and establish policies.
- Informed participation of immigrant women to empower them is highly recommended at each stage of the research project.
- We encourage future research to continue to focus on this target group of woman.
- We have to find more appropriate ways to facilitate women's expression and go beyond using translators.
- We would like to recommend an expanded three-year study using mixed methods to thoroughly investigate this issue.

3.1 POLICY RELEVANCE AUDIENCE

The health policy related findings which emerged from this research are applicable mostly to recent immigrant women of pre-and-post-menopausal age (Appendix C). Participants of our focus groups are all from the Halifax, Dartmouth and Bedford areas in Nova Scotia. Ninety-five percent of immigrants in Nova Scotia choose to live in these three areas. The Nova Scotian immigrant population is smaller than that of Ontario and British Columbia. Therefore, they may be more socially isolated than those who live in big cities with larger immigrant populations. Issues relevant to them may be more critical. Most of the women who attended our focus group play the role of homemaker and very few were working outside the home. One third of them were attending an English as a Second Language (ESL) class.

3.2 POLICY IMPACT

This project provided a venue for women to express their feelings and frustrations honestly. There were hugs and tears. Women found that they are not alone in their frustrations. Women seemed to use the focus groups as a venue for empowerment. Focus group participants were provided with some health promotional and disease prevention materials and pamphlets obtained from the N.S. Department of Health. Women exchanged phone numbers and contact information during these sessions, and we believe their social interaction network was expanded.

A proposal was submitted to CIHR to do expanded research on strategies to improve immigrant women's healthcare accessibility. Research findings were presented at regional, national and international conferences where policy researchers and administrators were present.

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APPENDIX A: FOCUS GROUP QUESTION TEMPLATE

(Going around the table)

Please say what country you are from and how long you have been in Canada.

What does health mean to you?

What religious or cultural beliefs does your home country have about good health/bad health and healthcare?

What surprised you about Canadian beliefs about good health/bad healthcare and healthcare?

How often have seen a doctor this year?

What would make it more comfortable for you to see a doctor?

What do you think about tests that the Canadian doctors are supposed to give all women? How do you feel about the doctor taking blood, doing an internal exam, breast exam, or other tests?

What would you think about going to the doctor when you are healthy?

How would you respond if your doctor asked you to change your lifestyle: walk more, stop smoking, eat less fat, etc. when you are feeling well?

What do you do to keep yourself healthy?

What are your priority health needs? What are your health education needs?

Here is a brief summary of what we have understood from today's group ... Does this sound like we understood you? Are there any changes?

Thank you, this has been very helpful. Is there anything you would like us to know about how you keep yourself healthy?

APPENDIX B: RESEARCH FACT SHEET

Research Finding #1: Immigrant women who participated in our study identified problems in accessing the Nova Scotia healthcare system.

Research Finding #2: The length of time living in Canada, the country of origin and, more specifically, the region of the home country, socio-economic status, income, education level, and English skills all contribute to the diversity of these women and their personal experiences.

Research Finding # 3: An immigrant woman's country of origin and the level of care she receives prior to immigration seems to influence her current level of satisfaction with the healthcare she receives in Canada.

Recommendations for Future Research

Future ethnocultural research must include informed participation through community-based workshops. These workshops should include immigrant women, their family members and community organizations.

Future research should include the participation of care providers and policy makers in order to address their perspectives on these issues.

It is necessary to involve the federal and provincial government health departments in order to transform research into action and to establish policies.

The informed participation of immigrant women is highly recommended at each stage of the research project as it empowering for these women.

APPENDIX C: POLICY FACT SHEET

Major Finding #1 Dissatisfaction towards diagnosis and prescription

Policy Implications

- Basic education regarding the Canadian healthcare system, including prescribing patterns and diagnostic mechanisms, is required at the time of arrival.

Major Finding #2 Provider and consumer communication problems

Policy Implications

- Education regarding how to access healthcare, including how to make appointments, is required at the early stage of settlement.
- Use of cultural health interpreters needs to be encouraged even at primary care level.

Major Finding #3 Clashes between ethnocultural beliefs and the Western healthcare system

Policy Implications

- Education of healthcare givers on ethnocultural beliefs and behaviours surrounding health is required.

Major Finding #4 Link between unemployment or underemployment and physical and emotional health

Policy Implications

- Relationship between under- and unemployment of foreign qualified and educated immigrants and their emotional well-being has to be recognized.